Patient Education and Counseling 95 (2014) 265–270

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou

E-Health

Expert and experiential knowledge in the same place: Patients' experiences with online communities connecting patients and health professionals

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ARTICLE INFO

Article history:
Received 23 September 2013
Received in revised form 8 January 2014
Accepted 5 February 2014

Keywords:
Internet
Patients
Physicians
Online health communities
Information
Expert knowledge
Lay knowledge
Reliability

ABSTRACT

Objective: To explore patients' experiences with online health communities in which both physicians and patients participate (i.e. patient-to-doctor or 'P2D' communities).
Methods: A qualitative content analysis was conducted, based on observations in five P2D communities ranging from 8 to 21 months, and semi-structured interviews ($N = 17$) with patients.
Results: Patients consider information from physicians and peers as two distinct sources, value both sources differently and appreciate accessing both in the same web space. According to respondents, physicians can provide 'reliable' and evidence-based information, while patients add experience-based information. Patients use this information for multiple purposes, including being informed about scientific research and personal reflection.
Conclusion: Patients find P2D communities beneficial because they help patients to collect information from both medical experts and experiential experts in one place.
Practice implications: Patients use P2D communities to perform medical, emotional and lifestyle activities. The presence of physicians in P2D communities may inadvertently suggest that the quality of information used for the activities, is controlled. When information is not officially being checked, this should be stated explicitly on the website and supplemented with a statement that information is only indicative and that patients should at all times contact their own physicians.

1. Introduction

In the past few years, virtual communities have rapidly increased in prevalence [1–3]. Virtual communities are social networks facilitated or formed online [4], "where people with common interests gather 'virtually' to share experiences, ask questions, or provide emotional support and self-help" [5:1]. Online communities are used in various sectors including healthcare, where they usually form around health-related conditions or goals, such as losing weight, living with back pain, or coping with disease.

Research on health-related online communities has explored how they are used and how users (mostly patients) experience them [6–11]. Research on this topic primarily focuses on communities where *patients or family members* share experiences, also known as online patient support groups or peer-to-peer (P2P) communities. These studies indicate that patients who use P2P health communities are better informed about symptoms and treatments [7–9,12], receive guidance on coping strategies [13], and find patient peers [12].

Online communities in which *patients and physicians* are linked (here defined as patient-to-doctor (P2D) communities) also exist [14,15], but are currently under-researched. In these communities, patients and healthcare professionals are able to communicate with each other regardless of geographical location or the professional's institutional affiliation. An offline medical treatment relationship between the members of the community is generally absent, with the focus being on self-help rather than provision of health services. Although knowledge exists on the consequences of using P2D communities [see e.g. 16–18], most studies focus on 'ask the doctor forums', rather than interfaces where questions can be posted to and answered by both patients and healthcare professionals.

This paper reports the results of a qualitative study of patients' experiences with online self-help communities in which both

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http://dx.doi.org/10.1016/j.pec.2014.02.003

physicians and patients participated. The research question was: *How do patients experience the use of online P2D health communities and what are the consequences of such use*? The research reported here addressed this question in relation to the Dutch website MijnZorgnet.nl ('my health net'), an online platform where patients and healthcare professionals communicated and exchanged knowledge within online health communities. The insights gained in this study are relevant for practice because patients are increasingly obliged to stay informed about health matters [19], which potentially leads to greater use of online health communities for this purpose. More information about how patients experience both participation in P2D communities and consequences of such participation, enable reflecting on the informed patient discourse [20] in light of practical experiences.

2. Methods

2.1. Observations of online health communities

Qualitative research was conducted on a single case in the Netherlands: the website MijnZorgnet.nl. MijnZorgnet.nl provided an online platform where patients and healthcare professionals within online health communities could communicate and exchange knowledge, and was in that format online from late 2010 to late 2013 [15,21]. The communities were supported by several applications, including blogging applications, forums, private messaging and wikis. These applications enabled end-users to produce and publish text, images and/or emoticons on MijnZorgnet.nl, in the absence of official moderators.

