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Function, Content and Process in Online Health Communities: Implications for e-Health

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Abstract: We argue that commercial and professional practitioners in e-Health can benefit from researching the ‘process’ inherent in online health communities. We briefly explore the function and content of an online community. Then turn to our primary focus on the process (holistic approach, decision-making, problem-solving, evaluating contributions) through which online community members interact and exchange knowledge. We also highlight the interpersonal processes supporting knowledge exchange. These processes are vital in informing the design and delivery of e-health applications and we offer a conceptual pathway to illustrate the impact of informal online health communities on e-Health based on six interconnected stages.

1. Introduction

“Online communities deserve better than their current treatment – where they are largely relegated to the fringes of healthcare” ([1], p.107)

We argue that commercial and professional practitioners in e-Health can benefit from researching the ‘process’ inherent in online health communities. Understanding the process is as important as understanding the function and content. Function defines the driving force behind participation, content informs what we deliver and process informs how we design e-health applications.

e-Health is a major priority within e-Europe, promoting quality, access and efficiency of health provision across Europe [2]. However, the success of e-health applications depends on better integration of citizens’ needs [3,4]. Online health communities offer an excellent opportunity for exploring real-time interactions between citizens about issues of importance to them, which is an approach advocated in Human-Centred Design [5,6]. This is in line with a central aim of the e-Health Action Plan - to make services more patient-focused and personalised [4].

One aspect of the Internet, providing patients with unprecedented access to medical information, results in a degree of consumer empowerment [7] and enables international comparison of treatments [8]. Such enhanced knowledge may promote more informed decisions by consumers [9,10], encourage consumer empowerment [11,12], better treatment decisions [13], and a stronger provider–client partnership [8,14,15,16]. However, systematic studies of the accuracy of web-based information have been critical [13,17,18,19]. Most health information posted is produced by lay people [20] and has therefore caused concern among medical professionals.

One of the prime ways in which citizen voices have become more prominent in recent years is through the Internet and its discussion forums. Informal online communities have equally been dismissed as providing ‘inaccurate’ medical information; not recognising the broader benefits of online communities. However, Eysenbach [21] posits that online communities are a ‘rich source’ of data and their potential in health research is still relatively ‘untapped’. Indeed, Jadad and Enkin [22] see experiential and scientific knowledge as complementary. More recently, the Internet’s potential as a health-management tool has been recognised. The study of online health communities is advocated as a means of informing the design of emergent e-health applications [23]. This is particularly pertinent given that Web 2.0 promotes interactivity and collaboration amongst users, supported by flexibility and an ‘architecture of participation’ [24].

We briefly explore the function and content of an online community; important in determining shared and disparate needs of different patient groups. We then turn to our primary focus on the process through which online community members interact and exchange knowledge; vital in informing the design and delivery of e-health applications [23]. We identified a need for a framework to understand how ‘process’ informs the design and delivery of e-health applications. To address this we offer a conceptual framework to illustrate the impact of informal online health communities on e-Health, based on six interconnected stages. Whilst this framework is conceptual, we hope that it stimulates further discussion around how learning from diverse communities can be aligned and integrated into future applications.

2. Objectives

Overall we develop a conceptual framework showing how e-Health can benefit from researching the ‘process’ inherent in online health communities. To achieve this we:

1. Briefly define the function and related content of an online health community.
2. Identify the main elements of ‘process’ in online health communities.
3. Highlight how studying the ‘process’ of online health communities can inform and enhance the design and delivery of e-health applications.

3. Methodology

This study is exploratory and in line with previous research in the area [25,26].

3.1. Community Identification and Data Collection

Utilising the technique of Netnography [26], we undertook community identification and data collection as follows. We identified breast cancer online communities (English language) using the largest available search engine (Google). We reviewed threads within 6 breast cancer forums based on (i) high traffic and postings (ii) many-to-many communications, and, for our study, (iii) focused and detailed discussion around two specific drugs of interest. We collected textual data retrospectively from an 11-month period between July 2004 and June 2005. We illustrate our findings by presenting a single critical case [27] focused on the discussion of two drugs used in the treatment of breast cancer. The case is a US-based site but with contributors from UK locations.

