

# Giving and Receiving Peer Advice in an Online Breast Cancer Support Group

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## Abstract

People have access to experiential information and advice about health online. The types of advice exchanged affect the nature of online communities and potentially patient decision making. The aim of this study was to examine the ways in which peers exchange advice within an online health forum in order to better understand online groups as a resource for decision making. Messages collected over a one-month period from an online breast cancer support forum were analyzed for examples of advice exchange. The majority of the messages solicited advice through problem disclosure or requests for information and opinion. A novel form of advice solicitation—"anyone in the same boat as me"—was noted as was the use of personal experience as a form of advice giving. Women construct their advice requests to target like-minded people. The implications in terms of decision making and support are discussed.

## Introduction

THE INTERNET OFFERS ACCESS TO experiential information for people across a large range of health issues. Studies have documented the social and emotional support these websites offer their members, for example, in relation to sports injuries,<sup>1</sup> irritable bowel syndrome,<sup>2</sup> infertility,<sup>3</sup> and HIV.<sup>4</sup> Analysis of message content has revealed that support groups vary according to the types and frequency of their exchanges. Some groups exchange more information messages, others more messages of emotional support and solidarity. These differences may reflect the nature of the health condition, the gender of the contributing members (see Mo et al., 2009, for a review), or the underlying ethos of the community.<sup>5</sup>

One type of exchange process that has received relatively little attention to date is that of advice exchange. The process of advice exchange within online community settings is interesting not least because it raises issues associated with trust, expertise, and disclosure. Expertise is not straightforward within peer settings.<sup>5</sup> Unlike traditional health settings in which there is one expert advisor (i.e., the medic) and one lay advice seeker (i.e., the patient), online support groups are by nature a community of supposedly equal peers. On a more practical level, advice exchange has potential implications for treatment decisions. Clinicians have queried the usefulness of peer support in offline settings,<sup>6</sup> and with little control over the accuracy of information and feedback provided on the

Web, there have been concerns that health information exchanged online might be incomplete or inaccurate. Research in this area has found instances of inaccurate or "non-evidence-based" information from online support groups.<sup>7,8</sup> An analysis of messages from an epilepsy forum, for example, found that 6% of postings were objectively inaccurate.<sup>9</sup> However, Sillence and Mo found very few examples of inaccurate information in their study of online prostate cancer support messages.<sup>10</sup> The aim of this study is to examine the kinds of advice exchanged with an online breast cancer support group and the processes underlying that exchange.

## Advice exchange

Advice has been defined as "opinions or counsel given by people who perceive themselves as knowledgeable, and/or who the advice seeker may think are credible, trustworthy and reliable," (pp. 519).<sup>11</sup> This definition highlights the difficulties involved for both parties in managing the interaction. For the advice seeker, asking for advice is in a way undermining their identity as a competent person, playing down their own knowledge and abilities while the advice giver has to demonstrate they are worthy of offering advice. Advice givers also have to pay attention to the cues of the advice seeker. They have to be sensitive to their needs, even recognizing that advice is being sought. The way that the advice is presented is crucial as well if the giver is to succeed in passing on his or her way of thinking on the topic. The context may

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require that the advice giving is mitigated. Locher and Hoffman suggest that such mitigation occurs in the form of humor or through the use of lexical hedges such as “maybe” or “perhaps.”<sup>12</sup>

The literature on expert advice giving has mainly concentrated on face-to-face settings or written expert advice often in the form of personal problem pages in newspapers, magazines, or online.<sup>12,13</sup> While relatively little research has examined “peer” advice online, it does seem that the extent to which advice exchange is seen as an important or even defining aspect of a community varies between forums. In a study of an online support group for depression, Lamerichs found advice exchange was not seen as central to the community’s functioning,<sup>5</sup> while Kouper, in a recent study of an online motherhood forum, noted that offering and receiving advice was an important type of social interaction within that community.<sup>14</sup> The structural and pragmatic features of the advice exchange process are one indicator of its value within the online community. The ways in which advice is solicited and the degree of directness map onto the look and feel of the community—its ethos. Kouper, for example, notes that advice requests were embedded within narrative structures that typically included long elaborations on the background, and advice seekers tended to justify their requests.<sup>14</sup> Replying to the messages, contributors dealt with the potentially difficult issue of “being an expert” by using personal experiences to encapsulate advice rather than using direct advice messages, for example, “You should do x.” Other studies within a health context have noted the importance of politeness strategies, for example, mitigated suggestions in the form of questions and stories or the use of positioning statements that allow the advice seekers to set the parameters by which they wish to receive advice.<sup>15,16</sup>

