Threading Together Patient Expertise
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Abstract
Patients are valuable sources of expertise for other patients in similar situations, but little is understood about the nature of this expertise. To address this knowledge gap, we investigated informational support as a mechanism for peers to help one another learn to cope with the breast cancer experience. We analyzed the types of problems discussed and recommendations offered by correspondents in three online breast cancer communities. Informational support was prevalent and directed towards problems in which correspondents were planning for future events or coping with emergent situations. Peers shared a wealth of patient expertise, including action strategies, recommended knowledge, suggested approaches, and information resources for dealing with problems. Our results highlight how peers are helping one another to learn. These findings bring insight to new support we could provide to patients for developing and sharing patient expertise, such as problem-based information organization and functionality for collaborative problem solving.

Introduction
Historically, in waiting rooms and in support groups, individuals have helped one another adjust to the experience of cancer by exchanging informational, emotional, and instrumental forms of social support.1 Informational support (e.g., exchange of advice, explanations, opinions, and experiences) helps patients understand and learn to cope with their illness. In contrast, emotional support can bolster interpersonal connectedness and self esteem as well as reduce distress through the expression of feelings, such as anxiety, concern, empathy, or reassurance. Instrumental support involves the exchange of practical assistance and material goods (e.g., financial support, transportation, or help with household chores).

Rapid growth in the popularity of online health communities (e.g., forums, chat rooms, listservs, message boards, wikis, blogs, online support groups) has opened a new channel for individuals to exchange these vital forms of social support. Although no conclusive evidence demonstrates that online communities improve the health of correspondents,2,3 their use by people experiencing breast cancer has been associated with lower levels of depression4 and improved quality of life.5 Many analyses of interactions among correspondents of online breast cancer communities6-10 support the broad recognition of these personal health environments as premiere resources for emotional support.11 For example, writing about illness through storytelling9 and the altruistic helping role of “emotion workers”10 could enhance emotional well-being. However, little research highlights the unique value of informational support exchanged in these environments,12,13 or the underlying characteristics of such interactions. For example, improvements in the health information competence of women who used the CHESS system might have related more to the experiential knowledge they shared in discussion group interactions than to medical knowledge shared by an expert trained with clinically-oriented resources (e.g., medical textbooks).12 Such informational support could provide a much needed way to support sharing of patient expertise, the experiential knowledge that patients have gained about effectively accomplishing the work of being a patient.

Our goal was to use online breast cancer communities as a window to understand the prevalence and characteristics of informational support that peers exchange and its role in facilitating patient expertise. This understanding can inform our development of a wide range of support for individuals to develop and share patient expertise, such as advice about what to take to the hospital or what to expect following surgery.13

Methods
We analyzed message board threads from three online breast cancer communities to (1) determine the prevalence of informational support and to (2) explore the characteristics of informational support exchanged by correspondents.

We examined a cross section of message boards that vary in formality (i.e., moderated or not, and affiliated with a health-related organization or not). We selected three well-established message boards with publicly accessible message content. We refer to them as Board A, Board B, and Board C rather than by name to increase the anonymity of correspondents.
We collected the first 60 archived threads from each message board with posting dates starting in February 2006. Each thread was composed of one or more related messages. We refer to the message that initiates a thread as its index message and all other messages in that thread as replies.

Table 1 shows characteristics of the message boards, threads and correspondents who posted messages in the threads. Correspondents were predominantly individuals who described their direct experience with breast cancer, or were their caregivers, family members, or friends.

Table 1. Board, thread, & correspondent characteristics

<table>
<thead>
<tr>
<th>Message board</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderation</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Affiliation</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Total threads</td>
<td>60</td>
<td>60</td>
<td>60</td>
</tr>
<tr>
<td>Total messages</td>
<td>458</td>
<td>246</td>
<td>312</td>
</tr>
<tr>
<td>Messages/thread (mean &amp; range)</td>
<td>8 (1.31)</td>
<td>4 (1.27)</td>
<td>5 (1.25)</td>
</tr>
<tr>
<td>Days of threads</td>
<td>3</td>
<td>8</td>
<td>45</td>
</tr>
<tr>
<td>Correspondents</td>
<td>163</td>
<td>78</td>
<td>77</td>
</tr>
<tr>
<td>Messages/correspondent (mean &amp; range)</td>
<td>3 (1.26)</td>
<td>3 (1.14)</td>
<td>4 (1.29)</td>
</tr>
<tr>
<td>Highly active correspondents*</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

*Posting 5% or more of all messages

We discovered that informational support appeared in some threads with index messages that we coded as emotional support. For example, even when the message originator emphasized emotional support, responses often would include informational support or the originator would seek informational support later in the thread. This mixture of support types in threads led us to change our unit of analysis from index messages in phase 1 to instances of informational support in phase 2. An instance of informational support is a statement or series of statements that offer or solicit recommendations to solve a problem.

