Will PatientsLikeMe.com affect the doctor – patient relation and the work environment of doctors?

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There have been large changes in the area of healthcare in the past decades concerning patient participation, patient empowerment and the development of knowledge in healthcare. This has consequences for, amongst other things, the relationship between patients and caregivers. Web. 2.0 made different types of online communities for patients possible and the concept Medicine 2.0 was developed for health issues on the Internet. This paper addresses one such community, namely PatiensLikeMe.com (PLM). PLM is designed for patients' independent use to get information and knowledge about their disease, and to get in contact with other patients with the same diagnosis to share experiences. Our aim is to analyse the online community PatientLikeMe.com from the perspective of how the type of information it allows for, can be used by patients and what consequences it may have for the doctor-patient relationship and thereby on the work environment of the doctors. Traditionally the doctor's knowledge base has been seen as specific and difficult to gain for actors outside the profession. This might now change due to the patients' opportunity to build their own knowledge base on PLM and other similar sights. This may enhance patient empowerment and literacy but also lead to impairment of the doctor-patient relationship and ultimately the working conditions of the medical profession through loss of control over their knowledge base.

Practitioner Summary: PatientsLikeMe.com is an example of an online community that enables patients to communicate, interact and share their information about their health conditions. Patients can thus build a knowledge base of their own on the site. Traditionally this type of knowledge base has been exclusive to the doctors. In the paper we discuss how this may change the doctor-patient relationship and the working conditions for the medical profession.

Keywords: Online Community, eHealth, work environment, doctors, knowledge base

1 Introduction

There have been large changes in the area of healthcare in the past decades concerning patient participation, patient empowerment and the development of knowledge in healthcare. This has consequences for, amongst other things, the relationship between patients and caregivers (Van De Belt, Engelen, Berben & Schoonhoven, 2010). The prevalent medicalization of society means that issues related to health and disease are not only handled within the traditional healthcare, but also in many other places and social contexts in society. The possibilities for information, communication and interaction on subjects related to health on the Internet is big (Institute of Medicine, 2009). The EU Commission has adopted eHealth as an umbrella term for the application of digital technology to improve and develop health at both the individual and societal level. This includes self-care, social services, health care and health care interactions with patients, families and other stakeholders (EU 2014).

Historically the doctor has been the expert considering health issues. However the development of the Internet has made it possible for patients to not only seek information but also, engage in social networking, learning and not least, interaction (Hughes, Joshi & Wareham, 2008). Web. 2.0 made different types of online communities possible and the concept Medicine 2.0 was developed for health issues on the Internet. According to Eysenbach (2008) the development of Medicine 2.0 stands in contrast to the hierarchical and closed systems that traditionally have characterized the area of healthcare knowledge. The combination of social media and health care is powerful and the concept of Medicine 2.0 may thus have a big impact on healthcare. The development is driven both by patients and by economic forces and it will be a challenge for the health profession to adjust to it (Winkelstein, 2013).

This paper focuses on a Medicine 2.0 solution, namely the online community PatientsLikeMe (PLM). The technical development of the Internet has enabled websites like www.patientslikeme.com,

with user-generated content in the health field. The company PatientsLikeMe Inc., can be described as one of the leading Medicine 2.0 companies in the world (Goetz, 2010). However, not much has been written about PLM yet by researchers external to the company. PLM is designed for patients' independent use to get information and knowledge about their disease and to get in contact with other patients with the same diagnosis to share experiences. PLM opened its first patient site in March 2006 (Frost & Massagli, 2008). One aim of the website is to empower patients to manage their health in the best possible way. In spring 2015 PLM had over 300 000 members and there are over 2 300 different diagnoses recorded on the site. The content on PLM is user generated and is made up exclusively of the experience that the members share. The patients themselves have created 25 million registered data points about their diagnoses, disease symptoms and treatments on the site. Kazmer, Lustria, Cortese et al (2014) have analyzed posts from the discussion forum in the ALS community at PLM. They explore how members in the patient community share and build knowledge together. In addition to the discussion forum for each condition, PLM has formalized mechanisms that help members find patients like themselves and tools for visualization of for example, symptoms, treatments and pain. The study found that patients were sharing, using and building distributed knowledge together in the ALS community. One of the effects of the development described above is that the basis of knowledge that previously was exclusive to the healthcare professions in general and doctors in particular, is now accessible and responsive.