3.2 Analysis

We focused on examination of contributions made by ‘insiders’ and ‘devotees’, who are proposed as the richest sources of data within communities [26]. ‘Insiders’ have strong ties to the online group and the topic and tend to be long standing and frequently referenced members [26]. We included some less well connected ‘devotees’ but excluded all with fewer than eight contributions. To identify ‘insiders’ and ‘devotees’, we evaluated the 252 community members in terms of (i) total number of contributions, (ii) threads contributed to, and (iii) reference by others to their postings [28]. Following familiarisation with the data, we analysed text sequences through a process of coding emergent themes [26,28]. These themes were organised according to three overarching categories related to: the function of the community; the content of the community threads; and, specifically for this paper, the ‘process’ of the community. Emergent themes are discussed below.

4. Function, Content and Process

In this section, we briefly outline the function and associated content of the community; the main discussion will focus on the process of the community.

4.1 Function

In line with other patient online communities [21,23], the driving force is to make sense of and manage a health event. It serves the concrete function of providing and gaining tangible facts and assistance with problems. However, at a more abstract level it serves as a ‘collaboration space’, not only for problem-solving, but also, for emotional expression, thinking, sharing and a sense of belongingness. As one member stated ‘’*It is nice to know I'm not alone with this struggle.*’’

4.2 Content

The content of the online community is multifaceted and hierarchically classified thus: experiential accounts relating to the condition; medical information (from various sources); emotional support; supplementary information. Contributions primarily presented and/or shared patient experiences. This usually emphasised a particular moment or encounter and was linked closely to the contribution of others in the discussion thread. Questions were asked; lifestyle advice and emotional support were offered. Alternative medical information was rarely offered. More commonly on this forum, information was derived from conventional allopathic medicine. Importantly, this medical information was referenced to a source, typically the member’s medical professional, but also the Internet or other media. Emotional support was highly valued.

This list does not provide a real sense of what members gain from the community. The experience of community participation provides something more intangible. By focusing on the process of the online community we get a clearer sense of what (and how) members gain from the community.

4.3 Process – ‘’A Collaboration Space’’

We explore the elements of process embodying the community’s ‘collaboration space’.

4.3.1 Holistic Approach

Members take a holistic approach to the discussion; demonstrating how members prefer to present, understand and evaluate information ‘within context’. Discussions were couched in everyday experiences, incorporating factual information/advice, emotional experiences, impact on life, supplemental lifestyle material, intended actions and feedback on actions taken. In this extract a member discusses treatment impact:

> “I DID gain weight on Tamox, about 20 pounds, no lie!! I packed on some more all by myself and can't blame it on that, but I DO blame it on slower metabolism due to menopause. I'm AM hoping to start walking more and exersising more in the new year. With my new breasts I feel more like slimming down and looking more like the old [self]!“

Members make sense of their experiences holistically. In the above extract the member presents a negative treatment effect (weight gain) whilst also discussing the positive impact (feels ‘more like’ looking like ‘the old self’) and expresses goals (starting new exercise regime). Discussions are integrative and reciprocal (one member’s story is woven into another’s), highly interactive and engaged. Discussions are often frank and realistic (presenting a ‘warts and all’ approach) and incorporate strong emotions. This is in contrast to the information/advice often provided by healthcare professionals, which can be disengaged, making it difficult to reach shared patient-professional understandings.

This holistic process facilitates fuller understanding of a condition, and is supplementary to interactions with healthcare professionals.

“I was diagnosed w/invasive ductal breast CA, Stage 1,Grade 2, negative nodes, ER & PR positive in 10/04. Had a lumpectomy, 6 sentinel nodes (all negative) followed by 7 wks. of radiation txs. Started taking Tamoxifen on 12/1 & hate this darn drug. On 5/26 went to see the gyn doc & he did an endometrial biopsy (stillwaiting for those results) & the pelvic US showed a "growth" on my left ovary. He feels it's just a cyst as it doesn't have the appearance or feel of a malignant growth but needs to be monitored closely as it wasn't there 6 mos. ago. Anyone else out there experience this?

