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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

## **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.

**Keywords:** Empowerment, HIV/AIDS, internet, online support groups, disadvantage

## 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, Siegel, Schrimshaw, & Siegel, 2003; Serovich, Brucker, & Kimberly, 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 & Liu, 2009; Mo & Coulson, 2008; Mo & Coulson, 2010). The literature has identified a number of ways in which online support group use might be helpful (Hess, Weinland, & Beebe, 2010). For example, studies have shown that online support group allow disclosure of emotions and insights, which is associated with psychological benefits (Han et al., 2008; Shim, Cappella, & Han, 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, Han, Shaw, McTavish, & Gustafson, 2008; Ziebland & 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 visualizing disease (Ziebland & Wyke,

2012). These unique features suggest that participating in online support groups might potentially foster patient empowerment (Barak, Boniel-Nissim, & Suler, 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, Drossaert, Taal, Seydel, & van de Laar, 2009; van Uden-Kraan et al., 2008). 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, Norris, Lester, & Marcus, 1999). Also, active forums can produce a large number of messages from various perspectives, reading the messages can be very time consuming (White & Dorman, 2001). The lack of visual and auditory cues may also result in the misinterpretation of messages being read (Waldron, Lavitt, & Kelley, 2000). In addition, due to anonymity, lack of real-time responses and lack of social status cues that normally inhibit inappropriate responses (Braithwaite, Waldron, & Finn, 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 & 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, Pennebaker and Dickerson (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 compared to those with hypertension. The authors conclude that having an illness that is embarrassing, socially stigmatising, or disfiguring may lead people to seek support from others with a similar condition. Therefore, we conjectured that the nature and pattern of HIV/AIDS online support group use and the ways which online support groups may promote empowerment might be different. This study seeks to explore this issue by examining the presence of potentially empowering and disempowering processes and empowering outcomes as it applies to the HIV/AIDS-related context.

## **Method**

### *Participants*

A total of 115 HIV-positive online support group members completed all sections of an online survey. The majority of the participants were male (89.7%) with a mean age of 46 years old (range 20-75 years). More than 90% of participants indicated that they were college educated or

higher and slightly more than half (55.6%) were in a relationship. In terms of medical characteristics, more than two-thirds of group members (69.9%) reported being in the asymptomatic stage. Their average length of time since diagnosis was 10.6 years (range <1 to 22 years) and their mean self-reported CD4 count was 557.92 uL. The demographic and medical characteristics of participants are summarised in Table 1.

Insert table 1 about here

### *Procedure*

Participants were recruited from four HIV/AIDS online support groups using convenience sampling. All the support groups were public in nature and were active with at least 10 messages posted to the group each week. A recruitment message was sent to group members and/or posted to the online bulletin board by the moderators of the groups. Inclusion criteria of the study were individuals aged 18 or above, were living with HIV/AIDS, and were able to read and write in English. Interested participants clicked the link contained within the recruitment message and were directed to an online survey. Informed consent was sought before they were able to complete the survey. The recruitment stopped after three weeks when no more new responses were received from the online survey.

### *Measures*

In addition to background information (see Table 1), a series of questions were asked to capture the level of online support group use (Houston, Copper, & Ford, 2002; Nonnecke, Andrews, & Preece, 2006; Turner et al., 2001) (see Table 2). In order to gain a richer insight into the experience of using HIV/AIDS-related online support groups, participants were then asked to respond to a series of open-ended questions which explored: reasons for participating in/accessing online support groups, differences between support obtained online versus that from the face to face context, perceived advantages and disadvantages of participating in/accessing online support groups, and impact of online support group use on disease management. These questions have

previously been used in studies examining online support group use experience across other health conditions (Buchanan & Coulson, 2007; Coulson & Knibb, 2007) and have been found to be useful in eliciting patients' online experiences. Ethical approval was obtained from the Institute of Work, Health and Organisations of the University of Nottingham.