Our aim in this paper is to analyse the online community PatientLikeMe.com from the perspective of how the type of information it allows can be used by patients and what consequences it may have for the doctor-patient relationship and thereby on the work environment of the doctors.

2 Theoretical framework

2.1 Online communities, social objects and knowledge

Historically, people have always been joining different groups with the purpose of sharing and getting information, although social media and the technical development has given human interactions global and asynchronous possibilities (Winkelstein, 2013). Online communities are examples of social media solutions. Gunawardena, Lowe and Anderson (1997) argue that knowledge creation can take place on both the individual and the social level. Knowledge is created at a social group level and at the same time the individual creates his/her own knowledge through the interaction in the group. Shirky (2008) believes that the characteristics of successful social media are that they are based on a reasonable promise, effective tools and acceptable terms. The promise is tied to the reason why one should participate, the tool is related to the question of how participation takes place, and conditions will determine the rules for participation. The individuals who are interested in participating and using the tools, can expect something and the provider of the social media expects in return something from the individual. Membership in an online community can provide changes in the offline world. Members found that the online support from people that understand their situation and can contribute with information is valuable (Maloney-Krichmar & Preece, 2005).

Social networking is a description often used to demonstrate what constitutes the reason to participate in social media related to developments in Web 2.0 (Hughes Joshi & Wareham, 2008; Eysenbach 2008). Social networks are composed of people who have a common interest in sharing social objects with each other. Engeström (2005) argues that it is a mistake to think that social networks are solely created by people. It is the content of the object that is important, what thoughts, actions and reflections are initiated based on this content? "The term 'social networking' makes little sense if we leave out the objects that mediate the ties between people. Think about the object as the reason why people affiliate with each specific other and not just anyone…" (Engeström, 2005).

The key with Web 2.0 is not that people are together, but what brings them together. Knorr Cetina (2001) argues that social interaction does not occur on its own and says that there is an increase in knowledge-based and knowledge-centered activities in many areas of our social life. The core of these practices is the epistemological objects. These objects of knowledge are characterized by their lack of integrity, their mutual differences, their variability and ability to continuous development as well as their meaning and unifying force. These are the characteristics that make the objects interesting as they invite further social interaction because there is always something new to relate to and interact around (Knorr Cetina, 2001). A social object can also be a driver in pedagogical settings if it has content that creates commitment, tools that enable social interaction around the content, and a group that considers the social object interesting (Weller, 2008).

Säljö (2012) suggests that the technological development we see in today's society implies that more knowledge and information is externalized in different external memory systems (EMS) and that the human knowledge is built into things around us. EMS mediate artefacts in which information and

experiences can be stored. They are collective and public in nature and they are created in the context of different activities. Säljö argues that these artifacts are not passive objects. They contribute actively to transform information and influence behavior. The development of digital technology has meant that artifacts are increasingly composed of objectifications of human experience (Säljö, 2012). Another result of this development is the increased opportunities for visualization. Visual representations are presented in the form of dynamic and interactive representations where you can track changes over time, providing learning opportunities (Säljö, 2012).

