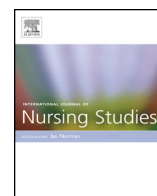




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Are online support groups always beneficial? A qualitative exploration of the empowering and disempowering processes of participation within HIV/AIDS-related online support groups

Phoenix K.H. Mo ^{a,*}, Neil S. Coulson ^b^a School of Public Health and Primary Care, The Chinese University of Hong Kong, Hong Kong^b Division of Rehabilitation and Ageing, School of Medicine, University of Nottingham, United Kingdom

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ABSTRACT

Background: Human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) is one of the leading concerns in healthcare. Individuals living with HIV/AIDS are often confronted with tremendous physical and psychosocial challenges. Online support groups can provide a valuable source of information, advice and support, and a medium through which individuals living with HIV/AIDS can interact with each other and share their experiences. However, very little is known about how online support group might promote empowerment and the potential disadvantages associated with online support group use among individuals living with HIV/AIDS.

Objectives: The present study explored the potential empowering and disempowering processes, and empowering outcomes of online support group use among individuals with HIV/AIDS.

Design, settings, participants: A total of 115 HIV-positive online support group members were recruited from HIV-related online support groups. They completed an online survey exploring their experiences of online support group use.

Results: Thematic analysis revealed six empowering processes arising from use of online support groups: exchanging information, sharing experiences, connecting to others, encountering emotional support, finding recognition and understanding, and helping others. Six empowering outcomes were identified: increased optimism, emotional well-being, social well-being, being better informed, improved disease management, and feeling confident in the relationship with physicians. Potentially disempowering processes were also identified which included: being unable to connect physically, inappropriate behaviour online, declining real life relationships, and information overload and misinformation.

Conclusion: Findings suggest ways through which individuals with HIV/AIDS may be empowered although some problematic features specific to the online context may also be present.

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What is already known about the topic?

- The diagnosis and management of HIV/AIDS are associated with significant physical and psychosocial challenges.
- Individuals living with HIV/AIDS require support and information but their needs have not been met.

* Corresponding author at: School of Public Health and Primary Care, The Chinese University of Hong Kong, Shatin, Hong Kong.
Tel.: +852 2252 8765.

E-mail address: phoenix.mo@cuhk.edu.hk (Phoenix K.H. Mo).

- Online support group can provide a valuable venue where patients can obtain information, support and share their experiences.
- Online support group participation is associated with better health-related outcomes for various health conditions.

What this paper adds

- Online support group allows individual living with HIV/AIDS to exchange information and emotional support, share their experiences, connect to others, find recognition and understandings, and help other members.
- Online support group use can potentially increase optimism, emotional and social well-being, improve disease management and relationship with physicians, and increase HIV-related knowledge for individuals living with HIV/AIDS.
- There are also some disadvantages associated with online support group use for individuals living with HIV/AIDS.

1. Introduction

Human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) is one of the leading concerns in healthcare. According to the UNAIDS ([Joint United Nations Programme on HIV/AIDS, 2010](#)), it is estimated that 33.3 million people worldwide are living with HIV/AIDS. The diagnosis and management of HIV/AIDS are associated with significant physical and psychosocial morbidity ([Bogart et al., 2000](#)). Previous studies have shown that individuals living with HIV/AIDS require support and health information in order to help manage the disease ([Abramowitz et al., 2009](#)) but that their needs have not always been met ([Schrimshaw et al., 2003](#); [Serovich et al., 2000](#)).

The Internet has revolutionised the way in which health information and support can be obtained ([Eysenbach, 2003](#)). A growing body of literature has shown that online support groups can provide a valuable source of information, advice and support as well as providing a medium through which individuals living with HIV/AIDS can interact with each other ([Bar-Lev, 2008](#); [Coursaris and Liu, 2009](#); [Mo and Coulson, 2008, 2010](#)). The literature has identified a number of ways in which online support group use might be helpful ([Hess et al., 2010](#)). For example, studies have shown that online support groups allow disclosure of emotions and insights, which is associated with psychological benefits ([Han et al., 2008](#); [Shim et al., 2011](#)). Furthermore, the experiences shared by patients on the Internet (i.e. through participation in online support groups) may be of particular interest to others, for example, when making decisions about health care and disease management ([Wise et al., 2008](#); [Ziebland and Herxheimer, 2008](#)). A recent review study has also identified seven ways through which patients' online experiences could affect their health, including finding information, feeling supported, maintaining relationships with others, affecting behaviour, experiencing health services, learning to tell the story, and visualising disease

([Ziebland and Wyke, 2012](#)). These unique features suggest that participating in online support groups might potentially foster patient empowerment ([Barak et al., 2008](#)).

Empowerment is an active, participatory process through which individuals, organisations, and communities gain greater control, efficacy, and social justice ([Zimmerman, 1995](#)). Recently, a growing number of studies have begun to explore the concept of empowerment within the health-related online support group context ([van Uden-Kraan et al., 2008, 2009](#)). These studies have identified a number of potentially empowering processes associated with online support group use including: exchanging information, encountering emotional support, finding recognition, sharing experiences, helping others, and amusement. Empowering outcomes were also identified and include: being better informed, feeling confident in the relationship with their physician, their treatment, and their social environment; improved acceptance of the disease; increased optimism, and enhanced self-esteem and social well-being.

On the other hand, disadvantages associated with health-related online support groups, though less common, were also noted. As participation in most online support groups is open to anyone with access to the Internet, there is little control over the accuracy of information and feedback provided to group members. There is a chance, therefore, that some members receive misinformation from others ([Hoch et al., 1999](#)). Also, active forums can produce a large number of messages from various perspectives, reading the messages can be very time consuming ([White and Dorman, 2001](#)). The lack of visual and auditory cues may also result in the misinterpretation of messages being read ([Waldron et al., 2000](#)). In addition, due to anonymity, lack of real-time responses and lack of social status cues that normally inhibit inappropriate responses ([Braithwaite et al., 1999](#)), interaction within online support groups may therefore become more disinhibited and the possibility of offensive or antisocial behaviour increases ([Lee, 1996](#)). Research in this area has identified some disempowering processes associated with online support group use. For example, one study among 295 members of online infertility support groups revealed that the most commonly cited disadvantages were reading about negative experiences, reading about other peoples' pregnancies, inaccurate information and the addictive nature of online support groups ([Malik and Coulson, 2010](#)). Another study among 32 participants of online support groups for breast cancer, arthritis, or fibromyalgia showed that the disempowering processes mentioned most by the participants were being unsure about the equality of the information, being confronted with the negative sides of the disease, and the presence of complainers ([van Uden-Kraan et al., 2008](#)).

However, little attention has been given to understanding how participation in HIV/AIDS-related online support groups may empower group members and in what ways, and the potential disadvantages of using online support groups. [Davison et al. \(2000\)](#) investigated the pattern of online support group activity for different health conditions and reported that individuals with HIV/AIDS were 250 times more likely to participate in a support group

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