### *Breast cancer on the Internet*

Breast cancer patients make use of online health resources in a number of ways, including increasing their sense of social support,<sup>17</sup> gathering information, and helping them make sense of the experience of cancer.<sup>18</sup> Some researchers, pointing to the different cultures thesis,<sup>19</sup> argue that online forums exhibit socialized, gender-appropriate ways of communication so that in breast cancer support groups, predominantly used by women, support and sharing personal experiences are more prevalent than information exchange and treatment issues. Mo et al. highlight the fact that certain conditions may require different forms of social support by patients.<sup>20</sup> Breast cancer patients may have clearer treatment paths than other forms of cancer and so may wish to focus on emotional and supportive exchange with peers. Advice exchange with breast cancer forums may not be restricted to treatment options and side effects but may also encompass advice about day-to-day living with breast cancer or interactions with doctors, friends, and family.<sup>21</sup>

## **Material and Methods**

### *Data collection*

Having received ethical approval from the School of Life Science’s ethics committee, the author collected data for the study between January and February 2011. This consisted of one month’s posts and comments to a breast cancer support

site. The site was chosen because it was public access, that is, the messages on the site were publicly posted with no membership or passwords required for access, and because it appeared to be active—the site contained at least 100 members with at least 50 messages posted within the last 30 days. In keeping with other online support groups, the site was split into sections, and messages were posted under headings and subheadings within those sections. Headings appeared to be comparable with other breast cancer sites and more broadly with other online support groups and included, for example, diagnosis and treatment and side effects. The site was moderated, and messages that contravened the stated rules were removed.

### *Analysis*

The data analysis consisted of three stages: Assessment of posting activity, analysis of advice solicitations, and analysis of advice giving. The general assessment of posting activity consisted of producing descriptive statistics such as numbers of posts with and without advice and numbers of comments. A qualitative examination of the messages in terms of advice solicitations was carried out using a modified version of Goldsmith’s typology.<sup>22</sup> The typology consists of four advice solicitation types, which vary in their directness and transparency: request for advice, request for opinion or information, and announcement of a plan of action. The fifth advice pattern (same boat) was added to Goldsmith’s typology (Table 1) after a preliminary examination of the messages. As increasing numbers of appeals to “people in the same boat as me” were identified, it became apparent that this could be considered a distinctive type of advice solicitation.

The author and one other colleague coded the postings with high intercoder reliability (0.97). To address further the issue of reliability of differentiating among the categories, a small subsample (10%) of messages were coded again by the author 2 weeks after the original coding exercise. The coding

TABLE 1. TYPES OF ADVICE SOLICITATION

No.	Advice pattern	Description
1	Request for advice	Explicit solicitation of advice using the following phrases: (a) “I need your advice”; (b) What should I do?; and (c) “Should I do X?”
2	Request for opinion or information	Questions such as “What do you think?” or “What do you think of X?” that can often generate advice responses even though they may be ambiguous about whether the poster wants to solve a problem or obtain emotional support.
3	Problem disclosure	Also potentially ambiguous, as it can be interpreted as a request for advice, sympathy, solidarity, etc.
4	Announcement of a plan of action	The poster may receive advice after announcing their intentions.
5	Anyone in the same boat?	The poster asks specifically to hear from anyone in the same boat as themselves or those who are going through the same experience.

produced identical results for both sessions, indicating that the categories in Tables 1 and 2 could reliably be differentiated by the researcher. Pieces of advice posted in comments in response to the original advice solicitation were examined for their degree of directness. The degree of directness is interesting to examine because of the tension that exists between showing support and appearing to impose. Advice seekers and givers have to make choices about the way in which they exchange advice and this impacts the ethos of the community. In this respect, the following categories were used in the analysis. These categories (see Table 2) are based on those reported by Kouper.<sup>14</sup>

