An analysis of social support exchanges in online HIV/AIDS self-help groups

Constantinos K. Coursaris *, Ming Liu

Department of Telecommunication, Information Studies, and Media, Usability and Accessibility Center, 424 College of Communication Arts and Sciences, Michigan State University, East Lansing, MI 48824, USA

A R T I C L E   I N F O

Article history:
Available online 25 April 2009

Keywords:
Support groups
HIV
AIDS
Computer-mediated communication
Content analysis

A B S T R A C T

Hundreds of thousands of people sharing concerns about HIV/AIDS have taken advantage of online self-help groups to exchange resources and support. Little research so far has focused on the nature and content of actual messages exchanged by group members. To provide an in-depth understanding of social support exchanges in online HIV/AIDS self-help groups, this study identifies and analyzes the dimensions and corresponding frequencies of exchanged social support as well as the group interactions facilitating those exchanges. A total of 5000 postings created within a 1 year period were randomly selected from a selected online HIV/AIDS forum. Content analysis was then conducted to assess the types and proportions of exchanged social support. A thematic analysis of the postings that could not be categorized with the adopted coding system was performed to find further patterns of positive group interactions. The results show that information support (41.6%) and emotional support (16.0%) were exchanged most frequently, followed by network support (6.8%) and esteem support exchanges (6.4%), whereas tangible assistance was quite rare (0.8%). The authors also suggest that three types of group interactions including sharing personal experience, expression of gratitude, and offering congratulations can facilitate social support exchanges among group members.

© 2009 Elsevier Ltd. All rights reserved.

1. Introduction

Computer-mediated self-help (CMSH) groups allow individuals to communicate with others who share an interest in the group’s theme, often in the context of exchanging support. These groups use either asynchronous (e.g., e-mail) or synchronous (e.g., chat rooms) computer-mediated communication (CMC) to perform their functions. The common feature is that group members express themselves by typing on a computer and then sending out messages through the Internet. By December of 2002, about 63 million or 54% of American Internet users had used online support communities and groups for specific medical conditions or personal problems (Fox & Fallows, 2003). This audience is estimated to be considerably larger currently (approximately double), given the Internet’s use growth rate among Americans of 125.6% between 2000 and 2007 (Internet usage, 2007).

The Joint United Nations Programme on HIV/AIDS (UNAIDS) (UNAIDS, 2006) estimated that there are about 40 million people living with HIV/AIDS worldwide. In the United States, more than one million people have HIV/AIDS and approximately 40,000 people become infected with HIV each year (Centers for Disease Control and Prevention, 1999). This particular population has begun taking advantage of CMSH groups. In August 2007, on Yahoo! Groups alone there were about 900 HIV/AIDS related support groups with thousands of members belonging to several of the larger groups. In addition to those groups hosted by Yahoo! Groups, there are virtually countless other CMSH HIV/AIDS discussion boards and chat rooms.

Social support plays an important role in coping with HIV/AIDS. Researchers have found that the more satisfied that individuals are with their social support, the more likely they are to experience positive adjustment to HIV/AIDS, less current depression, and less increase in depression 1 year later, more healthy coping strategies, and lower growth rate of their HIV-related symptoms independent of their coping styles and baseline medical status (Ashton et al., 2005; Hays, Turner, & Coates, 1992; Leserman, Perkins, & Dwight, 1992; Turner-Cobb et al., 2002). It was also revealed that about 40% of the people living with HIV/AIDS have unmet needs for social interaction (Smith & Rapkin, 1995). CMSH HIV/AIDS groups have significant potential for satisfying the social needs of those people by connecting them with others who are faced by the same needs.

Uses and effects of CMSH groups have been investigated in studies of groups for people with certain health related issues, such as breast cancer, disabilities, and irritable bowel syndrome (Barak, Boniel-Nissim, & Suler, 2008; Blank & Adams-Blodnieks, 2007; Braithwaite, Waldron, & Finn, 1999; Coulson, 2005; Rodgers & Chen, 2005). Researchers have tried to identify what dimensions of social support are provided in those groups to understand the substantial group activities that contribute to their benefits. To our knowledge,
however, no study has been conducted to examine specific social support exchanges in CMSH HIV/AIDS support groups. Thus, the purpose of this study is to provide an in-depth understanding of social support exchanges in CMSH HIV/AIDS groups. Specifically, this research (1) content analyzes 5000 messages that were randomly selected from an online HIV/AIDS forum and created within a 1 year period to identify the types and assess the amounts of social support exchanged and (2) conducts a thematic analysis to propose additional kinds of social interactions that may facilitate social support exchanges.