### *Data analysis*

The open-ended responses from participants were analysed using thematic analysis based on the empowering and disempowering processes, and empowering outcomes identified from a study of online support group use among patients with somatic diseases (van Uden-Kraan, et al., 2008). Although numerous studies have suggested the ways through which online health information seeking might affect health (e.g. (Ziebland & Wyke, 2012)), the framework developed by van Uden-Kraan (van Uden-Kraan, et al., 2008) was chosen as it did not only identify the processes which online support group use might be beneficial, it also described the possible positive outcomes and suggested the processes through which online support groups might be problematic. The coding process of thematic analysis involves recognising patterns from the data and encoding them prior to the process of interpretation (Aronson, 1994; Boyatzis, 1998). The responses were read and reread several times, across both questions and respondents, to increase familiarity with the data. Notes were made to reflect initial impressions and were progressively conceptualised into broader themes that best captured participants' viewpoints. The coding framework and results were discussed between the authors and any discrepancies were resolved to safeguard the reliability of the findings. The responses were read and coded independently by a second coder based on the coding framework. The Cohen's Kappa was .94 for the main theme and .81 for the subthemes

### *Development of the coding framework*

To evaluate the applicability of the coding framework in the present study, the responses from twenty respondents were randomly selected and a pilot analysis was conducted. As a



consequence, we refined, deleted or added to the coding framework which was based upon the themes identified by van Uden-Kraan, et al (van Uden-Kraan, et al., 2008). First, the “amusement” subtheme did not emerge in any of the selected responses and was thus eliminated. On the other hand, the analysis revealed that participants mentioned the connection and communication with other members as one of the important benefits of online support group participation. In response to this, a new subtheme “connecting to others” was created under the empowering processes. In addition, analysis of the selected responses suggested that sharing of experiences and helping others were two distinctive themes characterising the empowering processes of online support group participation. Therefore, the subtheme “sharing experience and helping others” under empowering processes was divided into two individual subthemes, “sharing of experiences” and “helping others”.

Furthermore, the results of our pilot analysis showed that the subthemes “collective action” and “confidence in dealing with the social environment” did not emerge in any of the selected responses and were thus eliminated. On the other hand, our analysis revealed that participants frequently described improvements in their emotional well-being as a result of online support group use. Therefore, a new subtheme “emotional well-being” was created under empowering outcomes. In addition, the results from the pilot analysis also suggested that the subtheme “feeling confident about the treatment” was less evident in the selected responses; instead, other aspects of improved disease management were mentioned more frequently. In response to this, the subtheme “feeling confident about the treatment” was renamed “improved disease management” to capture the broader aspects of the illness experience. Furthermore, examination of the responses and subthemes revealed a conceptual overlap between the subthemes “enhanced self-esteem”, and “social well-being”, and between “improved acceptance of the disease” and “increased optimism and control over the future”. It was decided to retain all sub-themes for the main analysis and to keep under review any continuing overlap with a view to identifying uniqueness going forward.

However, continued overlap of the subthemes remained as our full analysis of the data set progressed. Therefore, in order to resolve this issue, “enhanced self-esteem” and “social well-being” were eventually collapsed into one named “social well-being”, and improved acceptance of the disease” and “increased optimism and control over the future” were collapsed into one named “increased optimism and control over the future”.

Our pilot analysis of the disempowering processes revealed that none of the subthemes were evident in the selected responses, suggesting that the framework of disempowering processes was not applicable to our study context. Instead, other disempowering processes of online support group participation emerged. In response to this, responses characterising disempowering processes of online support group participation were noted and analysed inductively using thematic analysis.

## **Results**

### *Use of Online Support Groups*

Our data (see Table 2) revealed that 36.8% of participants reported accessing/using online support groups at least 5 times a week. Furthermore, participants reported having used online support groups on average 4.4 years, spending approximately 3 hours per week reading messages.

Insert table 2 about here

Members’ responses to the open-ended questions were conceptualised in the following themes:

### *Empowering processes within online support groups*

#### Exchanging information

This subtheme discusses the exchange of factual information or advice about HIV. Members described how the online support group was a useful way through which they could obtain a wide range of information about HIV/AIDS.

“it affords me the opportunity to query, poll, ask MANY (nationally as well as

internationally) to gain a better understanding of something that I am experiencing.” (P13, 38-year-old male).

The ability to search for and find information online via a support group was something that was relatively novel.

“These are the best things that have happened to people with chronic illness I remember the days when I had to go to a library to research on HIV. Not anymore!” (P97, 48-year-old male)

The online support group provided members with the opportunity to search for information anonymously and for more sensitive topics, this was particularly helpful. Moreover, it provided a means through which members could disclose information more freely as well as overcoming any potential fear of being seen to be ignorant about a specific topic.