The goal for phase 2 of our analysis was to understand the characteristics of informational support exchanged by correspondents in the three message boards. Specifically, we explored the kinds of problems for which correspondents exchange informational support and the kinds of recommendations correspondents offer for dealing with those problems. For each instance, we noted the problem discussed (e.g., I need help deciding on treatment) and each recommendation offered (e.g., consider a second opinion). We also noted whether the instance was initiated by a correspondent who was seeking support or giving support. Although a thread can contain more than one instance, in practice, we found there was typically one instance of informational support per thread, one problem per instance, and more than one recommendation per problem. We used affinity diagramming to explore themes in the types of problems and recommendations that surfaced.

Results

Phase 1: Prevalence of informational support

Table 3 shows the distribution of index messages across the four categories in our coding scheme. We identified exchanges for each kind of social support. Informational support was the most prevalent form of social support exchanged in each message board, followed by emotional support, then instrumental support. Only Board C contained index messages we could not place into any social support category. Those messages in the Other category included advertisements and negative responses to list abusers.

Table 3. Percentage of index messages in each category

<table>
<thead>
<tr>
<th>Message board</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informational support</td>
<td>68.3%</td>
<td>40%</td>
<td>70%</td>
</tr>
<tr>
<td>Emotional support</td>
<td>28.3%</td>
<td>35%</td>
<td>13.3%</td>
</tr>
<tr>
<td>Instrumental support</td>
<td>3.3%</td>
<td>25%</td>
<td>8.3%</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
<td>0%</td>
<td>8.3%</td>
</tr>
</tbody>
</table>
Emotional support interactions ranged from sharing personal updates about appointments, treatments, or personal life events (e.g., birth in the family) to sharing appreciation (e.g., Thank you for listening), reassurance, and empathy (e.g., I understand how you feel). Instrumental support was less common and included favors to accomplish community-specific projects (e.g., preparing for meetings or fundraisers, and coordinating contact, birthday, or remembrance lists) and personal projects (e.g., reviewing letters and seeking financial support for advocacy work).

Phase 2: Characteristics of informational support

We identified 115 informational support instances across boards (see Table 4.). Boards A and C provided more informational support than Board B, which is similar to the pattern we found in phase 1. More instances were initiated by seeking than giving across boards. Although Boards B and C were quite balanced, nearly 87% of instances in Board A were initiated by a correspondent seeking support.

Table 4. Informational support instances

<table>
<thead>
<tr>
<th>Message board</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of instances</td>
<td>47</td>
<td>26</td>
<td>42</td>
</tr>
<tr>
<td>Instances initiated by seeking</td>
<td>87%</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>Instances initiated by giving</td>
<td>13%</td>
<td>50%</td>
<td>50%</td>
</tr>
</tbody>
</table>

Types of Problems: The range of problems correspondents commonly discussed included issues related to prevention (e.g., carcinogens, vitamins, diet), diagnosis (e.g., understanding test results), treatments (e.g., decision making, managing side effects, work and home life, or social relationships during treatment), more general personal life issues (e.g., coping with emotions, creating memoirs, hospice planning), and current events (e.g., conferences and news stories).

We delved into the functional aspects of the problems correspondents discussed (i.e., what correspondents are trying to accomplish) and discovered two general themes in the majority of instances: (1) problems situated around planning for future events (i.e., What to expect) and (2) problems dealing with emergent events (i.e., What to do now). We could not clearly identify specific types of problems discussed in the small number of remaining instances, where correspondents discussed issues of general interest (i.e., General interest), such as news stories (14 instances), conference and fundraiser events (2 instances), and research (4 instances). Only 5% of these instances were initiated by seeking, whereas nearly 80% of What to expect and What to do now problems were initiated by seeking. Table 5 shows the number of instances associated with each of these three problem types across message boards.