2. Internet use among people living with HIV/AIDS

Individuals living with HIV/AIDS face social, emotional, and psychological challenges beyond the more recognized physical issues (Reeves, 2000). According to a recent national survey in the US, over 80% of the respondents thought that prejudice and discrimination exists against people living with HIV/AIDS (Kaiser Family Foundation, 2006). In light of these social conditions, researchers indicated that the Internet can be a feasible, acceptable, and promising source of information and emotional support for people living with HIV/AIDS (Brennan & Ripich, 1994; Kalichman et al., 2002). Kalichman et al. (2002) investigated the characteristics of people living with HIV/AIDS who have access to and use the Internet and found that Internet use is not associated with age, gender, ethnicity, HIV-related hospitalizations, or HIV-related symptoms, but it is positively associated with years of education and income. They also identified substantial differences in Internet use among this population; people with Internet access at home used much more e-mail and did more online searches for HIV treatment information, and 17% of them attended CMSH groups. Among people without home access, however, none used a CMSH group. The impact of Internet use on the coping ability of individuals with HIV was examined by Reeves through in-depth face-to-face interviews of ten HIV-positive people (Reeves, 2000). The results suggested that Internet use empowers individuals by allowing them to acquire more HIV/AIDS related information, facilitating their helping of others as a way of coping with HIV, and augmenting their social support. With respect to the augmentation of social support, it was found that the Internet acts as either a primary or a supplemental venue for social support, with informational and emotional support being frequently received among participants. In certain situations, the Internet was even considered a better source of support in coping with HIV.

3. Computer-mediated self-help groups

Although the history of CMSH groups is a lot shorter than that of traditional offline self-help groups, the number of participants in CMSH groups has been very large and steadily rising. At least 54% of, or 63 million, American Internet users have visited an online health-related group or community (Fox, 2005). CMSH groups are formed using various electronic venues, such as mailing lists, Internet newsgroups or Usenet discussion forums, Web based discussion/bulletin boards/forums, live chat rooms, and some commercial systems (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Walther & Boyd, 2002). Asynchronous bulletin board systems are the primary venue, where users post messages that are saved for a period of time for others to read at later convenient times (Walther & Boyd, 2002).

A number of previous studies have identified some of the advantages that CMSH groups can offer: lack of stigmatization due to anonymity, easier openness or more candor due to social distance within the groups, availability and easier access that minimizes barriers of time and location, diversity of members’ perspectives, similarity of members’ experiences, and a large amount of information and resources (Walther & Boyd, 2002; Wright, 2000). The greater anonymity provided by CMSH groups compared to offline support groups can particularly benefit people with stigmatizing diseases, such as AIDS, who may find CMSH groups an easier and safer venue to discuss private and potentially embarrassing topics and issues (Finn, 1999; White & Dorman, 2001). Participants in CMSH groups can exchange messages with others using pseudonyms or even do so anonymously so that cues related to their real-life identity or physical appearance are minimal. In Davison, Pennebaker, and Dickerson’s (2000) large-scale survey, it was found that people with stigmatizing diseases, such as breast cancer, AIDS, and prostate cancer, were more likely to seek support online using CMSH groups than people with non-stigmatizing diseases.

4. Types of social support

Previous research has also established the types of social support interactions that take place in CMSH groups. Some researchers have adopted or modified the classification systems from prior research on offline social support (Cohen & Wills, 1985; Cutrona & Suhr, 1992) and found that information and emotional support are, in general, the two most prominent types of social support provided in CMSH groups (Braithwaite et al., 1999; Coulson, 2005; Loader, Muncer, Burrows, Pleace, & Nettleton, 2002; Winzelberg, 1997). Other social support dimensions in CMSH groups have also been reported, as with the study by Braithwaite et al. (1999), which examined social support exchanges in a CMSH group for disabled people. The authors conducted a content analysis of posted messages to identify types of exchanged social support, using Cutrona and Suhr’s (1992) five-category system: informational, emotional, esteem, network, and tangible support. Consistent with Preece (1999), they found that emotional support was most frequently exchanged (40%). Information support (31.3%) and esteem support (18.6%) were also frequent. Network support (7.1%) and tangible support (2.7%) were found to be minimal. Similarly, in a qualitative study of a CMSH group for individuals living with irritable bowel syndrome, Coulson (2005) also found incidences of social support in all five categories described by Braithwaite et al. (1999); however, the amounts of each type of social support were not reported. Lastly, in Loader et al.’s (2002) study of a Usenet newsgroup for people living with diabetes, information support was found to be extremely frequent, and only a limited amount of self-esteem support and social companionship support were identified. Consistent with Braithwaite et al. (1999), a minimal amount of instrumental support (one thread) was also observed.

