

# Online support group use and psychological health for individuals living with HIV/AIDS

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## ABSTRACT

**Objective:** The Internet provides an opportunity for individuals with HIV/AIDS to obtain support and information in a timely and convenient manner. The present study examines the psychological effects of online support group use for individuals living with HIV/AIDS.

**Methods:** A total of 340 HIV positive online support group users completed an online survey.

**Results:** Results from structural equation modeling showed that individuals with higher levels of online support group participation had higher levels of empowering processes, which in turn, had higher levels of optimism toward life. Optimism was related to lower levels of loneliness and depression while loneliness was also related to higher levels of depression.

**Conclusion:** The findings suggest that participants with higher levels of online support group participation had better psychological health than those with lower levels of participation.

**Practice implications:** Findings suggest that the use of online support groups could be promoted to individuals with HIV/AIDS. Healthcare professionals should work to increase the motivation and confidence patients have in using online support groups. Health education should also be provided to patients with HIV/AIDS so to improve their skills and literacy in using online support groups.

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## 1. Introduction

### 1.1. Psychosocial issues of HIV/AIDS

Human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) is a chronic illness that is replete with physical and psychosocial challenges. According to the UNAIDS it is estimated that there are approximately 33.3 million people living with HIV/AIDS worldwide [1]. The total number of people living with HIV/AIDS is increasing steadily as a result of the ongoing acquisition of HIV infection, longer survival times, and a growing general population [2]. HIV/AIDS remains a major public health issue across the globe.

People living with HIV/AIDS are not only affected physically by the illness, they also experience psychological distress in the management of their illness including stigmatization and discrimination, social isolation due to the concealment of their serostatus and rejection from important others, as well as uncertainties associated with disease progression and treatment-related side effects [3,4]. The complexity of HIV infection, together with the many psychosocial challenges in coping with their disease, has

increased the need for information and social support for individuals living with HIV/AIDS [5,6]. However, many individuals living with HIV/AIDS report having unmet needs and insufficient social support available to them [7], further worsening their life satisfaction [8]. Research has shown that poor psychological health is prevalent among individuals living with HIV/AIDS. For example, a study of a nationally representative probability sample of 2864 adults with HIV in the United States showed that more than one third (36%) screened positive for major depression and more than one quarter (26.5%) experienced symptoms of dysthymia during the previous 12 months [9].

Although previous studies have shown participation in face-to-face support groups to be effective in enhancing the health and quality of life of patients with various health conditions [10,11], participation in such traditional face-to-face groups might be restricted by temporal and geographical barriers as well as any physical limitations of the individuals. Indeed, a range of barriers have been described in the literature which may limit the extent to which individuals living with HIV/AIDS can access or receive support [7,12].

### 1.2. Use of online support groups for individuals with HIV/AIDS

The recent proliferation of computer technology and the Internet provides a unique opportunity in addressing the needs

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of individuals living with HIV/AIDS by providing information and support, as well as connecting them with others who face similar challenges in a way which is convenient and accessible [13,14]. In recent years, a growing body of research has been conducted to examine the therapeutic potential of online support group participation for patients living with a range of both acute and chronic health conditions. For example, increased participation has been associated with an increase in perceived social support, lower levels of social isolation and depression, better coping skills as well as improved quality of life [15,16].

### 1.3. Online support groups as promoting patient empowerment

Empowerment is defined as a process through which people may gain greater mastery and control over decisions and actions affecting their lives, and a critical understanding of their environment [17]. Empowered patients are considered to be more successful in managing their illness, collaborating with their health providers, and maintaining their health [18]. Recently, a growing number of studies have considered the concept of empowerment within the online support group context [19,20]. For example, one qualitative study among patients with a range of somatic diseases identified several empowering processes which they argued were present within online support groups and which included: exchanging information, encountering emotional support, finding recognition, sharing experiences, helping others and amusement [21]. In a recent study of online support group participation for individuals living with HIV/AIDS [22,23], four empowering processes arising from participation within online support groups were identified: receiving social support, receiving useful information, finding positive meaning, and helping others. In addition, several empowering outcomes arising from online support group participation have also been identified and include: being better informed, feeling confident with their physician, their treatment and their social environment, improved acceptance of the illness, increased optimism and control, enhanced self-esteem and social well-being and collective action [21,24]. The present study aimed to test the mechanisms through which online support group participation may promote empowerment and psychological health among individuals living with HIV/AIDS.