## Findings

### Posting activity

During January and February 2011, 425 original messages were posted. All the messages were coded, for example, sharing emotions, support, information, and advice. Only the advice messages were quantified and examined further for the purposes of this study. Out of the 425 messages, 166 (39%) asked for advice in one form or another. Overall, 1,017 comments were posted in response to the 166 advice requests. Of these, 567 (58%) contained advice, recommendations, etc. Another 146 (14%) were replies from the authors of the original entries, expressing thanks or providing further information. The remaining 304 (30%) contained nonadvising comments, for example, solidarity, etc. Of the 166 messages asking for advice, 157 (95%) were posted by unique individuals. Six people asked more than one question. A total of 188 unique members replied with advice in comments; 86 of those replying more than once. Ten people posted 10 or more comments containing advice, with the highest single contribution being 38.

### Asking for advice

Messages containing advice solicitations were examined. Members asked for advice under a number of different headings, including treatment topics, after treatment has finished, living with breast cancer, and employment issues. The frequency of different types of advice solicitation is presented in Table 3. Looking at the pattern of advice solicita-

TABLE 3. FREQUENCY OF ADVICE SOLICITATION TYPES WITHIN THE BREAST CANCER FORUM

Type of advice solicitation	Frequency (%)
Request for advice	26 (9%)
Request for opinion or information	103 (34%)
Problem disclosure	106 (35%)
Announcement of a plan of action	3 (1%)
Same boat	61 (20%)
Total	299

tions, it is clear that few messages contained direct requests for advice. The majority of advice solicitations took the form of opinion/information requests or problem disclosures.

### The word "advice"

Very few posters asked the community to tell them what they "should do." In fact, "advice" was often presented on par with "comments." Members typically welcomed "any comments or advice" from readers without including a specific invitation to provide counsel. As such, messages containing the word "advice" were more often coded as requests for opinion or information. Advice itself can be a loaded term. People include the phrase "any advice?" in their post but then immediately follow up by saying that they don't want someone to "tell them what to do." In cases where advice was sought directly, it was typically accompanied by two possible options for the advice giver to comment upon, rather than leaving it more open-ended. In this way, online peers may act as conversational "sounding boards."<sup>23</sup>

Should I inform the breast service about this as with it being deep in my breast didn't think it was anything to bother them with.

My step-daughter to be has a family history of bc. So far, she herself and her father brush it under the carpet and do not want to discuss it at all. Will she be contacted from her medical history for tests or should she initiate it, and when please? Should I back off or should I try to encourage them to do something?

### Advice within a narrative

Within the community, a typical advice solicitation took the form of a narrative containing a number of different structures. In addition to the advice solicitations, narratives contain background and justification structures as well. The message below typifies this kind of narrative form and highlights the period of orientation to the circumstances of the poster.

Don't really know if this is the right place to post this but hoping someone might have some good advice to give me. Was treated for triple negative BC in 2003 and next month will reach the magic eight years post diagnosis so have much to celebrate and am very grateful to still be here. However for the past few months I have felt so tired and generally unwell that I am finding life a real struggle at the moment. My energy levels never returned to their previous levels following treatment but I have managed to continue working full time and get on with life pretty well until fairly recently. I'm just wondering if anybody else out there has had a similar problem and has any

TABLE 2. LEVELS OF DIRECTNESS OF ADVICE

No.	Type of advice	Description
1	Direct advice	Any comment that included imperatives or the modal verb <i>should</i> .
2	Hedged advice	Any comment that contained explicit hedges or hedging devices, e.g., "I think," "It seems," or "Why don't you?"
3	Indirect advice	Any comment that lacked explicit or hedged advice but had enough information to act upon it, for example, "Here's one possibility" or "There are a number of options."
4	Description of personal experience	An account of how the person dealt with the situation the advice seeker had described.

tips on how to deal with this horrendous lack of energy - any advice would be very gratefully received.