While the prevalence and importance of CMSH groups for people with HIV/AIDS is increasing, little is known about the dimensions and amounts of social support exchanged in these groups or the categories of group interactions that are closely related to or facilitate social support exchanges. By proposing the following research questions (RQs), the present study attempts to explore social support exchanges in CMSH groups for people living with HIV/AIDS.

RQ 1: What are the types and corresponding amounts of social support exchanges in computer-mediated HIV/AIDS self-help groups?

RQ 2: What are the categories of social interactions that can facilitate social support exchanges in computer-mediated HIV/AIDS self-help groups?
5. Methods

5.1. Group selection and procedures

The target CMSH group for individuals with HIV/AIDS was selected based on several criteria. First, a comprehensive online search was conducted to obtain a list of CMSH groups concerning HIV/AIDS. A total of 26 groups were identified and then tabulated in terms of the following aspects: time period in existence, size of group membership, volume of message activity, currency of message activity, technology platform used (e.g., bulletin board, listserv), and additional features (e.g., moderation, archiving of messages, rules and policies, awards). Lastly, an electronic bulletin board system with a higher activity, relatively long history, and with an award-winning record (e.g., JAMA Best of the Net, NBC Editor’s Pick) was selected. To protect the privacy of the group, the name and URL of the website will not be reported in this paper. Established in year 2000, the selected bulletin board system is a comprehensive CMSH group, with 14 sub-boards focusing on a variety of HIV/AIDS related topics (e.g., “I just tested positive”, “Living with HIV”, “Treatment”). Since its beginning, about 18,000 threads including 95,000 posts had been created on these boards, which are all made public. The 3700 or so registered members and countless anonymous visitors were able to post messages to any board at any time.

Posts across all sub-boards within the last 365 days were retrieved using the search engine of the website in order to focus on recent activities in the group. They were then placed in 950 batches of 100 consecutive posts, for the purpose of enabling the researchers to observe threaded discussions on topics with randomization (Preece, 1999). Fifty batches or 5.26% of the total activity of this group were randomly selected, resulting in a total of 5000 sampled postings.

5.2. Data analysis

In phase one, a content analysis of sampled messages was conducted to answer the first research question. One of the authors and an undergraduate student coded all of the postings. Coders first examined if a message was posted in order to offer or, on the other hand, seek social support, which is broadly defined as caring, belonging, esteem, or assistance that can be exchanged (Cushman & King, 1986). After that, the typology of social support proposed by Cutrona and Suhr (1992) was used to classify the identified social support. This typology was developed by surveying social support measures in the prior literature on offline social support, and had been found valid to categorize social support messages in the study of a CMSH group for disabled people by Braithwaite et al. (1999).

Cutrona and Suhr’s (1992) social support typology involves five general categories of social support including information support, emotional support, esteem support, network support, and tangible support. Information support refers to messages that convey knowledge or facts to reduce uncertainty. Emotional support is messages that express empathy or support the emotional expressions of the recipient. Esteem support includes messages that help improve the recipient’s self-concept, confidence, and rights as a person. Messages of network support are offered to broaden the recipient’s social network by connecting him or her to other individuals with similar interests or situations. Tangible support refers to the provision of specific material aid or service to assist the recipient. In this typology, each of the five categories has several subcategories. For example, there are subcategories under information support, including (1) advice, (2) referrals to experts and resources, (3) situation appraisals, and (4) teaching. The subcategory called “listening” was not used in the current study because it requires synchronous interactions and is not applicable in this mediated communication environment. Table 1 shows all the 22 subcategories under the five larger categories.

