

## Chapter 16

# Online Communication and Healthcare: The Diffusion of Health-Related Virtual Communities

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### ABSTRACT

*The chapter describes and analyses health-related virtual communities, which soon found their diffusion on the Internet. The chapter mainly focuses on those communities whose members are primarily or exclusively patients, exchanging online information and support, on a peer-to-peer base. It analyses their peculiarities, showing how they match users profile, desired and needs, providing them several benefits, despite initial concerns about their growth. Besides, the chapter identifies the nature and motives of the daily exchange happening among health related virtual communities members, and the peculiarities of their text-based communication, in terms of contents and style. In the last part, some implications for health organizations are identified.*

### INTRODUCTION

The “experience of illness” (Fitzpatrick et al., 1984) sets each person in front of their own fragility, marking their life from a physical, but also psychological, affective, behavioural, social and sometimes also spiritual point of view. Patients’ needs are multidimensional and do not find a full satisfaction neither in the personal, but fragmented relationship with doctors, nor in the many online informative resources concerning health, which

are easy to access, but remain impersonal (Preece, 2000).

Patients’ growing awareness, plus clinicians’ changing attitude, has been favouring in recent years a better patient-centered health, “*a care that is closely congruent with and responsive to patients’ wants, needs and preferences*” (Laine & Davidoff, 1996). This approach (Mead and Bower, 2000) adopts a “biopsychosocial” perspective (Duggan et al., 2006, p. 271), which means keeping in better consideration sick persons’ problems, needs and desires, and sharing both power and responsibilities between the physician and the patient.

DOI: 10.4018/978-1-61520-670-4.ch016

In this framework, an easier access and use of new technologies (see among others Jadad, 2006), has favoured in recent years the development of e-health tools, as health-related virtual communities (HRVCs).

HRVCs are applications of virtual communities; their proliferation is related to the state of a post-modern, fragmented society and soon appeared to be useful for sick persons and their relatives (e.g. parents of children or sons of elderly suffering of degenerative pathologies). In the most popular definition, VCs are “*social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyberspace*” (Rheingold, 1993, p. 6). Compared to other types of topics people talk about on the Internet, own health is involving enough to favour long discussions among participants, characterized by a high emotional exchange. This type of involvement is at the basis of the proliferation of HRVCs: groups of persons who, through the use of the ICTs, exchange information, ideas, opinions, support, feelings on health-related themes.

Today, HRVCs are an important part of the health information accessible online (Bell, 2003) -in October 2008 only Yahoo!Groups (<http://www.yahoo.com>) listed 49.253 electronic support groups in the health and wellness section-. They gather people of all ages, even children, as shown by some recent successful experiences (e.g. the Starbright case). Of the above mentioned total number of support groups, 4.229 were groups related to addiction and recovery; 17.907 were groups connected to diseases and conditions; 383 about procedures and therapies and 6.304 connected to weight issues; the rest concerned social issues.

Participants to a HRVC can be patients, professional caregivers and informal caregivers (e.g. patients' relatives). On the base of the degree of opening to different typologies of members, Demiris (2006) identifies four different types of HRVCs:

- **Virtual research teams:** Often international, they are composed just by researchers working on the same health issue, who can share their knowledge and know-how online
- **Virtual health care delivery teams:** They are online networks of professionals caregivers, able to respond to different patients' care needs; an effective application is patients home-care
- **Virtual disease management teams:** As the former type of HRVCs, they favour a distance physician-patient interaction. In them, patients play a more active role than in virtual health care delivery teams, as they self-monitor their conditions and communicate their doctors data online
- **Patient and caregiver peer-to-peer applications:** Online support groups, similar to offline self-help groups

Moving in the above classification from *virtual research teams*, where patients are absent, up to the peer-to-peer patients applications, it is possible to see how the degree of patients' active involvement increases.

In *peer-to-peer applications* patients play a very active and absolutely new role –see infra-.

These groups appear to be a very interesting expression of a patient-centered e-health: so, they are the focus of this chapter, that aims at identifying, describing and interpreting patients and caregivers peer-to-peer applications of HRVCs.

Specifically, this chapter analyzes those communities of patients who do not have any other occasion to meet offline (e.g. in self-help sessions).

In the first part, after an explanation why these groups can be meant as “communities”, both the nature of the exchange within the communities and the benefits members get are described and analysed.

In the second part, the chapter describes the features of members' participation to HRVCs -in terms

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