#### *Looking for someone in the "same boat"*

This new type of advice solicitation typically contained a problem disclosure followed by a call "is there anyone in the same boat as me?" in order to reach a specific set of people within the community. Twenty percent of messages in the forum contained an advice solicitation that was built upon the specific desire to hear from people in the same position as themselves or from people who had experienced the same issues.

I've been given the usual advice, one big op better than two and better cosmetic outcome, but the nearer this gets the more panicky I get as I can't imagine what it will be like having both front and back operated on. So would love to hear from anyone who's had this done.

Interestingly, the types of messages containing the "same boat" advice solicitation were more frequent under the treatment headings on the Web site. At least half the advice requests posted under the main treatment headings (i.e., chemotherapy and hormone therapy) were framed in terms of finding someone in the "same boat." Where treatment decisions are being considered, it appears that women are drilling down through the resources in the community to find very specific advice from very specific people, namely, those who match their own medical experience as closely as possible.

#### *Offering advice*

Advice was offered through comments posted in response to the original message. Most comments contained one piece of advice but others contained more. On the site, the 567 comments contained 622 pieces of advice, and members used all four strategies for providing advice, with direct advice and descriptions of personal experience being the most popular forms. Table 4 indicates that advice in the form of personal experience was most prevalent in the breast cancer support group.

#### *Being direct*

The direct advice in the forum typically called for posters to seek medical assistance or to start or stop a behavior immediately. Posters were told, for example, "you should go to see your doctor." Nearly half of the advice comments posted under the subheading "have I got breast cancer" were examples of direct advice. In contrast, there were no examples

of direct advice comments when members were posting requests for advice about simply "living with cancer." On the Web site, a similar number of messages contained hedged advice. Hedging devices such as "maybe," "I think," and "perhaps" were typically used when the poster was providing advice about diet, clothing, or exercise.

Of course you should mention anything that is worrying you when you go to your appt. They'll ask anyway but don't keep schtum.

There's no reason why your sister should suffer - it is often trial and error until you get the right balance of drugs that work for each individual, so she should insist that she tries something else. Reassure your sister that she shouldn't worry as there is no "right" way to get through the treatment and everyone is different.

#### *Personal experience*

Nearly half of the advice given in the BCa support group was presented through personal experience. This kind of advice giving was particularly noticeable when members were responding to advice requests concerning breast reconstruction, living with breast cancer, and treatment options, and less so when the advice pertained to, for example, employment rights. The use of personal experience allows the poster to emphasize the importance of making one's own decision while recognizing these kinds of messages can be useful to readers—"hope this helps." Personal experience messages offer the advice seeker an insight into the choices and thought processes of a "similar" person. The reader can then evaluate the experience in terms of their own preferences and biases and decide whether or not to use the experience as advice.

I had LD Flap immediate recon last November....I have to say, I am delighted with the results. It was the right decision for me to go to sleep with 2 breasts and wake up with 2 and I was amazed at how it looked immediately after surgery. The surgery itself was a long op and I spent 6 days in hospital and I did feel like I'd been run over for the first few days. I'd say I was feeling good 4 weeks later and off the painkillers....Hope this helps a bit. Take your time in making your decision though, don't feel rushed. I asked to see pictures of surgery that the surgeon had performed beforehand and that helped me see exactly what is achievable.

#### **Discussion**

This study adds to our knowledge about the prevalence and characteristics of advice exchange with an online breast cancer support group. In terms of posting activity, approximately 40% of all messages in this support group are advice messages, so clearly advice exchange is a key function of this site. People expect to be able to ask for and receive advice. Advice solicitations appear to be recognized as such and dealt with appropriately. Members do reply to advice requests (with 1,017 comments, and of those, nearly 60% contained advice). This exchange involves effort on the part of community members, but involvement in this form is important both on the individual level in terms of relationship development<sup>24</sup> and to the community's maintenance as a whole. As is common in online communities, there are different levels of contribution. Many members take the time to

