Mapping online peer exchanges on diabetes

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Abstract

Diabetes is a serious chronic condition affects the 10% of the world population; in order to avoid consequences, patients need to be able to self-manage their care & cure. Peer support groups help diabetic patients to improve their self-care; today they are simplified by the use of the Internet and Web 2.0. Even if the role of this medium into facilitate peer exchanges is well established, less attention is given to the way in which Web 2.0 contexts (e.g.: different Web 2.0 applications) could facilitate or inhibit the exchanges. The aim of this study is to understand the role of Web 2.0 contexts into shape online exchanges about diabetes in Italy. According to an ethnographic perspective, a systematic exploration of sites hosting exchanges about diabetes was developed. Findings show a map of different Web contexts and different online exchanges about diabetes, highlighting their main features and underlining relevant insights for the health expert field.

Keywords: Online patients exchanges; Web 2.0; Diabetes; Qualitative research

1. Introduction

Diabetes is a chronic disease that affects around the 10% of the world population (WHO, 2012): across the world around 220 million people have diabetes (Kneck, Klang & Fagerberg, 2011). It has consequences (such as stroke or renal failure) that can converge on the death of the patient (WHO, 2012). This means that diabetic patients have to learn to self-manage their daily care and lifestyle (Kneck, Klang & Fagerberg, 2011).

According to this perspective, patient empowerment (Anderson & Funnell, 2010) and patient engagement (Barello, Graffigna & Vegni, 2012)
are key processes necessary to make diabetic, and more in general chronic, patients able to manage their health and to cope with chronic disease and their consequences, by promoting and supporting daily self management of several aspects of life, such as diet, physical activity, but also stress or time management. Peer groups are useful in managing chronic illness and diabetes in particular because they give the opportunity for diabetic patients to receive feedback and suggestion about their care behaviours (Christie et al., 2008).

The Internet has been used successfully in the diabetes management; it gives to patients the possibility to become increasingly independent in the process of information-seeking and decision-making about self-care (de Boer, Versteegen & van Wijhe, 2007). Moreover, the advent of Web 2.0 make possible to patients not only to receive information but also to construct useful knowledge and make them main characters of their care management. In fact the Web 2.0 is “[...] the transition of use of the Internet from primarily information receiving to information generating [...] Web 2.0 tools are seen by some as a revolutionary leap in the ability to manage, remix, and transform health information” (Turner et al., 2011,). In practice, it facilities peer-to-peer support in diabetes care management throughout the online exchanges (Greene et al., 2010). Web 2.0 gives diabetic patients the possibility to participate in sharing and construction of knowledge about their illness, their care (Nambisan & Nambisan, 2009) and their identity (Arduse, 2011).

Literature has well established that online peer exchanges between diabetic, and more in general chronic patients, have three main aims /functions:
• to find information (Hoffman-Goetz, Donelle & Thomson, 2009);
• to reach emotional and social support (Barrera et al., 2002);
• to share experience, opinions and knowledge (Nambisan & Nambisan, 2009).

The Web 2.0 is composed by a variety of applications or tools such as blogs, forums, wikis, podcast, social networks, and many of them has been used to back online diabetic patients exchanges – such as, forums (Hoffman-Goetz, Donelle & Thomson, 2009), blogs, social networks (Greene et al., 2010).

Even if it’s clear that all this applications are characterized by different technical features, such as programming features or allowed activities (Holt, 2011) and a growing attention is given to the social features, such as trust (Riegelsberger, Sasse & McCarthy, 2005), social presence (Ning Shen et al., 2007), type of exchanges, less attention is given to the way in which these specific features may shape online exchanges; in particular it is not clear how different Web 2.0 contexts could facilitate or inhibit the exchanges and what consequences the Web 2.0 contexts could take on exchanges features and type and on the exchanges contents, in particular in chronic and diabetic patients’ online exchanges.
According to this premise, this contribute is aimed to understand what is the role of Web 2.0 contexts into shape online peer exchanges about diabetes in the Italian context, focusing in particular on:
1. If and how different Web tools and their features may define different online peer exchanges?
2. Who are the different actors involved in those exchanges?
3. What the differences in the contents dealt in the exchanges?

2. Method

This is an exploratory qualitative research designed according to an ethnographic perspective (Mayan, 2009).

A sample of Web 2.0 sites was found using the main Italian search engines: Google, Google discussions, Google Blog and Yahoo. Additionally, we included Facebook search engine as it is the main social network in Italy (sources: http://www.pandemia.info/2009/11/19/i-social-network-piu-popolari-in-italia-secondo-il-censis.html; http://www.italianbloggers.it/8800/elenco-dei-social-network-piu-popolati-della-rete). The used keyword for the search is the Italian word for Diabetes (diabete) and the research was performed in the 2011 (from February to September). The first 100 references for each search engine were considered.