I'd appreciate any feedback about this. I'm going today for my first 6 mos. post-op mammogram & am a trainwreck, didn't sleep all night. But then, sleep has pretty much been foreign to me since starting the Tamoxifen.”

In this extract the community member is looking for experiential feedback to supplement the more factual information provided by the physician. An appeal is being made to the community to facilitate coping with the broader uncertainty and emotional aspects of the disease and its treatment.

4.3.2 Decision-Making

Members’ narratives reveal what and how factors, including sources of information, are taken into account in decision-making. Understanding these processes can clarify, for example, why an individual may choose a medically-defined ‘less effective’ treatment or choose to stop treatment based on a consideration of impacts on daily life. In the following accounts community members share their decision-making with respect to treatment choice. These accounts explicitly reflect factors important to members.

“I had stage 1, grade 1, sentinal node negative, chose a lumpectomy because FOR ME< it was going to be the most comfortable for me (D cup meant I would really need reconstruction which I did not want to do at my age, . I am a three year survivor< took the radiation< again my choice: brachytherapy HDR-5 days only. I truly did not expect Arimidex to give me one minute of trouble, but it hit suddenly, between 3rd and 6th month, gradually getting worse. It did NOT affect my bones; had good results on bone density recently.

I was premenopausal, but during chemo (Jan - April 04) I did not have a period after 2/26. I began arimidex (one of the aromitase inhibitors) June 04, and then had another period 11/11/04 and called my medical oncologist. My medical oncologist referenced the "ATAC" trial (go to arimidex.com) and said I would have a 2% less chance of recurrence by going on arimidex vs. tamoxifen. I also thought the side effects of tamoxifen - higher chance of uterine cancer, etc., was less desireable.”

Similarly, members also explained why they stopped treatments, as illustrated in the following two extracts.

“I am a 3 year survivor, grade 1, stage 1, sentinal node(s) 3, negative, had lumpectomy and brachytherapy for my HDR radiation (five days only) before Mammosite was available, same except I had multiple catheters instead of 1 with balloon...I was 68, at the time...I did tamoxifen a year (misery) and switched to Arimidex and then at 3 months, bone pain and at 6, I quit....

To you girls that mentioned Effexor. I tried that about 3 years ago. My onc and I think I am allergic to it becuz I only took one pill, on a full tummy (I never take pills on an empty one) and I was severely nausated (SP?) for 24 hours. I couldn't even function it was so bad. Ick! It was just awful! So that idea is down the tubes, but I so appreciate the suggestion. It is nice to know I'm not alone with this struggle.”

In these extracts, treatment journeys are punctuated by references to met/unmet expectations (‘truly did not expect’, ‘2% less chance’) and the impact on self (‘it hit suddenly’, ‘misery’) that together influence decisions. The decisional balance is evident, taking into account a combination of personally salient factors, e.g. reported efficacy of a drug, comparison of side-effects, weight gain, regime, intrusion on life and acceptable risks. Alongside this we can see what sources of information are used and, importantly, how they are combined to build a picture of the situation and what can be done. Whilst understanding decision-making is important from an individual perspective, it also reveals common preferences, obstacles and experiences amongst patients in decision-making that can inform better service delivery.

4.3.3 Problem-Solving

The community provides an important space for problem-solving, where problems are shared and worked through together. In this ‘thinking space’ users are not restricted to a specific medical view. Online communities provide a rich source of the possible confusion experienced by those undergoing treatment, how they resolve such confusion and come to a ‘shared understanding’. For example, exchanges presented apparent paradoxes between predominant personal experience and reported medico-scientific ‘fact’. An important function of the community was to offer plausible explanations for such paradoxes. The following was posted to open a discussion of ‘side-effects’:

“I read the info I received with my first tamoxifen prescription, I started it yesterday ... Anyway, did anyone notice that one of the side effects listed is Weight Loss?????? I had to laugh at that, from everything I have read, women say they gain NOT lose weight! .Please... is there anyone out there who lost weight?? How did you do it???”