“I can sit quietly and ask the computer stupid questions and find things that I might be embarrassed to ask about, show my ignorance or reveal and I can do it in my undies or bathrobe or at 2am.” (P23, 61-year-old male)

The importance of information acquisition was emphasised by the following participant, who believed that gaining more knowledge about HIV/AIDS was crucial to management of the disease:

“I believe that knowledge is power, and I needed as much power as possible to survive this disease.” (P105, 50-year-old male)

The need for up to date, accurate and accessible information was, for some members, the result of feeling dissatisfied with that which was provided by healthcare professionals. As one member described:

“Many clinics do not give full or accurate information - only telling patients what they think they need to know. a bit patronising. This has been my experience both in \*\*\* [a state of the United States] and \*\*\* [a state of the United States]” (P83, 55-year-old male)

“...to get a better understanding of my illness, the doctors never dumbed it down enough for me to understand...” (P45, 20-year-old male).

### Sharing experiences

This subtheme describes the exchange of personal experiences or individual stories in coping with HIV. For most members, the online support group offered a venue through which they could discuss or share their personal experiences with other members. Members appeared to value the insights offered through the sharing of personal experiences and these were seen to be more personally relevant, meaningful and stood in contrast to the more technical information provided by health professionals.

“Well they seem to be the most relevant and due to the personal issues shared by the members these issues are heart felt and not in the third person, i.e.: not just the intellectual or the correct views.” (P88, 41-year-old male)

Similarly, another member felt that discussing the disease with other members was as important as discussing it with health care professionals:

“When asking for support it is usually in relation to information or knowledge I am seeking regarding medication or side effects. A physician can discuss the "disease" and side effects you might get. But discussing it with others is valuable tool and necessary support to live with this disease.” (P135, 42-year-old female)

### Connecting to others

This subtheme refers to the connection, development of friendship and bonding between members. Online support groups appeared to provide a platform where members could connect with others living with HIV/AIDS. Some members described how they did not know anyone who was living with HIV/AIDS in their offline world. For others, geographical barriers meant that it was difficult to access traditional face to face support and the online group was a helpful solution:

“I originally sought a 'connection' to the affected community since no services were

available to women in my rural town, despite being positive for over a decade. The on-line support community was an important way for me to interface with other positive individuals.” (P6, 53-year-old female)

Some members chose not to disclose their diagnosis to other people, for example, partners, friends, or family. Indeed, for some members there was a need to maintain anonymity and the online group provided a context in which they could be themselves.

“...At that time I wasn't capable nor really to approach an ASO nor disclose my status. I had so many guilty questions that I needed to talk to someone who would not know anything about my life nor recognise me, but only know that I'm HIV + and I need help. I always wanted to meet other youth out there that were HIV+, that I could relate to and look at.” (P131, 27-year-old male)

“Its easy to speak with and meet other positive people. I work in the social services field and if I use the groups in \*\*\* [a city of the United States] my clients are there and I never get support for myself because I am always the "worker"” (P89, 42-year-old female)

#### Encountering emotional support

This subtheme illustrates the disclosure of emotions and the exchange of empathy, concern, or affection between members. For many members, the online support group provided a place where they could share their feelings and emotions as well as a place to seek emotional support.

“It was a way for me to have support from other people while being able to hide behind the relative anonymity of the Internet. I was also just looking for sympathetic ears from people who could understand what I was going through at the time. I just post events from my life in order to share happiness and sorrow. In response, I receive sympathy, empathy, and broad shoulders on which I may sometimes lay part of my burden.” (P77, 38-year-old male)

The emotional support obtained from other members of the group was seen as particularly helpful in terms of encouraging them to continue on in their efforts to manage the illness. As the

following members described:

“As I improve from the effects from PML the support I need most is encouragement for what I’m doing to recover. I get this everytime I post updates about therapy to bloodwork.”

