Chapter 18 Peer-to-Peer Health-Related Online Support Groups

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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 groups. These groups offer many unique advantages, such as convenience, anonymity, and access to a diverse range of group members. However, there are potential disadvantages to their use, for example, misleading information. Within such groups, 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. While robust evidence for their effectiveness is lacking, there is much qualitative and cross-sectional evidence suggesting that participation in online support groups may be beneficial. However, there is an urgent need for randomized controlled trials of pure peer-to-peer online support interventions across both physical and mental health conditions.

INTRODUCTION

In recent years more and more individuals living with long-term conditions are turning to the internet for information, advice and support. In particular, there has been a rapid expansion of the number of online support groups (also known as 'online support communities') 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 groups (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 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.

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BACKGROUND

Unique Characteristics of Online Support Communities

Online support groups 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 groups.

Potential Advantages

A number of studies (e.g., Ferguson, 1996; Buchanan & Coulson, 2007) have documented the potential advantages of online support groups over more traditional face-to-face sources of support (e.g., face-to-face support groups).

Access Support at Any Time

In contrast to a face-to-face group where members typically meet once a week or less frequently, online groups are available 24 hours a day, 7 days a week (Malik & Coulson, 2008) thereby providing opportunities for peer support at any time of the day or night. As a consequence, this introduces considerable flexibility for individuals in terms of when they wish to access support and this flexibility has been shown to be very helpful for those who have work, family or educational commitments (Coulson & Knibb, 2007).

Asynchronous Communication

The asynchronous nature of many online support groups means that there is no pressure or commitment to engage in real-time communication with other members (Coulson & Knibb, 2007). Instead, members can take their time to read messages and reflect upon their feelings while considering if and how to reply, allowing members to control their level of involvement in a way that is not possible with traditional face-to-face communication (Malik & Coulson, 2008). 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 group (Joinson, 2003).

Anonymity

Online support groups 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.

Group Composition

Since participation in online support groups is not restricted by geographical, physical or spatial barriers, members can potentially access a larger and more heterogeneous mix of people with ease (White

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