For individuals living with chronic illness, maintaining a positive belief toward the future is important in managing the stressors associated with the disease. Previous studies have shown that the use of online support groups is related to greater levels of optimism across various health conditions [16,21]. This can be explained by the fact that the useful information, positive life experiences from others, and social support shared within the

group helps members maintain a more positive outlook toward life [25,26]. In addition, a growing number of studies have found that optimism plays a significant role in adaptation to chronic disease. According to the self-regulation theory, individuals with positive expectations for the future are more likely to make an effort to reach their goals than those without such positive expectations. They also show lower levels of emotional arousal and physiological-neuroendocrine reactivity in the face of stressful events [27]. On the other hand, research has suggested that individuals high in negative affectivity are at risk of loneliness and depression [28]. Therefore, it is expected that optimism will protect individuals against loneliness and depression. Indeed, optimism has been found to predict lower levels of loneliness and depression in the context of HIV/AIDS [29,30].

### 1.4. The present study

Although positive evidence of online support group use has been reported, as yet there has been little attention devoted to understanding the mechanisms through which participation in an online support group might be related to psychological wellbeing. The aim of the present study was, therefore, to examine the relationship between online support group participation, patient empowerment and psychological outcomes for individuals living with HIV/AIDS. Based on previous literature which has identified a number of empowering processes and outcomes arising from online support group participation [20,21,24], it was hypothesized that higher levels of online support group participation would be related to increased exposure to empowering processes which would be related to increased levels of optimism. It was also hypothesized that optimism would have a negative relationship with loneliness and depression and loneliness would have a positive relationship with depression. The hypothesized model is presented in Fig. 1.

## 2. Methods

### 2.1. Procedure

Participants in the present study were recruited from HIV/AIDS-related online support groups in 2009. Twelve HIV/AIDS-related online support groups were identified from an Internet search and moderators from the selected groups were contacted explaining the study and requesting permission to recruit participants from their group. Out of the twelve online support groups contacted, six replied and gave us permission to recruit participants from their group. These six online support groups were all public in nature, at

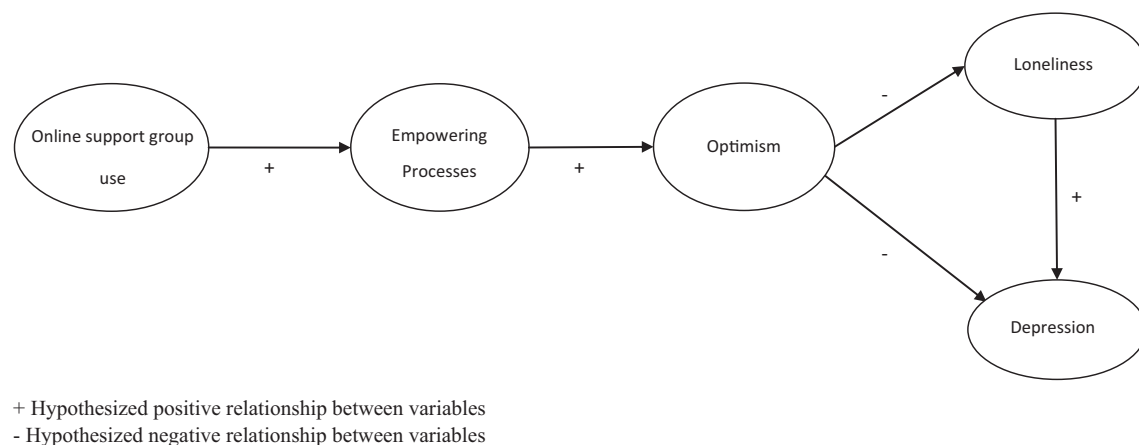


Fig. 1. Hypothesized model of the present study. +, Hypothesized positive relationship between variables. -, Hypothesized negative relationship between variables.

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