(P137, 37-year-old male)

For most members, the 24/7 availability of the online support network appeared beneficial as they could obtain emotional support whenever they needed it, no matter what day or what time. As a member noted:

“Sometimes when I am not coping with any aspect of my illness, I know that there will always be someone online, no matter what day, what time of the day or nite. Someone will always be there to support me, unlike face to face support, you can sometimes feel alone when services are closed. The internet never closes.” (P15, 36-year-old male)

#### Finding recognition and understanding

This subtheme describes the process which members seek for the acknowledgement from someone in the same position as themselves. Some members described how the online support group provided the opportunity to compare themselves with others, and in so doing find the recognition that they were doing fine in their journey. Alternatively, it was comforting to know that someone felt the same way as they did:

“Just knowing someone else is thinking of the same things you are is important.” (P120, 53-year-old male).

Members also appreciated the empathy displayed by other members of the group. In particular, shared experiences helped them feel that they were truly understood by people who had been there also. Indeed, for some, it was felt that the online group offered more comfort and understanding than their offline support network.

“For the most part I have no contact with these people other than in an online relationship. I find that support I have received has come from a place of understanding, a

type of peer support that does not exist in my real life relationships.” (P153, 37-year-old female)

### Helping others

For some, participating in the online group was seen as a way through which they could help others. This was particularly true for members who had been living with HIV/AIDS for quite some time and who wanted to have their voice heard by other members: “I want to get my voice heard as a long term survivor,” (P32, 46-year-old male).

Some members described how they had personally benefited from information, advice and support found online and that they now wanted to help others. For example, one member said:

“When first diagnosed and on treatment, I had a lot of problems getting the right therapy for me...lots of side-effects and complications. Some of these were complex and took a lot of effort to resolve...during this period, I was "new" to HIV, and relied on help from \*\*\* [name of a website]; now that I am better informed, I am "repaying" my debt to \*\*\* [name of a website] by being proactive in supporting them. During this initial period, I also had support on "softer" (emotional and social) HIV matters from \*\*\* [name of an organisation]... and again, I am still involved, now more as a "giver" rather than "receiver" of help.” (P129, 54-year-old male)

### *Empowering outcomes of online support group use*

#### Increased optimism and control over the future

For many members, negative emotional reactions seemed to be common following an HIV+ diagnosis. However, online support groups appeared to offer them a sense of hope. Through reading the experiences of other members, members realised that many people who had experienced similar challenges were able to manage their disease and enjoyed a good quality of life for many years. This appeared to reassure members that HIV/AIDS was a manageable condition, thus helping them feel more optimistic and positive about the future.

“The first time I found out that I was positive, I felt that my life was ending. The only thing that I thought about was suffering before I die. I promised myself that should that time come I will commit suicide and die peacefully other than going through pain and stressing my loved ones. But when I started posting to the forum, my mindset changed and I was given hope and people prayed for me to be strong and told me that if I take good care of myself I will live longer... ” (P76, 31-year-old female)

Similarly, the following member also described how the positive experiences of other members have given him hope and helped him stay optimistic.

“Yes. What I see is more HOPE than ever before. People are moving forward with healthy and productive lives. They are not waiting around to die. They are choosing education and medication that is now available to our community. I feel more positive about my future”. (P105, 50-year-old male)

#### Emotional well-being

In some cases, members described feeling anxious about living with HIV/AIDS and the online group helped them manage their fears.

“It helps me stay focused and most often calms any anxieties or fears I have. Often it simply normalized my emotional state.” (P136, 38-year-old male)

Some members described how the positive experiences shared by other members were instrumental in helping them stay emotionally strong.

“When people post messages about different things that they go through and how they manage to live with their situations, I must say they make me stronger and stronger each day. I always print out messages that are inspiring and courageous.” (P76, 31-year-old female)

Similarly, being able to help others in the online group was seen as emotionally beneficial to individuals.

“It does make me feel better and makes me feel like that I am helping others with my



comments.” (P74, 37-year-old male)

### Social well-being

For some members, participating in online support groups appeared to increase their social network. Indeed, there were instances where members had developed a strong connection and bond with other members of the group. As described by the following members:

“Only they know that I have HIV, and my doctor, nobody else. They are my virtual family ( I do want to have the real one too, family, but they do not know, I do not want my family to suffer).” (P80, male, age unknown).