Table 1

<table>
<thead>
<tr>
<th>Support category</th>
<th>Frequency of offering support</th>
<th>% of offering support</th>
<th>Frequency of seeking support</th>
<th>% of seeking support</th>
<th>Total % of total</th>
<th>Adjusted % of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information support</td>
<td>1458</td>
<td>29.1</td>
<td>626</td>
<td>12.5</td>
<td>2084</td>
<td>41.7</td>
</tr>
<tr>
<td>Advice</td>
<td>710</td>
<td>14.2</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral</td>
<td>140</td>
<td>2.8</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Situation appraisal</td>
<td>301</td>
<td>6.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teaching</td>
<td>484</td>
<td>9.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional support</td>
<td>646</td>
<td>12.9</td>
<td>154</td>
<td>3.1</td>
<td>800</td>
<td>16.0</td>
</tr>
<tr>
<td>Relationship</td>
<td>112</td>
<td>2.2</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical affection</td>
<td>46</td>
<td>0.9</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confidentiality</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sympathy</td>
<td>79</td>
<td>1.6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understanding/empathy</td>
<td>165</td>
<td>3.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Encouragement</td>
<td>223</td>
<td>4.5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prayer</td>
<td>141</td>
<td>2.8</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Esteem support</td>
<td>294</td>
<td>5.9</td>
<td>26</td>
<td>0.5</td>
<td>320</td>
<td>6.4</td>
</tr>
<tr>
<td>Compliment</td>
<td>112</td>
<td>2.2</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Validation</td>
<td>175</td>
<td>3.5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relief of blame</td>
<td>18</td>
<td>0.4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Network support</td>
<td>250</td>
<td>5.2</td>
<td>78</td>
<td>1.6</td>
<td>338</td>
<td>6.8</td>
</tr>
<tr>
<td>Access</td>
<td>16</td>
<td>0.3</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence</td>
<td>185</td>
<td>3.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Companions</td>
<td>76</td>
<td>1.5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tangible assistance</td>
<td>27</td>
<td>0.5</td>
<td>13</td>
<td>0.3</td>
<td>40</td>
<td>0.8</td>
</tr>
<tr>
<td>Loan</td>
<td>2</td>
<td>0.04</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perform direct task</td>
<td>1</td>
<td>0.02</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perform indirect task</td>
<td>5</td>
<td>0.1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active participation</td>
<td>0</td>
<td>0.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Express willingness</td>
<td>21</td>
<td>0.4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: N = 5000 messages.
Messages that offer social support were classified into the five general types as well as the subcategories. Messages seeking social support, however, were only classified into the five general categories due to the usually vague nature of this type of messages. For each posting that conveys more than one type of social support, the coders identified all the social support types and coded them using the adopted typology. In this way, a more accurate representation of various types of social support exchanges could be achieved.

To test the intercoder reliability, the two coders independently coded four randomly selected batches (400 postings) of the sample before the formal coding. Consistent with Cutrona and Suhr (1992) and Braithwaite et al. (1999), reliability tests were based exclusively on the five-category system. Scott’s pi was used and the reliability coefficients for each of the variables are acceptable as follows: seek social support (.93), offer social support (.85), information support (.86), emotional support (.87), esteem support (.76), network support (.84), and tangible support (1.00).

In phase two, all of the postings that did not fit into any of the five general categories were summarized and discussed by the coders. Common themes of those messages were then generalized to provide a view of social support related interactions in the selected group, thus answering this study’s second research question. The percentages of postings that could fall into each of the themes were also calculated.

6. Results

A content analysis of the 5000 sampled postings made by the selected CMSH HIV/AIDS group revealed that 16.3% (815) of the postings sought social support, while 46.2% (2310) of the postings included the offer of some type of social support. All five categories and all except two of the subcategories of social support in Cutrona and Suhr’s (1992) social support typology were observed in our data, though with considerable variance of amounts. Messages exchanging information support were most frequently identified (n = 2084, or 41.8% of the total 5000), including 626 (12.5% of the total) messages seeking information support and 1458 (29.1% of the total) messages offering information support. Emotional support messages were second in frequency of exchange (16.0%), followed by messages of network support (6.8%) and esteem support (6.4%). Tangible assistance was rarely exchanged, accounting for 0.8% of the 5000 messages content analyzed. This frequency distribution of social support exchanges was corrected by calculating adjusted frequencies for the fit data only (see Table 1 for a summary of the results). Additionally, 87% of the messages included only one type of social support, 12% of the messages expressed two types, and another 1% of the messages involved three types of social support. Below, we discuss each type of social support in the order above with quotations and examples from our data.

