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## 8 Sharing personal experiences and offering advice within online health-based social networks

**Abstract:** Online personal experiences (PEX) are becoming increasingly available to patients and provide an important resource for people to learn more about different aspects of a disease or treatment. Despite the availability of such patient stories, questions remain about whether or not they are beneficial to health decision making. Access to experiential information and advice can empower people to take control of their own health but can also leave patients feeling overwhelmed or isolated. One consequence of this rise in peer-to-peer healthcare is an increase in online advice exchange (i.e. asking for and offering advice to fellow patients). The process of advice exchange within online social networks is interesting, not least because it raises issues associated with trust, expertise, and disclosure. In practical terms clinicians have queried the usefulness of peer support in offline settings and raised concerns that health information exchanged online might be incomplete or inaccurate. In this chapter we review some of the key issues associated with online PEX and advice exchange. Drawing on the social and psychological literature we explore notions surrounding experience, expertise, and advice and provide illustrations from our own research. Using detailed online analyses we present findings from a study exploring advice exchange within an online breast cancer support group and in particular highlight the importance of personal experience as a form of advice giving. The implications for using online advice in health care decision making are considered along with a discussion of the issues surrounding this research method.

### 8.1 Introduction

Access to other peoples' online accounts of their health and wellbeing now provides patients and carers with a major resource for health information and advice (Ziebland & Wyke, 2012). Whilst studies have documented the social and emotional support these websites offer through their exchanges, there has been little attention given to the way in which people use these sites to exchange advice. How do people decide to trust one person's advice over another? What types of advice are people offered online and how does the advice translate into behaviour? This chapter aims to explore the notion of advice exchange within online forums and is organised as follows: In the next section we discuss the role of the Internet in the context of health information and advice, focussing on the role of personal accounts or narratives as a resource for

health information. In Section 3 we examine the context of advice within narratives and illustrate the concepts of expertise and experience with examples from our own research. Section 4 presents findings from a detailed study exploring advice exchange with an online breast cancer community. This section details the way in which advice exchange can be embedded within personal experiences. Section 5 draws together the literature and the results of the work to present some conclusions and considerations for future research.

## 8.2 Online Health Information

The Internet offers access to experiential information for people across a wide range of health issues including HIV/AIDS (Mo & Coulson, 2008), asthma (Sillence, Hardy, Briggs & Harris, 2012); antenatal diagnostic testing (France, Wyke, Ziebland, Entwistle, & Hunt, 2011) and informal caregiving (Hughes, Locock & Ziebland, 2013). Patients are increasingly the first source of information and advice for other patients in a new peer-to-peer process where patients are turning to others like themselves for advice and support and where detailed patient experiences (PEX) are offered online and used to inform health decisions (France et al, 2011; Entwistle, France, Wyke, Jepson, Hunt, Ziebland, & Thompson, 2011). This process of sharing information and advice appears to vary across different social networks according to, amongst other things, the types and frequency of the peer-to-peer exchanges they contain. Some social networks exchange more instrumental messages whilst others may contain more messages of social and emotional support (Mo, Malik & Coulson, 2009). 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 (Lamerichs, 2003; Sillence, 2010).

The process of advice exchange also varies across different online settings, with some studies indicating that it forms a key constituent of a particular online social network (Kouper, 2010) and others reporting that advice exchange is not seen as central to the community's functioning (Lamerichs, 2003). At a practical level advice exchange has the potential to influence treatment decisions. Because of this potential influence, clinicians have queried the usefulness of peer support in offline settings (Steginga, Smith, Pinnock, Gardiner & Dunn, 2007), and with there being 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. The picture here is mixed (Braithwaite, Waldron & Finn, 1999; Esquivel Meric-Bernstam & Bernstam, 2006; Hoch, Norris, Lester, & Marcus, 1999; Sillence & Mo, 2012) suggesting that the notion of how information and advice is exchanged within such settings may be more complex than first thought. Narratives or personal stories are one way in which people convey information about their health and wellbeing and are readily available on the Internet, on social media sites, and

in patient decision support tools. Narratives can be seen as consisting of different content types as people, for example, share the outcome of a treatment, explain the process behind their decision making, or provide details of their experiences (Shaffer & Zikmund-Fisher, 2013). Work on narratives within patient decision support tools settings has highlighted the fact that different narrative content types differentially affect outcomes and responses in terms of decision making (Shaffer, Hulseley & Zikmund-Fisher, 2013) so narratives containing process content (i.e. explanations of how the patient made his or her decision) appear to guide information search whereas narratives containing experiences, for example of treatments or side effects, improve evaluations of the decision process in an experimental setting. This suggests that the framing of the advice exchange (i.e. the way in which advice is both sought and subsequently offered) may affect readers subsequent search behaviour and decision making around the area, although this remains to be seen in more realistic settings.

