

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

Phoenix K.H. Mo^{a,*}, Neil S. Coulson^b

^a School of Public Health and Primary Care, The Chinese University of Hong Kong, Shatin, N.T., Hong Kong

^b Institute of Work, Health and Organisations, University of Nottingham, Nottingham, UK

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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

* Corresponding author. Tel.: +852 2252 8765; fax: +852 2645 3098.

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

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

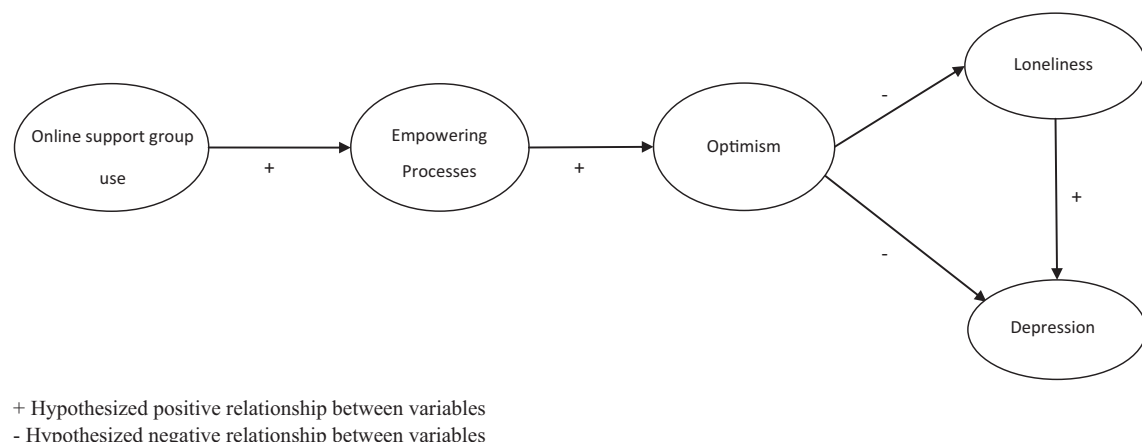


Fig. 1. Hypothesized model of the present study. +, Hypothesized positive relationship between variables. -, Hypothesized negative relationship between variables.

the time of the study, all the groups were active with at least 10 new messages posted to the group each day. All the groups were moderated with rules that messages which were not in accordance with the guidelines would be deleted. None of the groups appeared to have professional involvement in the group discussion.

Following permission from the moderators, a message was posted to the group explaining the objectives and the activities that were involved in the study. The investigator's contact details were provided and participants' confidentiality was assured in the recruitment message. A link to the survey was provided in the message, and interested participants were directed to the survey website. The aims of the study and inclusion criteria were explained, and informed consent was sought before they were able to complete the survey. Inclusion criteria were individuals who have been HIV positive for at least one month, were at least 18 years old, and had participated in any HIV/AIDS online support groups. No reimbursement was offered to participants.

2.2. Measures

2.2.1. Demographic and medical information

Participants were asked to provide demographic and medical information such as age, gender, relationship status, country of residence, education, and year of diagnosis. They were also asked to provide information on their disease stage and most current CD4 cell count based on the results from their last medical checkup.

2.2.2. Online support group use

A series of questions were asked to capture the frequency and pattern of online support group use of participants [31]. Specifically, participants were asked whether they have ever used any HIV/AIDS-related online support groups, how long they had been using HIV/AIDS-related online support groups, how many days have they accessed HIV/AIDS-related online support groups in the average week, how many hours they spend accessing HIV/AIDS-related online support groups in the average week.

2.2.3. Empowering processes

Exposure to potentially empowering processes arising from online support group participation was measured by a 43-item scale [32]. The scale measures 4 specific potentially empowering processes: receiving useful information, receiving social support, finding positive meaning, and helping others. Items were rated on a 5-point Likert scale ranging from 1 = never to 5 = often, with higher scores indicating a greater perceived occurrence of the empowering processes. The Cronbach's alpha of the 4 subscales ranged from .87 (helping others) to .95 (finding positive meaning).