TABLE 4. FREQUENCY OF ADVICE DIRECTNESS RESPONSES WITHIN THE BREAST CANCER FORUM

<i>Directness of advice in comments</i>	<i>Frequency (%)</i>
Direct	133 (21%)
Hedged	128 (21%)
Indirect	58 (9%)
Personal experience	303 (49%)
Total	622



respond to advice requests, with some members playing particularly central roles or adopting a "caretaker" participatory stance.<sup>25</sup> Advice exchange may seem an obvious function within a community in which people "new" to the subject are struggling to deal with unfamiliar terminology, but in other domains the attitude toward newcomers asking often basic and repetitious questions can be very different. "Newbies," as they are termed, can be met with ambivalence at the least and, at the worst, outright hostility (see the entry on "RTFM," pp. 307).<sup>26</sup> It appears then that this online breast cancer support community is indeed a place people go to in order to both ask for and receive advice. In addition to the social and emotional support for which these communities are well documented, people expect to be able to ask for advice without repercussions, and people offer advice both to newcomers and to more-established members of the community.

The fact that people want advice from similar people is not so surprising. Medical staff should be aware that the desire for experiential advice from someone who has also suffered from breast cancer (someone in the same boat) is commonplace and that people are responding to that need. Such an online community contains many pieces of potential advice on all aspects of life with breast cancer, from hairpieces to opting for immediate breast reconstruction.

In terms of asking for advice, there were very few explicit requests. Instead, members disclosed problems or sought opinions and information. These more subtle ways of asking for advice mitigate the potential power issues and also play to the strong emphasis placed on active decision making and individual choice within the health forum. A novel type of advice solicitation was identified as that of "being in the same boat." This format makes clear the kind of person someone wants to hear from. Advice responses are limited to those with very similar experiences,<sup>16</sup> and we know that people are more likely to adopt the advice offered when the source is more homophilous, that is, when there is a high degree of perceived similarity between receiver and message source.<sup>27</sup> Entwistle et al. also note that participants only find experiential information relevant if it's derived from people with whom they shared other key characteristics such as age, gender, or health experiences, or if they had other reasons to identify with the account.<sup>23</sup>

In keeping with previous research,<sup>28</sup> sharing personal experiences was evident on the site. People often act as scientists, testing out their own experiences and attitudes against the information they read online.<sup>29</sup> Having an active community with multiple members posting their personal experiences ensures readers are at least exposed to a range of advice perspectives. Although people report that they do not automatically rely on any single personal experience they read online,<sup>23</sup> they are selective about the advice and experiences they choose with which to engage.<sup>11</sup> In this study, the way in which people asked for advice appears to influence the type of advice response they receive. When people asked for advice using "the same boat" request, they received more advice responses in the form of personal experience. By seeking out people in the same boat, patients are trying to select the most appropriate person to offer them advice. Offering personal experiences, typically in the form of narratives, allows posters to present enough information for the reader to assess how applicable the advice is in terms of its

clinical compatibility and also its match for the reader's own point-of-view and biases.

The findings of this study are in keeping with previous work on breast cancer support groups in which sharing personal experiences remains a prominent feature of the group.<sup>28</sup> While advice giving does appear to be a key feature of other support groups (Sillence, in preparation), issues specific to breast cancer may limit the extent to which these findings can be generalized to a wider range of support groups. Those health conditions that present the patient with a higher degree of uncertainty regarding, among other things, treatment options (e.g., prostate cancer), may well favor a more direct advice exchange pattern (Sillence, in preparation), and it's worth remembering that online communities develop their own set of norms and patterns of acceptable behavior.<sup>30</sup>

## Conclusions

This study demonstrates that advice exchange among online peers is an important function of this particular community—an online breast cancer support group. Managing the process of advice is subtle and complex, with members using a range of strategies to ask for and present advice in an acceptable manner.

Healthcare professionals should be aware that patients are using these forums in addition to offline sources of advice. As patients try to narrow down the advice they receive, clinicians should support this process by ensuring that patients are given sufficient medical advice regarding which treatment options are suitable for them. This should assist in the patient's selection of appropriate and useful advice from peer support groups.

## Author Disclosure Statement

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