The analysis of the site was composed by two main phases focusing on:
1. Sites features, such as Web 2.0 applications type, information and trust indexes about the site itself and the participants, number and consistency of exchanges and people. The grid was both theory (e.g. trust toward the site derived from Orizio et al., 2010) and data driven. The analysis was organized using ATLAS.Ti software.
2. Exchange features: (a) exchange contents, (b) participants in the exchange.
The analysis was organized using ATLAS.Ti software. Moreover a content textual analysis was provided using T-Lab software.

3. Main results

Online peer exchanges about diabetes in Italy seem to be a relevant phenomenon. Table 1 describes the sample of found sites, it explains how many sites and why have been analyzed and it shows frequencies and percentage of the different Web 2.0 applications which support the exchanges (Table 1).
A variety of online applications, thus, support online exchanges about diabetes; although blogs and forums are the most used ones. But technical aspects seem to be not enough to explain differences into online peer exchanges about diabetes.

The detected variety of online peer exchanges about diabetes can be described by a conceptual map which articulates them according to Web 2.0 applications, actors involved and main contents of the exchanges (see Figure 1). In particular the map is created by the following two axes.

**Horizontal axis: Legitimation of the knowledge produced in the exchanges.** This axis describes the way in which the contents and the knowledge produced in the exchanges are legitimated (i.e. the reliability and credibility of the posts and exchanges contents). On the negative pole are positioned sites where there is a vertical legitimization of the exchange contents; practically, an institutional expert (a health professional, the blog manager …) guarantees for the produced content in the site/exchange. The contents produced mainly with therapies and cure. On the other side, there is a horizontal legitimization of the exchange contents: the credibility of contents shared is guaranteed by the people who participate in the online exchanges. In this case the “expert” is someone who experienced with the topic dealt in the exchange. Topics of these exchanges concerns diabetes related activities and feelings.

**Vertical Axis: Relational aim of the exchanges.** The vertical axis describes the type of linkage sought by people who takes part in the exchange. On the positive pole are positioned those sites where people are aimed to spread information and news within the biggest network of people as possible.

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### Table 1. Sample description

<table>
<thead>
<tr>
<th>Total of references not considered</th>
<th>Blogs</th>
<th>Total of references analyzed</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>188</td>
<td>77</td>
<td>156</td>
<td>51</td>
</tr>
<tr>
<td>No exchange activities allowed</td>
<td>84</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outside the chosen period of time</td>
<td>79</td>
<td>Personal blogs</td>
<td>14</td>
</tr>
<tr>
<td>Sites dealing with other topics</td>
<td>20</td>
<td>Forums</td>
<td>40</td>
</tr>
<tr>
<td>Sites/exchanges not in Italian</td>
<td>5</td>
<td>Chats</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social networks: pages</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social Networks: groups</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Q&amp;A sites</td>
<td>4</td>
</tr>
</tbody>
</table>

Total of references found: 344
In practice, in these sites the exchange activity is limited to post and forward to a reference network (that may change according to the topic), without adding other comments or knowledge. In terms of contents, this pole deals mainly with a public sphere of diabetes: practically people are interested to diffuse information about diabetes aspects of topical interest, such as scientific innovation, activities of a group or a patients association), diabetes prevention campaign … The other pole is characterized by sites in which people seeks for affiliation and feeling of group belonging. In this case, the exchange activities, mainly asking for and sharing opinion, and experiences, are oriented toward that particular group. In these sites the contents of the exchanges are mainly focused on the practical, emotional and social aspects of diabetes.

This conceptual map articulates four prototypes of online exchanges on diabetes:

1. **Popularizing scientific knowledge**: post and exchanges in these sites are aimed to spread information about diabetes toward the Web, trying to reach the main number of people. In terms of Web 2.0 applications, this
area is covered by blogs. In terms of contents, blogs are used to diffuse information current affairs news on diabetes new therapies, and research (e.g.: “Association between diabetes type 1 and enterovirus”). People do not use blogs to discuss (only 8 blogs presented discussions after the first post), but to share information (all blogs propose tools to share post and news by email and on other blogs or social networks). In terms of actors, this is the realm of the institutional experts (mainly physicians and nutritionists, but also health communication experts). They guarantees for trust and crediblity of the contents. In facts, sites in this area are furnished by many classic trust indexes like logos, copyrights, and contact information.

2. Informing about diabetes and related activities: in this area, the aim of posts and exchanges is to show information about the diabetes itself or a specific person or association strictly linked to the diabetes. In terms of Web 2.0 applications, this area is mainly covered by social network pages and personal blogs (and in part by Q&A sites), who work really similar to blogs: someone (a person or a group) posts something about diabetes but there are few interactions on the topics. Moreover less activities of sharing on other sites or networks are allowed by this site. The aim is merely informative. In terms of contents, post and exchanges refer to: (1) a person (personal blog) or news about projects, associations or organizations to inform/update people that are interested in it. Substantially they seem display windows: people and organizations use them to show their activities and their interest to the world. For example: the BCD (buon compenso diabete) Facebook page is about a temporary project for diabetes care. The Fondazione Italian Diabete Facebook page is mainly a place where people (e.g., administration, other associations, patients) share information about, books, conferences, and scientific papers. (2) Giving/receiving information about diabetes in general (mainly in Q&A sites) (“What is the difference between diabetes 1 and diabetes 2?”). This area is not characterized by one type of actors but the exchanges usually present mixed actors, especially because people, who is not directly involved in diabetes and its care, is looking for general information.