2.2.4. Loneliness

Loneliness was measured by the UCLA Loneliness Scale (3rd version) [33]. It is a 10-item scale measuring global feelings of isolation and alienation. Participants were asked to describe their own feelings on a 4-point Likert scale ranging from 1 = I never feel in this way to 4 = I often feel in this way, with higher scores indicating greater levels of loneliness. The Cronbach's alpha for the scale was .88.

2.2.5. Optimism

Optimism was measured by the Life Orientation Test-revised (LOT-R) Scale [34]. It is a 10-item scale measuring individual differences in generalized optimism and pessimism. Responses were rated on a 5-point Likert scale ranging from 1 = I agree a lot to 5 = I disagree a lot, with higher scores indicating greater levels of optimism. The Cronbach's alpha for the scale was .87 in the present study.

2.2.6. Depression

Depression was measured by the Center for Epidemiologic Studies Depression Scale-revised (CESD-R) [35]. It is a 20-item scale measuring depressive symptomatology and has been shown to be as reliable and valid as the original scale [36] but more relevant to current definitions of major depression [35]. Participants rated how often they experienced the symptomatology along a 5-point Likert Scale ranging from 1 = not at all in the past week to 5 = nearly every day in the past two weeks, with higher scores indicating higher level of depressive mood. The Cronbach's alpha of the scale was .92 in the present study.

2.3. Data analysis

First, zero-order correlations among all variables were examined. A two-stage modeling procedure recommended by Anderson and Gerbing [37] was used to evaluate the goodness of fit of the hypothesized model. Confirmatory factor analysis (CFA) was conducted to examine the adequacy of the measurement for each of the constructs under investigation, in which latent factors were allowed to inter-correlate freely. Structural equation modeling (SEM) analysis was performed to test the fit of the hypothesized structural model. SEM is a multivariate technique for modeling hypothesized relationships among variables using nonexperimental, quantitative data. Through SEM the hypothesized model can be either rejected or accepted as consistent with the data [38]. For both CFA and SEM, parcels were created for the variables. Using parcels of items as indicators is a common technique to manifest latent factors in SEM, with the advantages of being more parsimonious, decreasing the possibilities of correlated residuals and double loadings, and reducing sampling error [39]. To determine the suitability of the models, several fit indices were used: chi square of the estimated model (χ^2), comparative fit index (CFI), non-normed fit index (NNFI), and root mean square error of approximation (RMSEA) [40]. However, χ^2 is sensitive to sample size and the probability of rejecting the hypothesized model increases as sample size increases. Therefore, the use of relative goodness-of-fit measures was deemed to be more appropriate. CFI and NNFI ranged between 0 and 1, with values greater than .90 indicative of a good fit, whereas RMSEA values between .03 and .08 are interpreted as reasonable fit [41]. Analyses were performed using AMOS 16.0 with the maximum likelihood method of estimation.

3. Results

3.1. Sample characteristics

A total of 340 online support group members completed our online survey. The socio-demographic and medical characteristics of participants are presented in Table 1. Most of the participants were male (83.7%) with a mean age of 47.81 years. Over 95% of respondents had more than high school education. More than half of the sample (53.4%) reported being in the asymptomatic stage, while another one-third (30.1%) reported being in the advanced AIDS stage. On average, respondents had been diagnosed for 11.7 years (range 24–70) and their self-reported mean CD4 count was 505.60 uL.

Details of the nature of online support group use of participants are presented in Table 1. Participants reported accessing online support groups for an average of 55.7 months. They spent on average 3.83 days and 4.08 h accessing online support groups in the average week. A quarter (24.7%) of the participants reported they had never posted a message to the online support groups and were therefore classified as lurkers.

Table 1
Socio-demographic and medical characteristics of participants.