Usually there is an initial confirmation that the problem or confusion is shared by others. A sense of ‘shared misunderstanding’ can lead members to feel at ease, more ‘normal’ and able to more fully express themselves.

“I just started tamoxifen 3 weeks ago and noticed the same thing. I laughed and showed my husband. I too have lost my shape to my stomach and my pants fit a little funny. I have not gotten back into my excercise routine though and fully intend to do that soon.”

Finally, following discussion, an ‘insider’ brings some clarity to the problem:

“I have done a web search, and although weight gain is mentioned in most sites as a possible side-effect, it is usually accompanied by a sort of disclaimer explanation. Here is one:
"Weight gain: Large studies conducted by the National Surgical Adjuvant Breast and Bowel Project (NSABP) revealed that women who took a placebo (inactive pill) were just as likely to gain weight as women who took tamoxifen. It is difficult to determine whether weight gain is caused by tamoxifen or by other factors, such as prior cancer treatment (especially certain chemotherapy regimens), changes in physical activity, changes in eating habits due to the stress of coping with breast cancer, etc. A few women who take tamoxifen experience weight loss."

Thus forums can provide a rich source of the possible confusion experienced by those undergoing treatment, and the problem solving strategies applied to resolve such confusion.

4.3.4 Evaluating Contributions

How members choose to express and offer advice/information is indicative of how they seek to evaluate the credibility of a message and build trust in a source. Within this particular online community trust and credibility were established through (a) relevant personal experience of the disorder, and (b) a medical reference source (most often a healthcare professional, but also the Internet and other media). In the following extract, a ‘devotee’ firstly establishes her experiences, locates the information in a professional discourse and adds weight by placing the oncologist, of which the patient has experience, in an academic research context. This format is modal for the forum.

“I've been experiencing aches/pains/stiffness from Arimidex, and my radiation oncologist (and others) submitted an abstract at the San Antonio Breast Cancer Symposium this December concerning "musculoskeletal symptomatology". If your vitamin D levels are low your doctor may be able to give you a prescription for a high dose of vitamin D to be taken weekly (I think). Go to the link below, or search the abstracts for vitamin D deficiency."

Members used a process of triangulation where personal experience established themselves as a credible source and the medical reference lent weight to the information or advice offered. Given the literature on word of mouth in marketing we might consider such postings as important because they carry higher credibility than communications direct from producers, in this case, of drugs and medical services.

4.3.5 Established Modes of Sourcing Information

Information was commonly derived from conventional allopathic medicine. Importantly, this medical information was referenced to a source. Members' reference sources were typically the member's medical professional, but also the Internet, TV, academic research and clinical trials in combination with one another. Members often provide URLs for the sites mentioned and even direct quotes illustrating particular points. Often narratives will present information from two or three different sources, presented in an integrative manner.

4.3.6 Making Tacit Knowledge Explicit

Ultimately these processes, in combination within the 'collaboration space', offer the essential elements of making tacit knowledge explicit: supportive interaction; sharing knowledge; combining knowledge; feedback on actions [29]. Interaction is the first step in making tacit knowledge explicit – online communities offer the opportunity to externalise their own knowledge in a none-threatening, non-prescriptive, non-time constrained environment. The community offers the means to integrate or combine their knowledge into a shared resource. In some cases members are able to act on this knowledge outside of the community, and ensure that they share their experiences and learning with the community. In this way members have the opportunity to internalise the shared knowledge [29]. This is not only important for the members of the community but also much can be learnt about the learning process within the patient population, with important implications for patient education programmes.