The first author observed five web-based 'open' health communities on MijnZorgnet.nl for 8–21 months (between December 2010 and September 2012). 'Open' means that the community's content was visible to anyone who had Internet access. Registration to join these communities was only necessary when a community visitor wanted to respond to an existing message or post a new one. The online health communities on MijnZorgnet.nl were selected for maximum variation in disease subjects, community manager's background (i.e. patient or physician), community lifespan and number of community members. See Table 1 for the characteristics of the selected communities. In order to understand the use and value of online P2D communities for patients, screenshots were taken and archived of all content in the selected P2D communities, and the following aspects were examined and described in field notes using thick description: architecture (i.e. functionalities, such as blogs and wikis), how people converse (i.e. treatment), the content of the conversations, how people present themselves, and the contributions of the community manager. Data saturation was reached after seven months of observations and confirmed by the 14 remaining months. This extended period with different observation moments was chosen because newly created communities need time to mature [22].

2.2. Interviews

The observations led to an initial understanding of how P2D communities are used by patients and for what reasons. To gain more insight in how patients experience such communities and the consequences of using them, semi-structured interviews ($N = 17$) were conducted, by the first author, between June and October 2012 with patients from two of the observed communities: 'Parkinson's disease and labor' and 'Parkinson's disease in young patients'. These communities were selected because they have the longest lifespan of the five communities shown in Table 1 and a relatively high number of members, which increases the possibility of more activities and 'traffic' (i.e. postings) within these communities. Content-wise, these two communities are also interesting as they involve patients with Parkinson's disease (PD): a chronic and progressive movement disorder whereby patients arguably search for information at different moments in time and during an extensive period (i.e. for the rest of their lives). Patients were recruited through blog and forum messages posted with permission in the selected communities. After two weeks, private messages were sent to all the patients within the communities, with an interview invitation including a reminder of the blog and forum message. Table 2 shows the background characteristics of all interviewees. Respondents' activity levels varied from only reading to active posting of various messages.

During the interviews, patients were invited to talk about how, why and how often they used the online P2D community, and what their (positive and negative) experiences were with this use. In addition, they were asked to react on the findings from the observations. There were four telephone interviews and thirteen face-to-face interviews, conducted at the respondent's home (at their request), and lasted 73 minutes on average. Interviews were tape-recorded and transcribed verbatim. Six respondents wanted to receive their own transcript and checked it for accuracy. Data saturation (i.e. no new information) was reached after the 13th interview and confirmed by the four remaining interviews [23].

2.3. Content analysis

The observation field notes and interview transcriptions were both submitted to qualitative content analysis. A process of open coding was performed, by carefully reading all the data and by giving labels to words, sentences or paragraphs that related to each other [24]. Then, categories were created, by clustering codes that shared a commonality, also known as axial-coding [25]. This phase facilitated insight into relevant and less-relevant codes. Finally, themes were created (i.e. selective coding, [25]), by selecting the core category, relating it to other categories and determining the meaning of their interaction. This process of analysis involved a back and forth movement, just as the process of data collection and analysis [24], and was performed by the first author and checked for consistency of application of the codes to the data by the second author. All codes, categories and themes were recorded in Excel. Data was translated from Dutch to English by the first author and reverse-translated by the second author (a native English-speaker) to verify proper capture of diction, colloquialisms, etc.

2.4. Ethical considerations

Before this study was conducted, permission to perform the interviews was obtained by the Committee on Research Involving

Table 1
Characteristics of the selected communities on September 19, 2012.

Subject of community	Number of members	Background of community manager(s)	Online since	Followed for
Parkinson's disease & labor	158	Physicians (1 medical officer and 1 occupational therapist)	22-Dec-2010	21 months
Parkinson's disease in young patients	61	Patient	21-Jan-2011	20 months
Cerebrovascular accident	95	Patient	20-Feb-2011	19 months
Fertility care	2	Physician (gynecologist)	2-Feb-2011	8 months
Safe care for pregnancy and birth	18	Physician (obstetrics nurse in training)	9-May-2011	16 months