Variables	Total (N=340) ^a
Gender	
Male	283 (83.7%)
Female	55 (16.3%)
Age	M = 47.81 SD = 10.57
Education	
High school or less	12 (3.6%)
College	142 (42.3%)
University	92 (27.4%)
Graduate school or higher	90 (26.8%)
Relationship status	
Married/civil partnership	57 (17.0%)
In a relationship and live as married	51 (15.2%)
In a relationship	67 (20.0%)
Not in a relationship	139 (41.5%)
Disease stage	
Asymptomatic	181 (53.4%)
Symptomatic	56 (16.5%)
AIDS	102 (30.1%)
Length of diagnosis (in years)	M = 11.77 SD = 7.44
CD4 count (in uL)	M = 505.60 SD = 279.53
Length of online support group use (in months)	M = 55.66 SD = 43.88
Days spent on online support group per week	M = 3.83 SD = 2.29
Hours spent on online support group per week	M = 4.08 SD = 6.15
Nature of online support group use	
Poster	256 (75.3%)
Lurker	84 (24.7%)
Overall experience of online support group use	
Mostly negative	9 (2.7%)
Both negative and positive	166 (49.7%)
Mostly positive	159 (47.6%)

^a Sample size varied slightly for each variable due to missing data.

3.2. Correlation between variables

Results of the correlation showed that the variables in the model were correlated with each other in the way that supported the relationships between variables in the hypothesized model (Table 2). Specifically, numbers of days (r ranged from .25 to .44, $p < .001$) and numbers of hours (r ranged from .25 to .37, $p < .001$) spent accessing online support groups in an average week were positively correlated with exposure to all four empowering processes. Also, exposure to all four empowering processes was

positively correlated with optimism (r ranged from .13 to .24, $.05 < p < .01$), and optimism showed significant negative correlation with loneliness ($p = -.56$, $p < .001$) and depression ($p = -.66$, $p < .001$). Findings provided preliminary evidence for the hypothesized relationship between variables and allowed for further analyses to examine the hypothesized effects.

3.3. Measurement model

Results of the CFA showed that the overall model yielded a satisfactory fit, $\chi^2 (67) = 224.36$, $p < .01$, CFI = .96, IFI = .96, RMSEA = .06. Standardized factor loadings ranged from .58 to .99 and were all significant at the $p < .001$ level. The factor loadings of all indicators in the measurement model are shown in Fig. 2.

3.4. Structural model

Results of the SEM showed that the hypothesized model yielded a satisfactory fit to data, $\chi^2 (72) = 237.78$, $p < .01$, CFI = .95, IFI = .94, RMSEA = .07. In sum, online support group use was positively related to empowering processes, which in turn, was positively related to optimism toward life. Optimism was negatively related to loneliness and depression. Loneliness was also positively related to depression. Fig. 2 shows the standardized path coefficient of variables in the structural model.

4. Discussion and conclusion

4.1. Discussion

The present study aims to elucidate the mechanism through which participating in online support groups may be related to psychological health. The findings of the present study are consistent with previous studies that have argued that participating in an online support group might potentially, in a number of ways, have psychological benefits for individuals living with HIV/AIDS.