In other instances, they were able to develop a true friendship with other members:

“The connection with other positive individuals was invaluable. Once, I needed lodging in \*\*\* [a state of the United States] while participating in a clinical study, and one of the on-line members offered to put me up in his apartment in Bethesda! What ensued then was a wonderful friendship, one that couldn't have happened without the on-line site.” (P6, 53-year-old female)

Participating in an online support group also helped members to overcome their sense of isolation. Through reading the stories of other members, members were able to compare their own experiences with others which helped them realise that their problems were not unique and they were not alone dealing with the disease:

“It's very helpful to read about other people's experiences... and the responses that other people give...It gives me perspective on my situation compared to others, and also provides awareness that we're not alone...that there are MANY MANY other people out there in similar, better, and worse circumstances than myself. A lot of times I encounter situations similar to mine, so through other people asking questions and for support, they're asking the same questions I am, and I benefit as much as they do.” (P122, 26-year-old male)

### Being better informed

Given the importance of information in coping with the disease, the online support group, with its ability to provide up-to-date information, was often described as invaluable by its members as it allowed them to keep up to speed with current practices and developments in HIV/AIDS management.

“Yes definitely, I am much more informed. I have learned more in the \*\*\* [name of the online support group] group than anywhere else about HIV care and options”. (P112, 46-year-old male)

“I learn something new about HIV and other health related issues daily. I am not sure if I would be this healthy after 24 years of infection if it wasn't for the Internet.” (P97, 48-year-old male)

### Improved disease management

For some members, reading the messages posted by others, or sharing experiences with other members online appeared to improve disease management. Through discussing coping strategies with other members from a wide range of backgrounds and experiences, members appeared to gain greater insight into how to successfully manage their illness.

“I get to understand how other people are coping and how much is at their disposal, and how I can make or do with what is available to me.” (P26, 36-year-old male)

Another member discussed how the online support group helped him understand different perspectives about the disease and how it may impact on his own treatment:

“It allows me to see how other people from a wide spectrum of ages, race, nationality, sex and sexuality and social classes, also varied stages of the disease cope with, or are affected by any of the symptoms or side effects of the disease or medication. I get a better insight, I think, into best practice when it comes to treatment.” (P109, 47-year-old male)

### Feeling confident in the relationship with their physicians

Participating in an online support group also seemed to improve the relationship between members and their healthcare physicians. The knowledge and perspectives gained from the online support group appeared to formulate and clarify some of the questions members would be asking.

“Yes I have gained several good points of information to discuss with my ID DR...about Meds and the dosing/use of certain combinations” (P11, 65-year-old male)

In some cases, members even seemed able to educate them in certain aspects of the disease. As illustrated by one member:

“I'm able to take the information I learn into my doctor's office and share my finding with him. And, on many occasions, I've actually been able to educate him about something I've learned. We're all in this together and it's our obligation to share as much education as possible with as many people who will listen to us.” (P105, 50-year-old male)

### *Disempowering processes within online support groups*

Although online support groups appeared to be a useful source of information and support for members, some disadvantages were also described:

### Being unable to connect physically

As communication within online support groups was essentially text-based, members described the challenge of there being no physical connection between members. For example, not being able to meet or see other members face-to-face was considered a drawback.

“you don't get the hands on approach, or just like sometimes you would just like to reach out an (and) touch someone for there (their) support or to give real time support” (P65, 42-year-old male)

“Sometimes just touching another can make ALL the difference; it is difficult to touch 'online'.....”(P47, 43-year-old male)

The lack of physical presence also meant that forming relationships online was more

difficult. Some members described how difficult it was to convey emotions simply through text. Moreover, they also had more trouble understanding what was meant by a comment made by another member and described instances of misunderstanding and confusion.

“There is no face-to-face contact. Sometimes, the words we write do not adequately convey the emotion behind those words and things get misunderstood. With face-to-face contact, we hear voice inflections and see facial expressions so it is more difficult to misconstrue what is being said.” (P77, 38-year-old male)

#### Inappropriate behaviour online

The anonymity of the online support group also meant that inappropriate or disrespectful behaviour was sometimes witnessed. On occasion, members described how they felt personally attacked or ridiculed for the views and opinions they expressed. Feelings of mistrust and fear were sometimes experienced.