6.1. Types and prevalence of social support exchanges

6.1.1. Information support

Information support messages were observed in terms of four specific subcategories, including (a) advice, (b) referrals to experts and resources, (c) situation appraisals, and (d) teaching (Cutrona & Suhr, 1992). Advice messages suggest courses of action or guidance for coping with HIV/AIDS related challenges and were most frequently found under the category of information support (14.2% of the 5000 postings) in our data. The majority of the advice suggested the taking of an HIV test to become certain if the individual was infected or not:

Do not diagnose the symptoms, if you feel worried you may want to get your symptoms evaluated from your health care provider. You have mentioned you are 6 weeks post your expo-sure, I would urge you to test at 6 weeks, since MOST who have been recently infected would test positive within 6 weeks. However irrespective of your result, you have to test again at 12 weeks for a definitive result.

Referrals are a type of information support that provides the recipient with a source of expertise or resources. We found that almost all of the referrals were for online resources or help instead of offline professionals, probably because members do not live in the same geographic locations but all have Internet access and experience using it. For example, a member waiting for her HIV test result posted, “I am so scared. Nowhere to turn, small town, no infectious disease doctors, no experts...” Another member then responded, “A really good website is aidsmeds.com. They have a lot of information and really supportive people on the message board.”

In another example, after someone expressed his need for a second opinion because he doubted his doctor, another member posted, “I would ask Dr. Barbara McGovern on the Ask The Experts Forum of this site.”

Situation appraisals were also found as a type of information support, which itself helps to “reassess or redefine circumstances, often in a manner that helps make them more positive or reveal new information that could be helpful” (Braithwaite et al., 1999). A typical message in this category reassures a recipient to believe that he or she is actually not infected with HIV. For example, a member posted the following in response to another who thought he had HIV symptoms:

I agree with what the others have said here. There’s no way you’re positive, especially with negative AB test at 6.5 months, negative PCR and a t-cell count of 1100. I’m surprised your doctor would even suggest that you need to test more.

Teaching refers to messages that provided factual information about HIV related situations or about the skills needed to deal with the situations. For example, when responding to another member’s uncertainty about his negative test result, one member posted: “With the new third generation tests, antibodies are detectable within 3–4 weeks and the vast majority by 6 weeks. Even the old first generation tests could detect antibodies by 45 days.” In another example, someone asked a series of questions about a rapid HIV test and got several responses, such as “The new oraquick is an oral swap now. They do not [pick] your [finger]. It takes 20 min for the result. They are as good as it gets.”

Postings seeking information support usually included specific questions concerning HIV. Some of the questions that were asked to obtain factual information, like, “Where would you find an HIV specialist?” Some were asked for an evaluation of a certain situation, like, “Yikes. I have lost 6 lbs in just 2 weeks. Is losing weight another early symptom? or am I just making myself sick worrying and that’s why I lost the weight????” Also, suggestions or advice were also sought in some postings, like “If I were to test positive would you think I would receive better support from a family doctor, or a clinic?”

6.1.2. Emotional support

Emotional support was categorized into seven subcategories: (a) relationship, (b) physical affection, (c) confidentiality, (d) sympathy, (e) understanding, (f) encouragement, and (g) prayer. In our data, confidentiality, defined as “promises to keep the recipient’s problem in confidence” (Braithwaite et al., 1999), was not found, probably due to the fact that anonymity in this CMC environment already secures confidentiality. Relationship support was found in postings that emphasized the importance of closeness and love within the CMSH community (Braithwaite et al., 1999). For example, a member wrote:
hello my family, I know I haven’t been here as much as I’d like. I’m going to school during the day and working at night. I really tried but I’m still here and I’m still kicking. I love you all and miss ya I’ll keep in touch more till then.

We also found that physical affection messages, which express physical contact verbally, were sent by group members, such as, "I’ll give you a kiss to show I care..." and "Thank you so much!!! Kiss kiss hug hug!!" Understanding messages showed a type of emotional support that expressed empathy or emphasized the similarity of one’s own experiences with another’s (Braithwaite et al., 1999). For example, someone responded to another person who was very afraid that he or she was infected with HIV after having unprotected sex with, "I totally understand your fear because I’ve been there, but the stress is our worst enemy in this situation..." Similarly, members also expressed sympathy, pity and sorrow for the distress of others, providing emotional support, such as, “Sorry to hear you are feeling this miserable.”

