

Chapter 57

Health-Related Online Support Communities

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ABSTRACT

In recent years, the Internet has provided new opportunities for individuals living with health-related problems to communicate with each other via online support communities. These communities offer many unique advantages, such as convenience, anonymity, and a diverse range of group members. However, there are potential disadvantages to their use, for example, misleading information. Within such communities, patients may talk about a range of issues and provide support to one another, particularly informational and emotional support. Through self-disclosure and empathic communication, members may feel able to share personal stories as well as help others. Whilst robust evidence for their effectiveness is lacking, there is much qualitative and cross-sectional evidence suggesting that participation in online support communities may be beneficial. However, there is a need for randomised controlled trials of pure peer-to-peer online support.

INTRODUCTION

In recent years more and more individuals living with chronic health problems are turning to the internet for information, advice and support. In particular, there has been a rapid expansion of the number of online support communities (also

known as ‘online support groups’) and this rise in popularity is arguably related to many of the unique characteristics inherent within this form of communication. Researchers have begun to examine the nature of online support communities (e.g., Wright & Bell, 2003), their role in the lives of those living with illness (e.g., Mo & Coulson, 2010) as well as the activities which are taking place online (e.g., Malik & Coulson, 2010). There

DOI: 10.4018/978-1-4666-0315-8.ch057

is much qualitative and cross-sectional evidence (e.g., Coulson, 2005) describing their impact on individuals but as yet there are few well-designed studies which have clearly tested the effects of peer to peer online communication and support. This entry will consider the current state of knowledge with regards key aspects of this growing online phenomenon.

Unique Characteristics of Online Support Communities

Online support communities present several unique communication characteristics, which can include anonymity, asynchronous text-based communication and the ability to transcend geographical and temporal barriers (White & Dorman, 2001; Joinson, 2003; Coulson & Knibb, 2007). These unique characteristics also give rise to a number of unique advantages and disadvantages for individuals choosing to seek support through the medium of online communities.

Potential Advantages

A number of studies (e.g., Ferguson, 1996; Buchanan & Coulson, 2007) have documented the potential advantages of online support communities over more traditional face-to-face sources of support (e.g., face-to-face support groups). For example, in contrast to a face-to-face group where members typically meet once a week or less frequently, online communities are available 24 hours a day, 7 days a week. The asynchronous nature of the online environment thus allows members to access the online community to share experiences or seek support at virtually anytime of day or night. This not only offers a convenience factor but also means participants can potentially offer and/or receive valuable support and advice at times when traditional sources of help are likely to be unavailable.

An additional benefit associated with asynchronous communication is the opportunity

for members to spend time reflecting on their thoughts and feelings as well as interactions with other members. Indeed, it has been argued that asynchronous communication reduces the pressure associated with real-time communication thereby allowing participants time to carefully construct their messages before contributing to the community (Joinson, 2003). Online communities also offer a degree of anonymity that would not be possible in face-to-face communication. This may encourage certain individuals, particularly those patients who feel stigmatised because of their condition, to openly discuss their experiences without fear of a negative reaction.

Additionally, since participation in online support communities is not restricted by geographical, physical or spatial barriers, members can potentially access a larger and more heterogeneous mix of people with ease. This is likely to be of particular benefit to patients suffering from chronic health conditions, as these individuals, may experience difficulties attending a regular face-to-face meeting due to limitations arising from their condition such as problems with mobility or treatment side effects. The Internet thus offers a novel opportunity for individuals to communicate with similar others in the comfort of their own home.

The ability to reach people from geographically diverse locations also increases the chances of finding others with similar experiences (White & Dorman, 2001). This is particularly helpful for individuals with rare conditions who may be unable to locate people with the same problem in their geographical area. At the same time, due to their diversity, online communities are advantageous because they can offer participants a wide variety of different perspectives, viewpoints and experiences on issues related to their condition (Wright, 1999; Wright, 2000).

Walther and Boyd (2002) argue that for this reason online communication provides numerous opportunities for people with health concerns to seek support from 'weak tie' relationships. 'Weak ties' refer to relationships between people who

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