“I was becoming overwhelmed by the data and the number of personalities on one site. I became disillusioned after almost one year of involvement due to a certain divisiveness between long term members and short term members ('flame wars' ensued after membership surge), and experienced a public derision by two individuals whose malicious intent hurt me personally. (The moderators allowed this to happen.)” (P6, 53-year-old female)

#### Declining real life relationships

For some members, there appeared to be the risk of becoming over-reliant on online relationships, resulting in decreased time devoted to face to face relationships or other aspects of daily lives.

“At first, the involvement with the on-line support community was an amazing place to receive emotional support from people all over the world who understood what it's like to live positive; however, I noticed that my real-life relationships were declining due to the time I invested in the on-line community...” (P3, 49-year-old male)

Similarly another member wrote:

“We can get stuck online, and not venture out to contact people in person. Meeting other HIVers in person is a totally different experience. Human contact, making acquaintances and friends is so important. Online support can open doors and help bring us into the rest of the HIV community, but the risk is that some people only get that far, and in a sense, remain isolated in their real life, having only the online world as their support.” (P122, 26-year-old male)

### Information overload and misinformation

For some members, misinformation or information overload appeared to diminish the value of the online support group. As the amount of information available increases, through members posting messages, the potential for some of that information to be inaccurate, opinion-based or contradictory was a concern for some members.

“You need to choose your source of support carefully...there can be misinformation on the web.” (P129, 54-year-old male).

Also, information overload appeared to be daunting, especially to members who were new.

“There is so much information on the net that people who have just been newly diagnosed and are looking for information may find themselves overwhelmed. Eventually, the amount of contradictory and even misleading information not only lead to confusion but also depression.” (P83, 55-year-old male)

### **Discussion**

The present study aimed to explore the potential ways in which HIV-related online support group use may be empowering. Our analysis revealed a number of potentially empowering processes which members may experience online along with potential outcomes. The empowering processes identified in the present study are consistent with the benefits of online support groups identified in previous reviews (Hess, et al., 2010; Ziebland & Wyke, 2012). In

addition, our analysis also revealed a number of potentially disempowering processes which may also be present. These findings will now be discussed in turn.

#### *Empowering processes within online support groups*

The majority of members described how searching for information was their primary purpose for accessing an online support group, suggesting that information needs appear to be particularly important irrespective of background or disease characteristics. Furthermore, a motivating factor for information searching appears to be, at least for some, dissatisfaction with the information provided by health professionals. Accessing relevant, up to date and understandable information through the online support group was viewed as highly beneficial and as previous research suggests, is important when making informed decisions about health (O'Connor et al., 2003).

Our findings also highlight the fact that patients living with HIV/AIDS seek more than just scientific facts or technical information whilst online. Many members appeared to value the experiential knowledge gained whilst online and acknowledged that online support groups provided them with unique access to many first-person perspectives and experiences about the disease which would otherwise not be available in their face to face world. Indeed, many studies have documented that people living with chronic diseases often exchange their personal experiences and considered other members' lived experiences more vivid than facts (Weis, 2003; Ziebland & Herxheimer, 2008). For persons living with HIV/AIDS, the positive experiences described by other members may help them confront their own fears associated with the disease. They may also seek to reduce the sense of loneliness often experienced by members and help them realise that they are not alone (Buchanan & Coulson, 2007; Cunningham, van Mierlo, & Fournier, 2008; Sillence, 2013).

Our findings revealed that many members often reported that they did not know anyone living with HIV/AIDS in their face to face social network. Furthermore, they also described the

difficulties surrounding disclosure of their HIV status to friends, family and colleagues. However, the online support group offered them new opportunities to connect with many others facing similar challenges without fear of judgement or rejection. Indeed, our findings suggest that online support may be preferred by some participants due to its accessibility, ease of use and anonymity.

Another benefit of online support group use seems to come in the form of exchanging emotional support. The online support group appears to help participants' deal with their negative emotions. This was evidenced by participants' descriptions of how the anonymous nature of online support groups allowed them to express themselves more openly and receive more honest responses from other members. Our findings are consistent with previous research which has shown that online support groups serve as a useful venue where members can both offer and receive emotional support (Bar-Lev, 2008; Han, et al., 2008; Lieberman et al., 2003).

