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Giving and receiving peer advice in an online breast cancer support group

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 analysed 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.

Advice, Internet, Breast cancer, Decision making, Community

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 injuries¹, irritable bowel syndrome², infertility³ and HIV⁴. 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 (see⁵ for a review) or the underlying ethos of the community⁶. 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 settings⁶. 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 their 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 settings⁷ 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^{8,9}. An analysis of messages from an epilepsy forum, for example, found that 6% of postings were objectively inaccurate¹⁰. However Sillence & Mo¹¹ found very few examples of inaccurate information in their study of online prostate cancer support messages. 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’¹², p519). 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, whilst 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 recognising that advice is being sought. The way in which that 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 require that the advice giving is mitigated. Locher & Hoffman¹³ suggest that such mitigation occurs in the form of humour or through the use of lexical hedges such as ‘maybe’ or perhaps’.

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 (e.g.^{13,14}). Whilst 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. Lamerichs⁶ in a study of an online support group for depression found advice exchange was not seen as central to the community’s functioning whilst Kouper¹⁵ 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. 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 of advice map onto the look and feel of the community – its ethos. Kouper ¹⁵, for example, notes that advice requests were embedded within narrative structures which typically included long elaborations on the background and advice seekers tended to justify their requests. 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 e.g. “You should do x”. Other studies within a health context have noted the importance of politeness strategies e.g. mitigated suggestions in the form of questions and stories or the use of positioning statements which allow the advice seekers to set the parameters by which they wish to receive advice ^{16, 17}.

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, ¹⁸ gathering information and helping them make sense of the experience of cancer ¹⁹ Some researchers pointing to the different cultures thesis ²⁰, argue that online forums exhibit socialised 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, Malik and Coulson ⁵ highlight the fact that certain conditions may require different forms of social support by patients. 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 ²¹.

Method

Data collection

Having received ethical approval from the School'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 i.e. the messages on the site were publicly posted with no membership or passwords required for access and because it appeared to be active i.e. 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 number of comments. A qualitative examination of the messages in terms of advice solicitations was carried out using a modified version of Goldsmith's typology ²². The

typology consists of four advice solicitation types which vary in their directness and transparency: request for advice, request for opinion or information, 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.

<Table 1>

The author and one other colleague coded the postings with high inter coder reliability (.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 two weeks after the original coding exercise. The coding 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 upon 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 Kouper¹⁵.

<Table 2>

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 1017 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 non-advising comments e.g. solidarity etc. Of the 166 messages asking for advice 157 (95%) were posted by unique individuals. 6 people asked more than one question. 188 unique members replied with advice in comments; 86 of those replying more than once. 10 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 solicitations 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.

<Table 3 combined>

The word 'advice'

Very few posters asked the community to tell them what they “should do”. In fact ‘advice’ was often presented on a 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’ 23

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 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. 20% of messages in the forum contained an advice solicitation which 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 frequently those under the treatment headings on the website. 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 on offer within the community to find very advice from very specific people namely those that 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 advice in the form of personal experiences was most prevalent in the breast cancer support group.

<Table 4>

Being direct

The direct advice in the forum typically called for posters to seek medical assistance or to start or stop a behaviour immediately. Posters were told, for example, "you should go to see your doctor". Nearly half of the advice comments posted under the sub heading '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 website 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 ones own decision whilst recognising 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 on 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 recognised as such and dealt with appropriately. Members do reply to advice requests (with 1017 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 ²⁴ 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 respond to advice requests with some members playing particularly central roles or adopting a 'caretaker' participatory stance ²⁵. 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 towards 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 ²⁶ the entry on 'RTFM', p.307). 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 that these communities are well documented for offering 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 common place 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 whether or not to choose 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 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 ¹⁷ and we know that people are more likely to adopt the advice offered when the source is more homophilous i.e. when there is a high degree of perceived similarity

between receiver and message source²⁷ Entwistle et al.,²³ also note that participants only find experiential information relevant if its 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.

In keeping with previous research e.g.²⁸ 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 online²⁹. 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 online²³ they are selective in the advice and experiences they choose to engage with¹². 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 people 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 group²⁸. Whilst advice giving does appear to be a key feature of other support groups (Sillence in prep) issues specific to breast cancer may limit the extent to which these findings can be generalised to a wider range of support groups. Those health conditions, for example prostate cancer that present the patient with a higher degree of uncertainty regarding, inter alia,

treatment options may well favour a more direct advice exchange pattern (Sillence, in prep) and its worth remembering that online communities develop their own set of norms and patterns of acceptable behaviour³⁰.

Conclusions and implications

This study demonstrates that advice exchange amongst online peers is an important function of this community. Managing the process of advice is subtle and complex with members using a range of strategies both to ask for and present advice in an acceptable manner.

Health care 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 could support this process by ensuring that patients are given sufficient medical advice to be aware of which treatment options are suitable for them. This should assist in their selection of appropriate and useful advice from peer support groups.

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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?" ; 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 posters wants to solve a problem or get 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 who is going through the same experience.

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 personal dealt with the situation the advice seeker had described.

Table 3: Frequency of advice solicitation types within the forum

Type of advice solicitation	Frequency (%)
Breast Cancer forum	
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

Table 4: Frequency of advice directness responses within the forum

Directness of advice in comments	Frequency (%)
Breast Cancer forum	
Direct	133 (21%)
Hedged	128 (21%)
Indirect	58 (9%)

Giving and receiving peer advice

Personal experience	303 (49%)
Total	622