Table 5. Instances associated with problem types

<table>
<thead>
<tr>
<th>Message board</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>What to expect</td>
<td>25</td>
<td>13</td>
<td>16</td>
<td>47%</td>
</tr>
<tr>
<td>What to do now</td>
<td>22</td>
<td>8</td>
<td>11</td>
<td>36%</td>
</tr>
<tr>
<td>General interest</td>
<td>0</td>
<td>5</td>
<td>15</td>
<td>17%</td>
</tr>
</tbody>
</table>

In the remainder of this section, we categorize the two major problem types into topical categories. We include representative quotes to exemplify each category and indicate the number of instances in parentheses.

What to expect problems revolved around the need to prepare for, plan for, and make decisions associated with specific future events or situations:

- Treatment-related decision making & planning (22)
  - Understanding treatment options & recommendations (10): “Can you explain [a tram flap] for me?”
  - Deciding between treatments and in special circumstances (e.g., pregnancy) (12): “Have any of you participated in the clinical trial dealing with...? If so, what can you tell us about it?”

- Preparing for clinical procedures & appointments (17)
  - “Can anyone tell me what to expect after surgery?”
  - “I am seeing my Oncologist...[and] would like your advice on any specific questions to ask...”

- Preparing for home & work life (11): “Did you work [during treatment]? I feel like I need help...my husband is overwhelmed with house, work,...”

- Special event planning, such as preparing to attend & participate in fundraisers or conferences (4): “I'm trying to make a difference by raising awareness and funds [for] breast cancer...I welcome any suggestions or advise”

What to do now problems revolved around the need to cope promptly with specific emergent problems:

- Determining whether a situation is problematic (10): “Does my reaction [to surgery] seem normal?”

- Solving specific types of emergent problems (31)
  - Understanding test results (4): “I've been reading all I can now that I received my report...but I am still confused”
  - Defining terms (3): “What does 'ac treatment' refer to?”
  - Coping emotionally (8): “I flipped through this book...It touched on exactly what I am feeling and thinking right now [about coping with anger]”
  - Dealing with people in your social network (6): “my daughter [wants] to find [people] with similar diagnosis to communicate with”
Managing personal & health tasks or projects (8):
“I have lost most of my hair which was [hard], but did anyone’s scalp hurt? My scalp is very... tender... If so any suggestions”

Clinic-related tasks or projects (2): “If anybody has had contact with [these clinics], would you please give me info...”

Types of Recommendations: We identified 856 recommendations offered by correspondents in response to the kinds of problems discussed in informational support instances. On average, correspondents offered 7 recommendations per problem, but offered as many as 63. We identified four types of recommendations correspondents offered in response to problems: action strategies, recommended knowledge, suggested approaches, and information resources (see Table 6). Next, we describe themes in these types of recommendations, and include representative quotes with numbers of recommendations in parentheses.

Table 6. Recommendations offered for problems

<table>
<thead>
<tr>
<th>Message board</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total recommendations</td>
<td>508</td>
<td>146</td>
<td>202</td>
</tr>
<tr>
<td>Recommendations per problem (mean &amp; range)</td>
<td>10(0.63)</td>
<td>5(1.18)</td>
<td>5(0.27)</td>
</tr>
<tr>
<td>Action strategies</td>
<td>40%</td>
<td>53%</td>
<td>32%</td>
</tr>
<tr>
<td>Recommended knowledge</td>
<td>37%</td>
<td>16%</td>
<td>46%</td>
</tr>
<tr>
<td>Suggested approaches</td>
<td>14%</td>
<td>18%</td>
<td>8%</td>
</tr>
<tr>
<td>Information resources</td>
<td>9%</td>
<td>13%</td>
<td>14%</td>
</tr>
</tbody>
</table>

Action strategies (346) offered specific advice on what to do about specific problems. These were the most frequent type of recommendation. The types of action strategies fell into the following categories:

- Side effects (66): “I understand that some stores...sell after-mastectomy clothes such as a special camisole/robe with pockets for the drains”

- Interacting with the health care system (83): “Ask the doctor who recommended the bilateral mastectomy why he recommended this”

- Choosing treatments and tests (54): “…another option for you may be a LAT flap where they take muscle from your back”

- Personal tasks & projects (59): “write several letters for any young person you care about (yours or someone else's) for their upcoming birthdays”

- Understanding your health situation (24): “turn these figures around and look at risk of recurrence or death rather than probability of disease-free survival.”