2.2 The knowledge base of the doctor

The medical profession is often portrayed as one of the classic professions in society (Brante, 2010). Within healthcare the dominance and power of doctors is dependent on their exclusive knowledge (Currie & White, 2012). According to Freidson (1970) the exclusivity of expert knowledge is also salient for professional autonomy. Both Abbott (1988) and Freidson (1994) have pointed out the importance of the professional knowledge base for the actions of professions and their possibilities to survive and evolve. Fournier (1999), in turn, argues that the creation of professions' knowledge base is a part of the construction of boundaries through "boundary work" which is central to the establishment and reproduction of the professions. Fournier (1999) describes two processes of "boundary work" – "the constitution of an "independent and self-contained field of knowledge" as the basis upon which the professions can build their authority and exclusivity; and the labour of division which goes into erecting and maintaining boundaries between the profession and various other groups" (p.p. 69). It thus becomes important for professions to shelter their exclusive base of knowledge from external threats. This has been noted for doctors on an individual level (Warring & Currie, 2009) and as a collective (Jonnergård & Erlingsdóttir, 2012). Jonnergård and Erlingsdóttir (2012) also point out that the need to shelter their knowledge base is stronger for doctors than, for example, for auditors as doctors' expert knowledge traditionally has been more exclusive and harder to obtain or copy by other groups in society.

Fournier (2000), however, argues that the logic of the market, as in the New Public Management (NPM) reforms, transforms patients into empowered customers that may challenge the relation of dependence between the patient and the doctor. According to Bejerot (2008), patient empowerment and the aim to put the patient at the centre of the healthcare situation in the "post NPM" era, continues to circumscribe the doctors' autonomy and power. This change of balance becomes even more obvious with the patient empowerment embedded in many of the eHealth services that have surfaced during the past years (Erlingsdóttir & Lindholm, 2015). Patient empowerment, in eHealth, is often connected to patient access to and control over their health condition and their health information (Erlingsdóttir & Lindholm, 2015). The doctors' jurisdiction over their expert knowledge or their knowledge base that Abbot (1988) describes as compact might thus be challenged in a way that it has never been before.

3 Method

3.1 Research on the Internet

In today's society, the Internet is the most comprehensive place for information storage. Websites and virtual meeting places such as blogs, discussion forums and chat rooms are all filled with presumptive empirical data for various research projects. This study is directed at an online community that contains a wealth of data that normally is confidential. In order to understand the impact sites like PatientsLikeMe.com may have on the doctor-patient relationship we analyze the social and pedagogical practice described on the PLM site. After a general survey of the public part of the site demarcations were made. The demarcations in the material are that no data from specific patient communities or individual patients is included in the study. The study does thus not involve the site contents consisting of different patient's descriptions of their disease and symptoms or discussions at the forum communities that is connected to each condition. Instead the empirical material has been gathered from the public area of the site. Allen, Burk and Davies (2006) claim that it is considered as natural that the information that is available in a public area of a site is spread. The parts of the site that were investigated is the text contained in "About Us" on the start page and the content that can be found in FAQ. Under these headlines there are descriptions of the site and its contents. The selected domains constitute the basis for the analysis in this study.

3.2 The analyze process

The material is analyzed by the use of qualitative content analysis. Content analysis is a well-established method, and it can be used on online resources. The procedures to analyze the web-based content are the same as in content analysis of traditional sources (McMillan, 2008). This study focuses on the latent content of the text. Latent content analysis is appropriate when interest is directed at the underlying meaning of the text (Lundman & Hällgren Graneheim, 2004). In a content analysis of inductive data, the analysis goes from the specific to the general, smaller units are combined into a larger whole (Elo & Kyngäs, 2008).

At the start of the analysis process, we reflected over the text's main content, what was the key in the text related to the research question? This process resulted in the text of the analysis being divided into the two domains Terms and Offers. Domains are identifiable with a low degree of interpretation (Lundman & Hällgren Graneheim, 2004). The reason these two domains were selected is that we believe that the presentation of the terms and offers available to users are two important aspects of the overall knowledge production on the website. A patient's participation is situated and dependent on the conditions that are prevailing the website. How are the conditions of participation presented? There are offers in various forms on the site. How are these offers to the users presented? The last step in the analysis process was to create a theme. A theme consists of the underlying content in more than one category, and answers the question "How"? The theme is based on the text as a whole, the content of the categories and the researcher's attention to the underlying message (Lundman & Hällgren Graneheim, 2004).