While a face-to-face support network remained important, many members felt that talking to other members from the online support group were more preferable. Members valued, in particular, the empathic understanding and acceptance from other members who had experienced similar struggles and challenges, which would not have been possible to receive from persons who were not HIV+. Our findings are consistent with other research which has found that people who come from similar backgrounds or who share similar health-related concerns tend to exhibit more empathy towards each other in health-related online support groups (Preece, 1998, 1999). Therefore, the compassion and empathy derived from online support group appears to be unique and instrumental.

It also appears that some members may be empowered through actively helping other members of the group. Through providing support, it is argued, the helper is no longer restricted to the patient role but can actively serve as a role model to others (Levy, 1999). The therapeutic benefits of helping suggest that the sharing of one's own stories helps participants make sense of what has happened to them and may help an individual to let go of the past (Beck, 2005; Murray,

2003). In addition, helping others may be one strategy through which an individual may feel more personally satisfied (Winefield, 2006).

#### *Empowering outcomes of online support groups*

The findings from our study suggest that online support group use appears to help participants to feel more positive about the disease and help address the sense of hopelessness, which is often experienced by those newly diagnosed. Through accessing the stories and experiences of other members, members may read about similar others living with HIV/AIDS who enjoy a fuller and longer life as a result of HIV/AIDS medications. This knowledge appears to foster a sense of hope and some control over their life and is consistent with the findings of studies examining traditional face to face support groups (Herth, 2000; Mok & Martinson, 2000).

The opportunity to express emotion, and exchange emotional support in the online support group also appears to benefit members' emotional well-being. Members reported that participation in online support groups helped reduce their fears and anxieties associated with the disease and helped them become emotionally stronger. This is supported by previous studies which have described the benefits of emotional disclosure in times of psychological distress (Lepore & Greenberg, 2002; Pennebaker, 1997), and the fact that disclosure of emotions in online support groups is associated with psychological benefits (Han, et al., 2008; Shim, et al., 2011). Furthermore, the emotional support and encouragement offered by other members in the online support group may help reduce any emotional discomfort either directly, or buffer members against the negative effects of other stressors (Cohen, Gottlieb, & Underwood, 2000).

Our findings also suggest that connecting to individuals with similar concerns seems to be beneficial in helping reduce social isolation and feelings of perceived loneliness. Indeed, simply reading about the experiences of other members appears to be helpful, as seen through the many comments made by our survey respondents about the realisation that they 'were not alone' and reading about others reassured them. Indeed, to date there has been a growing body of literature



which describes how accessing online support groups may be helpful for those who feel alone or isolated (Dunham et al., 1998; Malik & Coulson, 2008; Weinert, Cudney, & Winters, 2005) and that reading messages alone, regardless of whether one eventually posts a message to the group or not, can be helpful (Klemm, 2012).

For many members, the rich and varied source of information about the disease appeared to help them manage their illness, including decisions about treatments and other healthcare choices. Our findings are consistent with previous research which has found that online support group participation may provide participants with the knowledge and skills to become more active in their healthcare (Ziebland et al., 2004). In the context of the present study, it can be speculated that access to health information from online support groups and positive experiences of how other members cope with the disease may give members a sense of competence and autonomy, which in turn may have increased their confidence to take a more active role in their illness management.

Participation in the online support group also appears to contribute to an improved doctor-patient relationship by helping members keep up to date with information about HIV/AIDS as well as providing them with opportunities to develop, rehearse and clarify questions or issues for discussion with health professionals. Whilst the medical profession has historically been viewed as a patriarchal system in which the doctor is considered the 'expert' and directs all treatment decisions (Goodyear-Smith & Buetow, 2001), participating in an online support group may be one way through which patients are becoming more empowered, autonomous and perform a more collaborative role in the medical encounter.

#### *Disempowering processes within online support groups*

While the vast majority of responses were positive, there were nevertheless some disadvantages to online support which were described by respondents. Some members reported the frustration of not being able to have physical contact with other members they met in the group. Moreover, they also expressed concerns that the people they were interacting with online

might not always be honest about their identity, motivations or experiences. Indeed, knowing the identity of the people one communicates with is essential for developing an interaction. However, as online communication is based mainly on textual messages, identity is more ambiguous and it has been argued that this may contribute to a greater likelihood of dishonesty (Donath, 1999). Moreover, online disinhibition may also contribute to more hostile or aggressive expressions online, a phenomenon which is termed "flaming" (Lea, O'Shea, Fung, & Spears, 1992; Walther, Anderson, & Park, 1994).