3. Educating on diabetes and its management: this is the area where health experts and lay people (patients and general public) meet. In terms of Web 2.0 applications, this area is covered by some forums and less blogs where recognized expert (such as practitioners, nutritionists, psychologists) discuss with people, explaining what diabetes is or what are is symptoms, and with patients, addressing them towards diagnosis and cure. It’s evident that when the expert participates in the discussion, the exchange become dyadic and polarized (i.e. expert-patient) and the peer exchange
tends to be inhibited. In terms of contents, the exchanges are focused on cure & care of diabetes.

4. **Sharing knowledge and support**: the sites in this area host exchanges aimed to discussion and sharing opinions, experiences, emotions and knowledge between people recognized as qualified (mainly patients or caregivers) to say something about the topic. In terms of Web 2.0 applications, this area is covered by forums and Facebook groups. They support a variety of exchange activities oriented to the group itself and not to other networks: not only to post experiences and comments, but also to express appreciation for other participants’ messages (many forums have tools to express that people like others’ comments or to thank or to quote other people’s words). In terms of actors, this area is domain of patients and caregivers and the legitimation of knowledge is provided by the expertise that they have in the diabetes field. For this reason, sites in this area provide a lot of indicators about other participants. For example, in all the forums, enrollment is mandatory for participation; moreover in forums is usually possible to see each other’s profiles (26 sites), and it is easy to find exchange where people share similar interests (e.g., swimming) (33 sites) or recall prior conversations/discussions (6 sites). A great example of the sites in this area is “Mamme e diabete” Facebook group where caregivers (mothers) participate in the discussion in order to improve their children care and to support each others. In terms of contents, the focus is on a private sphere of diabetes concerning mainly: the daily management of diabetes and all the topic related (devices, food …) (“Try to control in the wizard bolus settings what values the device has and maybe you can high them up, or check how much activity time you set for your insulin […]”) and the emotional and social support (“To talk here is different … We totally understand each other … without seeing us … !!!!!!”).

4. **Discussion and conclusive remarks**

This study showed the variety of online peer exchange about diabetes retrievable in the Italian context. The differences in these exchanges are not assignable only to the technical aspects of Web 2.0 application that support them, but to a mix of technical and social components. In particular two psycho-social dimensions (across Web 2.0 applications) seem to rule the variation of online peer exchanges. The first psycho-social dimension refers to the process of “legitimation of the knowledge produced in the exchanges”. The negative pole of this dimension concerns a traditional vertical model of knowledge
legitimation, where an expert proposes institutionalized knowledge to lay people. Referring to the literature on the topic, this model is really similar to the concept “knowledge transfer” (Ekberg et al., 2008). At the opposite side, it’s possible a horizontal way of knowledge legitimation, in which lay actors are experts, since they “experienced the disease”. Thanks to Web 2.0 development, the topic of lay or patient “expertise” is gaining relevance into health studies, (Civan et al., 2009).

The second psycho-social dimension refers to the “Relational aim of the exchanges”: network or group oriented. This dimension opposites processes aimed at knowledge diffusion, in which “the goal […] is to disseminate knowledge in the best possible way” (Baez et al., 2010) and online exchanges aimed at sharing and participating in a discussion within a particular group of reference. The literature about online patients exchanges on diabetes is mainly focused on the exchanges happening in this second area (sharing in a specific group), because they are really similar to peer-to-peer support exchanges (Barrera et al., 2002), without considering why those exchanges are happening in that specific site and how the Web 2.0 contexts may shape them.

Even if health literature focuses on group oriented exchanges, we found other types of exchanges oriented not only to the sharing of the knowledge, but also oriented by other aims, such as the spreading of information. Moreover, these exchanges involve not only patients but also caregivers and the general public. It will be necessary to deepen the role and the needs of these actors.

According to a pragmatic perspective, this study states the importance to consider Web 2.0 not as a whole and unique context: in the Web 2.0 different contexts have different technical and social aspects and may support different online exchanges. This study presents a preliminary description of the ways in which different online contexts shape the online exchanges and further research will clarify and determine the role of each features of the context into configure the exchanges. For now, it’s clear that it’s possible to choose and construct different Web contexts, both for their technical and social aspects in order to reach different aims (e.g. to diffuse information or to provide peer support) and different targets (e.g. patients, caregivers, general public …). As already said, it will be necessary to deepen what are the ingredients that allow configuring different Web contexts.
REFERENCES