4 Results

4.1 The online community PatientsLikeMe

PatientsLikeMe Inc. was founded in 2004 and the description of the company and the online site they provide is taken from the site. PatientsLikeMe.com opened in March 2006 for patients diagnosed with ALS. The business concept is derived from the experience of having a loved one diagnosed with ALS. The founders are represented in the management team along with various investors and venture capitalists. These investors and venture capitalists have, in many cases, previous experience of setting up online businesses which have achieved great success. The company's income comes from collaboration, including pharmaceutical companies, as PLM sells anonymized data from the site to these partners. The overall aim of these partnerships is to increase the opportunities for research according to the site. The company also has collaborations with academic institutions and patient associations. Patients with certain diagnoses can become members of PLM without charge. The members of the different communities of patients are diagnosed with diseases such as ALS, HIV/AIDS, MS, epilepsy, Parkinson's and various forms of mental illness (www.patientslikeme.com).

Each patient on the site is presented with demographic data. There are also descriptions of the most common symptoms and treatments for the disease, how many members of the community who have updated their profile during the week and how many forum posts have been made during the week. The patients who can be found by non-members are the members who have chosen a low degree of security. The patients who have chosen a high level of confidentiality and security are only reachable for other members in the community.

The content on PLM consists of both terms and offers to the patient. The terms consist of the categories Knowledge sharing, Identifiability, Visions, and Risk & agreement. The offers to the patient consists of the categories Communication, Control, Learning, Visualizations and Community Development. Based on these categories and the text as a whole, the following theme emerged; PLM is designed as an online practice for knowledge production that contained dilemmas, see table 1.

The owners of PLM describe that they have a mission with the site and that is to change and democratize the health care system. Thus, one of the conditions of participation on the site is that patients accept this vision. The members of the sight are invited to be involved in this change through their membership and participation. Knowledge generation on a societal level is thus dependent on the members contribution of their patient information and experience. This allows for knowledge sharing at a group level on PLM. Social networking and cooperation are emphasized as two of the key elements of the concept Medicine 2.0 (Eysenbach, 2008). PLM thus emphasizes that membership on PLM provides the patient with an opportunity to get in contact with other patients who have similar diagnoses and similar or other experience of their illness. The social interactions make it possible to create knowledge sharing. The content of the texts also show that the site allows for externalization of knowledge by containing a wealth of information and experience from the members.

The visualizations offered by PLM are, in turn, created by the information experiences shared by patients. They change all the time depending on the updates that the members make. The visualizations also have a meaning and unifying force and a content that invites social interaction, which creates the conditions for knowledge generation at the group level.

Table 1: Domains', subcategories, categories and theme

Domain	Subcategory	Category	Theme
Terms	Share information	Knowledge sharing	
	Collaborate		
	Contribute to research		
	Create openess	Identifiability	
	Create privacy		
	Creating change	Visions	
	Change healthcare system		
	Contribute to democratization		
	Risk utilization	Risk	
	Risk stigmatization		
	Accept change in the future	Agreement	An online practice
	Know about the obligations		of knowledge
Offers	Participate in community discussions	Communication	production that contained dilemmas
	Ask questions to other patients		
	Get advise from other patients		
	Improved dialogue with doctors	Control	
	Control over your own data		
	Control of the disease		
	Learn from others experiences	Learning	
	Find other patients with the same disease history		
	Knowledge of your disease development		
	A profile over your condition	Visualizations	
	A graph of the development of your condition		
	Better treatments	Community	
	Change healthcare system	Development	

In the next section we will discuss how the knowledge that is produced on the online community PLM can be used by patients and what consequences it may have for the doctor-patient relationship and thereby on the work environment of the doctors.