Group members also exchanged encouragement messages that provided each other with hope and confidence (Braithwaite et al., 1999). For example, below is a response to an individual who had a pessimistic attitude toward building relationships with others as a HIV positive person:

Just a note to you, I have dated many HIV pos people and am neg, I assume anyone I date is pos and play safe, your status doesn’t tell me whether I should fall in love or not, just your heart, I imagine you will have no problem finding someone to share your life with love and peace.

The last subcategory under emotional support is prayer, which referred to straightforward offers of prayer messages for members who were suffering or needed help (Braithwaite et al., 1999), such as: “I am praying for you, sweetie...hang in there!!” and “You are in my prayers.”

Postings seeking emotional support differed from those seeking information support in that the former usually did not include specific or rational questions to reduce uncertainty but rather showed emotional or psychological weakness and need for comfort. The posting below titled, “Help me stay strong,” illustrate. The poster experiencing serious regret for what she had done:

I know that most of you think or know I don’t have HIV, so just talk to me as a friend that has something, please... How could I have done what I did? How could I have put myself in a position to maybe cut my life just even a day shorter... I have no where to go besides here to vent and just lay it out on the table... How do you stay strong? How do you stay happy around the people you love, so you don’t bring them down with you? ... I am at my breaking point, and I need to hear words from people who have had to face adversity. Please do not pick on me today, I’m just asking for somebody to pick my spirits up just a little. I so wish someone could step in my body and feel the things I’m fighting with on a day to day basis. I have never in my life been like this mentally and physically. I’m just talking out my rear tonight, just having a temporary breakdown.

6.1.3 Esteem support
Esteem support included three dimensions: (a) compliment, (b) validation, and (c) relief of blame (Braithwaite et al., 1999). Compliment messages contained positive comments about another’s personality or abilities. For example, in response to a touching story of a woman who was infected with HIV by her husband but still chose to keep loving and taking care of him until he died, someone wrote:

That was wonderful. He was a lucky guy for having someone so loving as you and he knew it... He knew you loved him despite your problems or illness. You are such an inspiration to many no matter how you think. You are a wonderful mother, a loving wife and a great friend! Don’t you ever think any less of yourself.

Validation refers to messages that expressed agreement with the recipient’s perspective on the situation, including the person’s beliefs, actions, thoughts, or emotions, for example, “Yeah, I know, the waiting is the worst part. But you’re doing the right thing by being attentive to the (slim) possibility and getting tested”, and simply “I agree with you...” Some messages were also extended in order to alleviate another’s feelings of guilt about HIV infection, and those were coded as relief of blame, for example, “Don’t get into the blame game. Even if you made a mistake, that’s all it was... a mistake. Just about everyone here has gone through the same thing.”

6.1.4 Network support
Network support was examined using three subcategories: (a) access, (b) presence, and (c) companions (Braithwaite et al., 1999). Access involves messages that provide the recipient with access to new contacts and companions, who usually have similar interests to or situations as the recipient. The introduced new contacts can usually be reached online. For example, someone posted:

Positive Link is a social networking group for HIV+ Gay and Bi men. We have a Brunch on Saturday morning at 11 am and if you are interested in what we are all about or would like to check out brunch this week. You can email us at positivelink@mnaidsproject.org. Looking forward to hearing from you.

This one differs from a referral message within information support in that the aim of this posting was not to refer recipients to an expert or some form of help but to invite them to join an existing social group to increase the mutual social network. Presence messages emphasize the presence of listeners for the recipient and encourage continued use of the support group (Braithwaite et al., 1999), for instance, “Good luck, and we’re here to help you with your questions”, and “If you need to talk I’m here.” The last category of network support is companionship, which emphasized the availability of companions of others who have similar interests or experience. Presence of listeners and companionship are often woven together. For example, a senior group member replied to a message posted by a new member:

I welcome You to this wonderful group/family/circle of friends, who have GREAT big caring hearts and always have an ear to listen.....They all truly understand and are in the same position... PLEASE, never feel alone...We are here!!!!! = )))))

6.1.5 Tangible assistance
In terms of tangible assistance (0.8%), four out of five subcategories were observed in our data: (a) loans, (b) performed direct task, (c) performed indirect task, and (d) expressed willingness, with all except the last one having minimum incidences (n ≤ 5). Loans refer to an offer to lend the recipient a material object or money and was found in only two postings. One such case involved a member offering to send another member a book entitled, “The First Year HIV,” written by someone diagnosed in the middle of the 1980s. In the other case, a member wished to contribute financially to help people in the group.