- Work (39): “avoid the temptation to 'force yourself' or 'carry on as normal' - you need rest and recovery time [from work]”

- Coping with stress (21): “There are support groups for newly diagnosed women. Your doctor or hospital should be able to put you in touch with one”

Recommended knowledge (305) included vicarious experiences, factual explanations or opinions, and conceptualizations that correspondents offered to help in understanding and solving problems. The types of knowledge fell into these categories:

- Personal stories carrying vicarious experiences about what has worked for others and why (175): “I returned to work about three weeks after my mastectomy. I scheduled the chemo on Fridays so I would have the weekend to recover”

- Providing explanations or descriptions about symptoms, treatments, clinical procedures, side effects, risks, prognosis, or clinical terminology (108):
  - Term definitions: “[‘comorbidities’ is] shorthand for ‘other illnesses at the same time’.”
  - Expected side effects: “You only are likely to lose your hair with an adriamycin/cytoxan chemotherapy”
  - Test results: “Even though our risk is doubled, there is still about an 80% chance that we won't get [breast cancer] again”

- Describing expected time courses (22):
  - Treatments: “It took a total of 2 hrs for the infusion”
  - Side effects: “starting two days after Taxol treatment, and lasting about 2-3 days”
  - Coping with information overload: “There are definitely stages of absorbing everything”

Suggested approaches (112) included attitudes and ways of being or thinking offered by correspondents as ways of dealing problems. The types of approaches fell into the following categories:

- Having patience (27): “focus on one day at a time”

- Being open to emotions & change (27): “you are actually mourning your old life and you need to give yourself time to do that”

- Drawing upon inner strength (28): “we each must be our own best advocate”

- Being aggressive and taking care to prevent potential problems (19): “cancer is not the only culprit we need to worry about”

- Maintaining optimism (11): “A positive attitude will do you more good than anything”
Information resources (93) that correspondents recommended included external material they pointed to or embedded within messages. Types of resources fell into the following categories: websites (46), news articles (17), books (10), contact information (e.g., clinicians, wig shops, etc) (9), research articles (7), poems and letters (3), and magazines (1). Websites varied widely, including products, services, clinical guidelines, decision tools, blogs, forums, cancer organizations, events, and personal homepages.

Conclusion

In addition to sharing emotional support, peers use online breast cancer communities to exchange a wealth of informational support. We found that the prevalence of these exchanges varied by community, thus supporting the study of multiple communities, even though most work to date has typically studied only one community at a time. However, the characteristics of informational support were fairly similar across boards. Support centered on collaborative problem solving surrounding future and emergent events across a range of personal and health topics. The action strategies, knowledge, approaches, and information resources peers recommended reflect the patient expertise they have gained through their own breast cancer experience and offer a source for others to learn from as they face similar situations.

These findings bring insight to the range of support we could provide individuals for developing and sharing patient expertise. For example, problem-based structures for organizing information and support for collaborative document management might enhance opportunities for learning through peer mentoring as well as discovery.

Online communities could help users find a breadth of available expertise relevant to their needs by structuring threads by classes of common problems. Communities could group threads into predefined categories (e.g., future or emergent events). Alternatively, communities could incorporate collaborative tagging\(^{(14)}\) to allow users to develop problem-based structures more organically. Common forms of recommendations (e.g., action strategies, knowledge, approaches, and information resources) could be offered as facets for users to browse across these different types of problems.

The collaborative approach that peers used to solve problems in the online communities we studied suggests that collaborative document management could be useful. Communities could provide workspaces and tools for subgroups to connect and share strategies for common problems or goals\(^{(15)}\) or to manage common collections of relevant information resources.\(^{(16)}\) Such features could also meet aspects of instrumental support needs we observed, such as management of community member contact lists.

Learning about the nature of informational support provides a tremendous opportunity to characterize both the types of problems patients face and seek help from peers to solve and the kinds of expertise peers can provide. Studies such as ours provide a new view of patient expertise that could be utilized to support patients as they adjust to the breast cancer experience.

References