5 Discussion

One of the most important offers that the PLM site gives the members is an online community that enables accumulation of knowledge. Patients get access to other patients' experience-based knowledge that is not available in any other context and they have the opportunity to come in contact with other patients who are in a similar condition. PLM fulfills the characteristics of a successful media according to Shirky (2008). The offers that the site provides are attractive enough to draw patients' attention and participation to the site. When patients share their information, experiences and knowledge on PLM where it is added to other patients' information, they create a knowledge base of their own. A knowledge base that is exclusive to them as patients i. e. without the interference of the medical profession. PLM thus enables knowledge production on both the individual and group/social level (Gunawardena, Lowe & Anderson, 1997).

Creating and having access to a knowledge base of their own enhances the patient empowerment. Schulz and Nakamoto (2013) argue that patient empowerment and health literacy are linked to each other. Increased patient empowerment aims to increase patients' willingness to be more

involved in health care decisions. One could thus argue that PLM enhances patient literacy as well as their empowerment. However Schulz and Nakamoto (2013) claim that a health literate patient does not by default imply that the patient has the same expertise knowledge that the doctor has. Still a patient who has been diagnosed with MS, can, for example, log onto PatientsLikeMe.com and share experiences and knowledge from the other 41,000 members in the MS Community. Doctors already testify that they encounter patients who are more well-informed and knowledgeable about their disease than the doctor him/her self is. The question is though, what type of knowledge base the 41 000 members in the community for MS create with the support of the technical solutions on PLM?

Traditionally the doctor's knowledge base has been seen as "specific and difficult to gain for actors outside the profession" (Jonnergård & Erlingsdóttir, 2012 p. 682). However the doctor's knowledge base is to a large degree based on the information that a doctor gains from treating the patient over time. This information can now not only be shared with the doctor but with other patients on PLM. This together with other Internet sites on medical conditions, give the patient the possibility to be better informed about their specific condition than a doctor. This in turn may lead to a change of balance in the doctor-patient relationship.

The possible benefit of PLM for the doctor-patient relationship is that it may lead to a more knowledgeable patient taking a more active role in his/her care and patient compliance might increase. Also patients may experience support and solidarity from other patients that they do not receive from healthcare systems and one of the benefits might thus be a more content patient. On the other hand patients may make decisions based on the information that they receive on PLM and other patients' experience which is not adequate for him or her. Patients might also experiment with their medication based on other patients' accounts of their medical history. This in turn might impair the trust between doctor and patient and ultimately the doctor-patient relationship. As doctors are still socialized into a profession where it is assumed that the doctors have a knowledge advantage this can be disturbing for the doctor. Such loss of control and changed roles can lead to impaired work environment for the doctors. From a study on the deployment of patient access to their electronic medical records we know that doctors have reacted strongly to the fact that patients can access their medical information as they fear that patients might misinterpret and/or be frightened by the information (Erlingsdóttir & Lindholm, 2015).

The pace of technological development through eHealth services of different types is vast in today's society. This puts healthcare providers, the medical profession and patients in situations that they have not previously been in. There are new conditions to deal with where there is no possibility to fall back on past experiences. When Abbott (1988) wrote that the medical profession's jurisdiction over knowledge of the body was compact, he could probably not anticipate the digitization that surfaced a few decades later.

6 Conclusions

The launch of Web. 2.0 has raised opportunities for patients to build communities to share information and create their own knowledge base on sights like PLM. This enhances patient empowerment, patient literacy and possibly patient participation and compliance in their care situation. At the same time patients may also gain more information about their diagnosis and illness than their doctors have, changing the imbalance from doctors' having the traditional information advantage to a patient information advantage. Patients may also draw conclusions about their own health condition based on other patients' information and make decisions that are not supported by their doctors. All in all, both positive and negative effects of sites like PLM may threaten the traditional exclusivity of the doctors' knowledge base and impair the doctor-patient relationship. As the technical development of the Web is not in the hands of the medical profession the changes cannot be influenced by the doctors and they are thus losing control over their knowledge base and their working condition in a way that they have never experienced before.

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