Direct and indirect task messages are those through which individuals offer to perform tasks that directly or indirectly relate to the recipient’s HIV/AIDS related conditions. Only one case of direct
task was observed in our data, in which a member wished to do some online research to help another member find a local AIDS institution. In one of the five identified indirect task cases, a senior member provided others with the help they needed to add their pictures to their member profiles by using an online album service. Expressing willingness is the last type of tangible support, which was reflected in messages that expressed the poster’s willingness to help without specifying the exact nature of the assistance, such as, “I would be glad to help you out anytime you need it.”

6.2. Additional positive social interactions

After all of the posting were coded, a thematic analysis of 1855 postings that did not fit into Cutrona and Suhr’s (1992) social support typology was conducted to identify interactions that could facilitate the occurrence of social support exchanges within the group. The following three themes or categories of social interactions were proposed and assessed: sharing personal experiences (n = 419, 22.6% of the 1855), expressing gratitude (n = 244, 13.2% of the 1855), and offering congratulations (n = 54, 2.9% of the 1855).

6.2.1. Sharing personal experiences

Very often, members spontaneously shared their personal conditions, thoughts, and feelings related to HIV with others. Making this type of posting differs from responding to others using one’s own experience in that it is an initiating and spontaneous act. Disclosing can not only function as a way of venting but also promote reciprocal group communications. For example, one member posted:

I’ve been pretty quiet on the boards for a while now. Several of you know of the struggle I had starting meds. Well, I’m happy to report that about 4 weeks ago the side effects pretty much became minimal. I’m back to working more than 1 probably should and even doing a bit of traveling. A cruise is in the works for September. And then the best news is from my latest labs. CD4 at 546 and 23% with a VL of <50. So happy dance time. I’m so ready to just get on with my life. And oh… I’ve even had a date <smile>.

6.2.2. Expression of gratitude

These messages expressed straightforward thankfulness for the recipient’s previous support. As a type of behavior that acknowledges the help of others, exchanging gratitude messages appears to have positive effects on fostering caring relationships among group members. For example, after one member wrote that she thought she had certain symptoms and was afraid of getting a HIV test, several persons replied saying that those could not be HIV symptoms if she was exposed to a HIV risk more than 13 years ago. The original poster then responded, “Thank you both so so very much. I feel so much better, and I believe I will muster the strength to be tested sometime soon. You both are in my thoughts. Thanks again!”

6.2.3. Congratulations

Messages in this category express joy or acknowledgment of the recipient’s achievement or good fortune, for instance, “That’s great news! Nothing like good health insurance to help you sleep better at night. Congratulations!” In another example, where several members responded to someone who just received a negative test result, these respondents expressed their excitement for him by offering congratulations, for example:

WO H0000000000000000.....ShadesOfGray...Congrats... I know the feeling! Hang on and have fun with your new life! Stay really safe and above all please stick around. We and many people looking for help in this forum will need you. Congrats Again!

7. Discussion

The research questions of this study concern what types and amounts of social support are exchanged, as well as what kinds of social interactions facilitate social support exchanges, in CMSH HIV/AIDS groups. The findings from our content analysis indicated that information support was most frequently sought and offered. Emotional support was provided at a moderate level. Esteem support and network support were rather infrequently exchanged, and tangible social support was minimal. Three kinds of social interactions that may facilitate social support exchanges were proposed after a thematic analysis, including sharing personal experiences, expressing gratitude, and sending congratulations.

Content analysis as a method of analyzing data has several uses that can be broadly categorized as inferring antecedents, characteristics, and/or effects of communication (Holsti, 1969). In this study, the objective was to infer characteristics of the communication among members of a selected online HIV/AIDS self-help group. With bulletin board postings serving as the unit of analysis, the presentation of this study’s results included key trends in the communication content, which also suggests the potential effects of the communication. These trends are further discussed below and compared with previous findings of similar communication content.