4.4 Interpersonal Processes Supporting the Collaboration Space

The maintenance of the supportive nature of the collaboration space underpins successful problem-solving, decision-making and ultimately knowledge transfer. Indeed, members are careful to maintain the supportive environment and ensure that feedback is given on suggestions made. Further, members are sensitive to interruptions in the 'flow' of the space. When seemingly 'incorrect' or contested material is presented members quickly seek to re-establish equilibrium within their experiential culture. The following series of extracts clearly illustrates their conflict resolution processes. An 'insider' advises on the medical difference between two drugs, their mode of action and their 'side effects':

"Aridimex is a stronger drug [than Tamoxifen] (they first used it 5 years ago on women with end stage B.C.) and has worse side effects than Tamox."

However, within two days this post is challenged by another 'insider' who contests her statement both on the drugs mode of action and side effects.

"You know, I've heard the opposite about Arimidex, that its potential for side effects is less severe than Tamoxifen. It's not so much that it's a stronger drug, as it is a differently-acting one. Tamoxifen blocks estrogen receptors on the breast cancer cells but doesn't affect overall estrogen levels; Arimidex is an aromatase inhibitor which prevents the production of estrogen."

The preface 'You know' can be interpreted as a reluctance to be directly confrontational. Additionally, 'I've heard' deflects attention from the contributor to unnamed 'others' whose opinion conflicts with the original view. The challenge is couched in medical terminology and, unusual for this forum, not grounded in personal experiences. The exchange is closely followed by a number of contributions from 'devotees' commending the prime contributor for her consistent support and replies to postings. These are expressed in emotional language and indicate her valued position. The importance of this exchange is that it is a crisis in the established experiential culture in the forum. It therefore, offers an example of forum participants negotiating knowledge in the absence of a formal normative hierarchy and repairing the fabric of their experiential culture. The effective methods for maintaining a supportive environment and conflict resolution are essential underpinnings for knowledge transfer.

5. Implications for e-Health

Examining process alongside function and content within online health communities can greatly enhance understanding of how patients manage their own health and, consequently, inform design and delivery of e-Health applications. However, there is a paradox; whilst communities can offer distinct advantages to patients and professionals alike [7,8,9,10,11,12,14], they may also have a negative impact, particularly through the provision of inaccurate information [13,17,18,19]. We offer a conceptual framework (figure 1) of the impact of online health communities on e-Health, based on six interconnected stages. One of the main philosophies driving this framework is that, rather than dismissing communities, we should harness their potential; even, and perhaps especially, focusing on the 'negative' elements. This is a framework for, not only focusing on the positive aspects of communities, but also for considering how we can align disparate elements (e.g. medical versus lay person viewpoints); such issues may be the result of misunderstandings that would be evident in community discussions. Further, communities that, for example, challenge current health systems/thinking can be an important source of information, highlighting sources of resistance to health policies and treatments. As practitioners, we should ask ourselves what we can learn from both the positive and negative aspects of communities and how we can turn this knowledge to advantage all stakeholders in e-Health. It is not that processes are 'correct' or 'incorrect' but that they exist and either way they can be a useful source of information for e-Health. These processes tell us something about potential 'holes' in health service provision and it is a matter for future research to consider if these 'holes' need be addressed by formal healthcare.