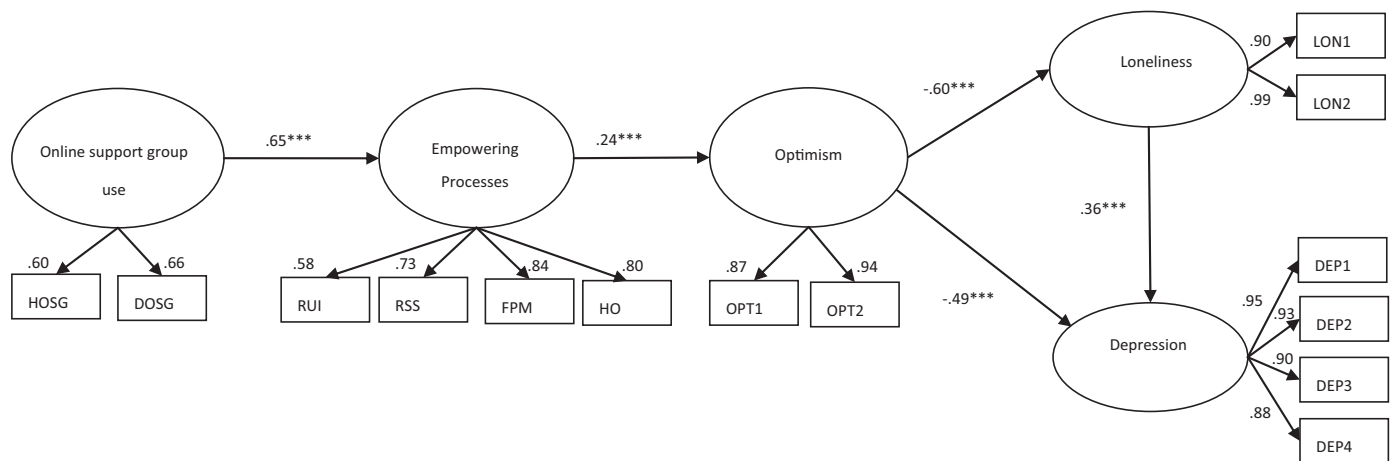
Our study revealed that participants with higher levels of online support group participation reported higher levels of optimism toward their disease indirectly through higher levels of exposure to various empowering processes, namely receiving useful information, receiving social support, finding positive meaning, and helping others. It can be argued that accessing an online support group provides the opportunity for group members to obtain useful information which may aid their management of the disease [42,43]. In addition, reading about the experiences of other

Table 2
Correlation between variables in the study.

	1	2	3	4	5	6	7	8	9	10	11	12
1	–											
2	.39***	–										
3	-.10	.20***	–									
4	-.06	.12*	.18***	–								
5	.18***	-.05	.17***	.39***	–							
6	.10	-.15**	.03	.44***	.29***	–						
7	.25***	-.22***	.24***	.32***	.37***	.36***	–					
8	.10	-.18***	.12*	.33***	.32***	.45***	.59***	–				
9	.11*	-.22***	.07	.25***	.25***	.42***	.55***	.62***	–			
10	.11*	.05	-.08	.23***	.05	.19***	.13*	.13*	.24***	–		
11	-.12*	.04	.04	-.19**	-.04	-.20***	-.13*	-.19**	-.20***	-.56***	–	
12	.01	-.04	.15**	-.14*	.00	-.08	-.05	-.04	-.16***	-.66***	.62***	–

1, Gender; 2, age; 3, disease stage; 4, number of days using online support groups in an average week; 5, number of hours using online support group in an average week; 6, empowering process: receiving useful information; 7, empowering process: receiving social support; 8, empowering process: finding positive meaning; 9, empowering process: helping others; 10, optimism; 11, loneliness; 12, depression.

* $p < .05$.** $p < .01$.*** $p < .001$.



All path coefficients shown were standardised. *** $p < .001$.

HOSG=Hours spent on online support group per week, DOSG=Days spent on online support group per week, RUI=Receiving useful information, RSS=Receiving social support, FPM=Finding positive meaning, HO=Helping others, OPT1=Optimism parcel score 1, OPT2=Optimism parcel score 2, LON1=Loneliness parcel score 1, LON2=Loneliness parcel score 2, DEP1=Depression parcel score 1, DEP2=Depression parcel score 2, DEP3=Depression parcel score 3, DEP4=Depression parcel score 4.

Fig. 2. Model of online support group use and psychological health for individuals with HIV/AIDS ($N = 340$). All path coefficients shown were standardized. *** $p < .001$. HOSG, hours spent on online support group per week; DOSG, days spent on online support group per week; RUI, receiving useful information; RSS, receiving social support; FPM, finding positive meaning; HO, helping others; OPT1, optimism parcel score 1; OPT2, optimism parcel score 2; LON1, loneliness parcel score 1; LON2, loneliness parcel score 2; DEP1, depression parcel score 1; DEP2, depression parcel score 2; DEP3, depression parcel score 3; DEP4, depression parcel score 4.

members may also help them make sense of their illness and thus, increase their perceived level of control of the illness and their future. Indeed, this is consistent with previous studies which report that online support group members feel more optimistic about their future after reading “success stories” posted by other members [21,24]. In addition, individuals who reported receiving social support from other members might feel less alone in coping with their disease and therefore, are more likely to feel more positive about their future. Finally, helping others in online support groups allows the individual to view themselves as having strengths, and provides opportunities to take on new roles and responsibilities [44]. This would help them perceive themselves and the future in a more positive way which leads to higher levels of optimism.