### 8.3 Advice Exchange

The process of advice exchange within online social networks is interesting not least because it raises issues associated with trust, expertise, and disclosure. Expertise is not straightforward within peer settings (Lamerichs, 2003), unlike traditional health settings in which there is one expert advisor (i.e. the medic and one lay advice seeker, the patient), online support groups are by their nature a community of supposedly equal peers and so issues of expertise and credibility in such settings may prove more difficult. 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’ DeCapua & Dunham, 1993, 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 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 & Hoffman (2006) 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. Locher & Hoffman, 2006; Silverman, 1997), however the structural and pragmatic features of the advice exchange process are one indicator of its value within the online community (Kouper, 2010). These features can include the ways in which advice is solicited and the degree of directness of advice

mapping onto the look and feel of the community – its ethos. Kouper (2010), for example, notes that advice requests can be embedded within narrative structures which typically include long elaborations on the background and advice seekers tend to justify their requests. In replying to the messages, Kouper (2010) notes contributors dealt with the potentially difficult issue of ‘being an expert’ by using personal experiences to encapsulate advice rather than using direct advice messages such as “You should do x”. Richardson (2003) noted that members who respond to requests for advice use a number of warranting strategies to indicate their credibility and suitability for the task. These include presenting their own history and experiences through their profiles and their message posts, presenting their own key statistics and making reference to other websites and sources of information.

Our own work has shown how expertise in online health forums is managed through the adoption of quasi-medical conventions in which more senior posters display the technicalities of their conditions in medical short hand. They also request this form of patient notation from each new patient asking for advice before they offer any advice response (Sillence, 2010). 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 (Harrison & Barlow, 2009; Sillence, 2010).

## **8.4 A study of advice exchange within an online breast cancer forum**

Breast cancer patients make use of online health resources in a number of ways including increasing their sense of social support, (Fogel, Albert, Schnabel, Ditkoff & Neugut, 2002) gathering information and helping them make sense of the experience of cancer (Rozmovits & Ziebland, 2004). Advice exchange within 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 (Setoyama, Yamazaki, Nakayama, 2011).

### **8.4.1 Method**

Data for the study were collected between January and February 2011 and consisted of one month’s posts and comments to a breast cancer support site. The site was chosen because it was publically accessible (i.e. the messages on the site were publicly posted with no membership or password 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).

### 8.4.1.1 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 (2000) typology. 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 8.1.** 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.

To address the issue of reliably 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 Kouper (2010).

**Table 8.2.** 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 e.g. ‘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.

### 8.4.1.2 Findings

During January and February 2011, 425 original messages were posted (for more details on the message corpus see (Sillence, 2013). The analysis of the advice messages focused on both the ways in which advice was sought and the ways in which advice was offered. In this chapter we focus on two main findings: the search for advice from someone in the same boat and the offering of advice within the structure of a personal narrative.

#### Asking for advice

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 8.3.** Frequency of advice solicitation types within the forum

Type of advice solicitation	Frequency (%)
	<b>Breast Cancer forum</b>
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%)
<b>Total</b>	<b>299</b>

Very few posters sought direct advice from other posters. Members of the social network 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. 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’.

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. Should I back off or should I try to encourage them to do something?

Within the social network a typical advice solicitation took the form of a narrative containing a number of different structures. In addition to the advice solicitations, narratives contained 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.

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

Within the narrative structure a new type of advice solicitation was seen. This 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. Where treatment decisions are being considered it appears that women are drilling down through the



resources on offer within the community to find 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. Members used all four strategies for providing advice with direct advice and descriptions of personal experience being the most popular forms (see Table 4).

**Table 8.4.** Frequency of advice directness responses within the forum

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

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.

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.

It is interesting to note that nearly half of the advice offered on this forum was offered through personal experiences. 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 whilst recognising these kinds of messages can be useful to readers “hope this helps”.

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.