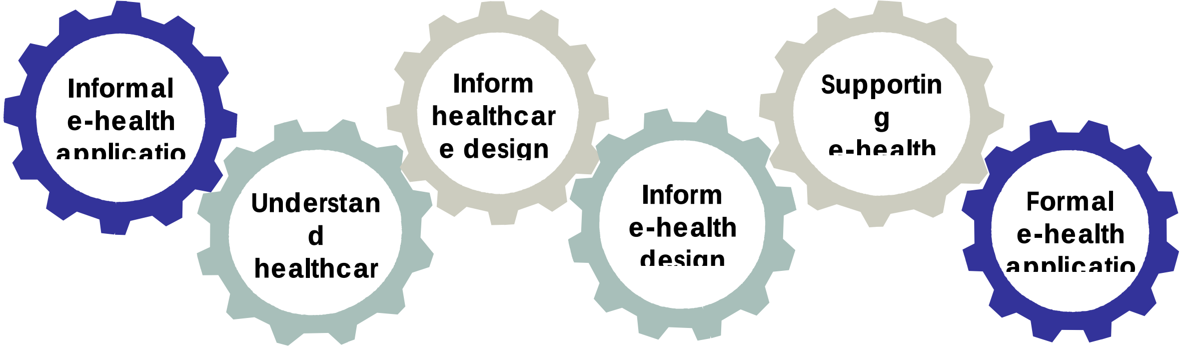

Figure 1: Using Online Communities to Inform e-Health

We stress that this is an overarching organisational framework and different elements may be focused on by different projects. We suggest that at a strategic level consideration is given to these six stages, as a means of informing requirements capture, interface design and identifying where problems may occur in the implementation process. At the first stage, we emphasise that informal online health communities are an informal 'e-Health' application in their own right. Citizens will continue to use these Internet resources as a means of managing their own health and that, whilst recognising their potential shortcomings, they should not be dismissed as uniformly unreliable. We need to harness the benefits. At stage 2, examining the process inherent in informal online communities help us to understand patient choices, preferences, sources of information, attitudes to healthcare professionals and the impact on a citizen's interaction with formal healthcare services. This is taken to a more formal level in stage 3, where learning from the patient's holistic approach to health, needs, common misunderstandings, obstacles and problem-solving and decision-making processes can greatly enhance our design of future healthcare services. For example, illustrating how we can effectively present/deliver information to enhance patient understanding and engage patients more effectively in decision-making through mechanisms such as social marketing and patient education campaigns. Knowledge transfer is more than simple provision of information; by reviewing the processes through which members come to understand their condition we can learn more about how to better provide information and promote understanding amongst patient groups.

Most importantly, this is particularly the case for e-health applications where, at stage 4, we can utilise these same mis/understandings to inform the design of a diverse range of e-Health applications. At one level, communities are good indicators of health service needs and applications can be designed to support these needs. At another level, communities reveal important processes that can underpin the design of applications, particularly in the areas of decision-making, patient education and patient engagement. At stage 5, specifically designed online health communities can be an important support structure alongside more formalised e-healthcare. The importance of the interpersonal processes underpinning the community cannot be overemphasised and thus communities can be a worthwhile 'support plug-in' to complement other e-Health applications. Finally at stage 6, online health communities can be used as a formal e-Health application in their own right. By harnessing the 'natural' way in which people interact and exchange information, we can design communities that facilitate knowledge transfer within a supportive structure.

We hope that this framework will stimulate further discussion about harnessing the benefits of online communities, and the potential for future research is manifold. We have focused on devotees and insiders for this study, we must not, however, overlook 'lurkers' [30]. There are a larger proportion of citizens who use online communities as a resource, whilst not participating in the community itself. Understanding of how these 'lurkers' use online communities is an essential element in informing our conceptual framework [30]. The first two authors are currently undertaking an extensive programme of research to gain a holistic view of how the Internet impacts on healthcare, an essential element of this research focuses on the role that informal online communities have to play.

6. Conclusions

In this paper we argue that examining the process within online health communities can greatly enhance our understanding of how patients manage their health in everyday life. The online health community is an experience rich environment far removed from the 'traditional' model of the health service encounter. Studying the function of the community facilitates understanding of motivations. Studying 'process' facilitates understanding of how we can better fulfil patient needs, engage patients in e-Health and improve e-Health service delivery. This challenges the prevailing concern solely with the accuracy of medical information and misgivings about lay knowledge. Online health communities are more than the sum of the information provided therein or the sum of lay knowledge. They provide the user with a sense of belongingness and a non-threatening 'collaboration space' within which to share decision-making, solve problems and learn from each other to reach a 'shared understanding'. We offer a 6 step pathway indicating how exploring these processes within informal health communities can impact on e-health service.

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