An important potential issue arising from online support groups is the extent to which incorrect information may be exchanged. Indeed, previous studies which have assessed the quality of information found within online groups reported only a small proportion of information was indeed inaccurate or non-scientific (Esquivel, Meric-Bernstam, & Bernstam, 2006; Hoch, et al., 1999). However, concerns regarding information were not limited to the accuracy of it but also the volume of it. For some members, having to search through vast archives of information for that which was directly relevant was found to be a stressful and emotional experience and not always successful.

#### *Limitations of study*

Although participants were recruited from several online support groups, it would be plausible that the composition, aim, and group dynamics across other HIV/AIDS-related online support groups might differ to those represented in the present study. Similarly, participants in our study were self-selected and it might be possible that those who chose to participate had a more positive view towards online support groups. That is, members who did not find the online support group experience to be a helpful one would be less likely to continue accessing it and therefore unlikely to see any recruitment invitations posted to the group. In addition, our participants varied in the length of time they had been using an online support group and since our study did not stipulate a minimum length of membership it is likely that some participants were not able to

provide as rich a description of their online experiences as compared with others. This limitation should be considered when interpreting the findings of this study.

### *Implications*

The findings of the present study suggest that online support groups can be a useful venue where individuals living with HIV/AIDS can share information and personal experiences, connect with similar others, and to obtain emotional support. Furthermore, engaging with online support groups may also be beneficial in improving social and psychological well-being, and disease management. Whilst health care professionals are arguably well placed to provide factual information and advice about the disease, they may lack the lived experience of the disease and may not understand what it feels like to live with HIV/AIDS. As a consequence, health care professionals may therefore encourage individuals living with HIV/AIDS to engage with an online support group, in conjunction with their standard treatment, as a supplementary source of information, support, and understanding. However, online support groups are not without their limitations and health care professionals may find it helpful to discuss with patients the positive aspects of their use whilst also reminding and warning patients that there are some potential disadvantages.

### *Conclusion*

With recent advancements in online technology, it has become increasingly popular for patients to use online support groups to seek information, advice and support. The results from our study suggest that online support group use may potentially empower individuals living with HIV/AIDS in a number of important ways. However, there may be some limitations to the use of online support and these should be kept in mind if directing patients with HIV/AIDS to online groups as an adjunct form of care. As online support groups continue to grow, more research is needed to investigate the benefits of these online communities as well as exploring any potential

limitations.

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**Table 1 Demographic and medical characteristics of participants**

Variables	Total (N=115)
Gender	
Male	102 (88.7%)
Female	13 (11.3%)
Age	M= 45.92 SD=9.96
Education	
High School or less	7 (6.3%)
College or University	65 (58.0%)
Graduate School or higher	40 (35.7%)
Employment	
Student	4 (3.5%)
Part-time	14 (12.3%)
Full-time	55 (48.2%)
Unemployed because of poor health	17 (14.9%)
Unemployed because of other reasons	2 (1.8%)
Retired	13 (11.4%)
Others	9 (7.9%)
Marital status	
In a relationship	60 (55.6%)
Not in a relationship	40 (37.0%)
Separated/ divorced/ widowed	8 (7.4%)
Country of residence	
North America	80 (69.5%)
South America	7 (6.3%)
Africa	3 (2.8%)
Europe	14 (12.8%)
Asia	3 (2.8%)
Australia	2 (1.8%)
Disease Stage	
Asymptomatic	79 (69.9%)
Symptomatic	8 (7.1%)
AIDS	26 (23.0%)
Length of diagnosis (in years)	M=10.59 SD=13.77
CD4 count (in cells/mm <sup>3</sup> )	M= 557.92 SD=300.95

**Table 2 Level of online support group use of participants**

Variables	Total (N=115)
Length of online support group use (in years)	M=4.36 SD=2.97
Frequency of online support group use	
Daily	32 (28.1%)
5-6 times a week	10 (8.8%)
3-4 times a week	10 (8.8%)
1-2 times a week	33 (28.9%)
Less than once a week	29 (25.4%)
Time spent on reading messages per week (in hours)	M=2.93 SD=9.84