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. As a further step we examined the extent to which these personal experiences contained a variety of content types (see Shaffer & Zikmund-Fisher, 2013). To explore this we took those advice messages given in response to queries under the forum sub-heading 'reconstructive surgery'. There were a total of 31 responses containing personal experiences as a vehicle for offering advice. These responses were broken down into Outcome (5) Process (3) Experience (7) Outcome and Experience (7) Outcome and Process (4) and finally Outcome, Process and Experience (5). Responses that related more directly to decision making contained more process content (i.e. explanations of the process by which people had arrived at their decisions). This was in comparison to advice, for example, about how long to wear a particular piece of supportive clothing or what to take into hospital. Overall the narrative content type of 'experience' was the most prevalent with more than half the messages containing an experience narrative.

## 8.5 Discussion

The findings from the study presented here add to our knowledge about the prevalence and characteristics of advice exchange within an online breast cancer support group but also point to the wider issues concerning advice exchange within online social networks. Using this form of research method allows the subtleties and complexities of advice exchange to be examined in more detail. In terms of this specific forum it is apparent that advice exchange is a key function of the social network. People expect to be able to ask for and receive advice. Advice solicitations appear to be recognised as such and dealt with appropriately. 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 (Parks & Floyd, 1996) 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 (Jones et al, 2011). 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 (Raymond, 1991). Likewise this forum goes beyond what is often referred to as social Q&As (Shah, Oh & Oh, 2012) in that it offers a safe space for advice exchange, discussion, and social and emotional support.

The subtle range of ways in which members sought advice highlights the struggle they face in terms of mitigating potential power issues and displaying expertise against the backdrop of reduced cues, identity, and time flexibility (Suler, 2004). In addition this network (as seen in other health communities (e.g. Sillence, 2010) plays to the notion of active decision making and individual choice within the health forum.

Our work in the lab has established similar patterns of advice exchange within other health communities including prostate cancer (PCa) although subtle variations exist between social networks, with PCa forums demonstrating a preference for more direct advice exchange.

The study reported in section 4 identifies a novel type of advice solicitation - 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 (Sillence, 2010) 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 source) (Wang, Walther, Pingree & Hawkins, 2008). Entwistle et al., (2011) also note that participants only find experiential information relevant if it is derived from people with whom they share other key characteristics such as age, gender, or health experiences, or if they have other reasons to identify with the account.

In keeping with previous research (e.g. Klemm, Hurst, Dearholt & Trone, 1999) 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 (Sillence, Briggs, Fishwick & Harris, 2007). Having an active community with multiple members posting their personal experiences ensures readers are exposed to a range of advice perspectives. Although people report that they do not automatically rely on any single personal experience they read online (Entwistle et al, 2011), indeed, they are selective in the advice and experiences they choose to engage with (DeCapua & Dunham, 1993). By seeking out people in the 'same boat' readers are trying to encourage and select the most appropriate people to offer them advice.

Lab based studies (e.g. Shaffer et al., 2013) have indicated that the type of content within personal stories may affect the readers' subsequent search behaviour and decision making. Our own work, focussing on more realistic settings, also suggests that the framing of advice exchanges is important. However, in such settings, the advice seeker appears to play a more active role in determining the type of content they receive. People faced with real health concerns and questions 'position themselves' for different types of advice (Sillence, 2010), making it clear which kinds of advice they are open to receiving. 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. Within social networks these narratives often contain multiple content types with stories detailing outcomes, decision making processes, and experiential information. The results presented in section 4 do suggest that different types of message content are used in response to different types of advice requests, with experience content being prevalent. Other studies have indicated that people do provide more 'process' content (i.e. providing an explanation of their decision making reasoning if asked to by advice requesters) (Sillence & Mo, 2012). The proportion of content types within personal experiences

may well vary depending on the nature of the community itself or be specific to a health domain, and these differences warrant further investigation. These findings suggest that the link between online advice and decision making behaviour is both subtle and complex and unpacking this relationship lies at the centre of our current research agenda.

## 8.6 Conclusions and implications

This chapter highlights that for some online social networks advice exchange remains an important function. 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. In practice terms 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. Using this form of research method allows some of the nuances of advice exchanges within social networks to be explored. Going forward we are keen to explore the mechanisms of decision making in more detail and investigate the factors that make personal experiences such a powerful resource for people in social networks.

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