The finding that participants with higher levels of online support group participation reported lower levels of perceived loneliness is also consistent with previous studies [45,46]. Loneliness is one of the most common stressors reported by individuals living with HIV/AIDS [47]. In addition, as a result of the stigma often associated with the disease, many individuals living with HIV/AIDS have reported not disclosing their disease status to their friends and family members [48,49]. The present study suggested that online support group participation was related to lower levels of loneliness indirectly through higher levels of optimism. Individuals who have a more positive view toward the future might also be more able to maintain a positive psychosocial state. Therefore, those with higher levels of optimism might report lower levels of loneliness in general. The findings of the present study suggest that online support groups have the potential to reduce feelings of isolation and loneliness by facilitating online social connections with others also living with HIV/AIDS and promoting a more positive view toward the future.

It has been widely reported that individuals living with HIV/AIDS often suffer from depression [50]. The results of our study suggest that higher levels of online support group participation was related to lower levels of depression indirectly through higher levels of optimism. Loneliness is an important psychological state

that contributes to maladjustment and lack of well-being [51]. It has been linked to depression in a number of studies [52]. On the other hand, it has been suggested that optimism is more resistant to negative emotional well-being such as depression [30]. The findings of the present study are supported by previous studies suggesting that participation in online support group empowers members to conquer the fears related to their condition [53], and is related to lower level of depression [54].

Whilst the present study has proposed a model through which participants with higher levels of online support group participation have higher levels of optimism, and lower levels of loneliness and depression, there are a number of limitations to the study which should be considered. First of all, participants in the present study were self-selected. Therefore, it is unclear whether those who did not respond to the survey felt empowered in the same way (if at all) as those who participated. It might be possible that those who participated in the study were more likely to have more positive experiences from using online support groups than those who did not. In addition, due to the small number of participants who were classified as lurkers ($N = 84$), multi-group analysis on whether active or passive participation in online support groups altered the pathways in the model was not possible. Finally, the study was cross-sectional and therefore no causality could be inferred. Although our speculation that online support group participation leads to greater exposure to potentially empowering processes which in turn, predicts better psychological outcomes makes theoretical sense, it might also be possible that members with better psychological outcomes felt more exposed to empowering processes during the online support group participation process. Longitudinal or randomized-controlled studies are warranted to examine the effects of online support group participation in both the short and long term.

4.2. Conclusion

To conclude, results of the present study suggest that participation in online support group is related to better

psychological outcomes as measured by higher levels of optimism, and lower levels of loneliness and depression. Future studies should seek to explore the effects of online support group participation using longitudinal designs. Furthermore, future research could identify possible ways to recruit online support group members who might be reluctant to take part in an online survey, and examine whether the pathways between online social support group participation and psychological wellbeing would be different for persons newly diagnosed and those who have been living with HIV for a number of years.

4.3. Practice implications

The present study suggests that participants with higher levels of online support group participants reported better psychological outcomes. Our results are promising as online support groups can offer a low-cost means of providing information and support to a large number of individuals. In addition, online support groups have the potential for reaching population groups which previously may have been difficult to access by conventional means and may go some way to removing geographical barriers, or physical limitations which may prevent individuals from seeking face-to-face support. As the number of Internet users is growing, it is expected that more patients would participate in online support groups in order to obtain information and support. The findings of the present study suggest that use of online support groups could be promoted to individuals with HIV/AIDS in order to improve their psychological health.

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