The adopted typology, with its five supra-categories and 22 sub-categories, employed in this content analysis worked well in capturing the social support exchanged in the selected self-help group. Therefore, the generalizability of Cutrona and Suhr’s (1992) typology for the purpose of measuring social support exchanges in CMSH groups has been supported, although modifications are encouraged as deemed appropriate in the context of use (Krippendorf, 2004).

Furthermore, a closer inspection of the results highlights that two-thirds (or 67.2%) of the messages that fit the typology used in this study were offering one or more types of social support in contrast the remaining one-third (or 32.8%) of messages posted. Therefore, the group’s members were twice as active in terms of offering support compared to seeking it. Thus, in an era where the availability of support resources is limited, computer-mediated self-help groups promise to fill the gap between patients’ needs and institutional support. Consequent policy implications suggest the funding of similar and scalable computer-mediated support mechanisms targeting the low literacy rates with respect to HIV/AIDS prevalent among Americans.

Also of interest is that 1855 messages (or 37.1% of all of the sampled activity) were neither seeking nor offering support according to the typology used; however, a closer inspection of these messages revealed that many of them were in fact contributing positively to the effectiveness of the self-help group, as they contributed to building ties among group members. This was achieved by extending one’s personal involvement in the CMSH group by either sharing personal stories, expressing gratitude, or sending congratulations, as is evident by the thematic analysis and corresponding percentage results described earlier.

This study supports the conclusions of a recent national survey on HIV/AIDS that shows that the public still does not have enough knowledge of HIV/AIDS to effectively prevent or/and cope with HIV/AIDS (Kaiser Family Foundation, 2006). According to the survey, Americans would like more information about the different types of HIV tests available (44%), how to protect their privacy when getting tested (40%), where to get tested (35%), and how to communicate with their partner about getting an HIV test (31%).
As for HIV treatment, few of the respondents knew that “there are drugs that can lengthen the lives of people with AIDS” (13%), or that “there is no cure for AIDS at present” (12%). The need for additional knowledge was also reflected by the results of this study, with 41.6% of all messages (or 58.2% of the data fitting the adapted typology) falling in the context of either seeking or offering information support, mostly focused on HIV/AIDS testing issues.

Information plays an important role in coping with HIV/AIDS and is much valued by people with HIV/AIDS. According to Reeves’s (2000) interviews of HIV-positive individuals, finding HIV-related information online promoted empowerment, a sense of confidence and control during their coping process. Our results show that participating in a CMSH group is very likely to improve the coping ability and self-efficacy of individuals with HIV/AIDS by providing them with HIV-related knowledge, advice, and evaluations.

Emotional support emerged as the second most frequently exchanged type among the CMSH group members in this study. Reeves’s (2000) study showed that social support from CMSH groups was perceived to be supplemental by some individuals with HIV, but to be a primary source of emotional support for others. The anonymity offered by CMSH groups is of tremendous value to those individuals that are reluctant, because of this stigma, to participate in offline social support groups or share their HIV/AIDS-related situations with family or friends (Walther & Boyd, 2002). These individuals may find CMSH groups an easier and safer venue to discuss emotional and psychological issues associated with living with HIV (Finn, 1999; Reeves, 2000; White & Dorman, 2001).

These findings (i.e., that information and emotional support are the most frequently observed social support exchanges in this online HIV/AIDS self-help group), are consistent with several studies of social support exchanges in both offline and CMSH groups (Braithwaite et al., 1999; Coulson, 2005; Loader et al., 2002; Winzelberg, 1997). Summarizing this relevant subset of the earlier literature review on self-help groups: (i) Preece (1999) found 44.8% of messages about torn knee ligament to be Empathetic (parallels emotional support) and 17.4% of messages to contain Information (here, the frequency of emotional support exceeded that of information); (ii) Winzelberg (1997) found Information support (30%) and Emotional support (21%) messages about eating disorders as the leading themes; (iii) Braithwaite et al. (1999) found Emotional support (40%) and Information support (31.3%) as the types of most frequently exchanged messages among disabled people (again, the frequency of emotional support exceeded that of information); and (iv) Loader et al. (2002) found Informational support to be the dominant (138 out of 149 discussions) topic among people living with diabetes.

Future research in this area should consider all aspects of data analysis prior to selecting a sampling method (Krippendorf, 2004). During the data collection in this study, a very small number of duplicate messages (30 or 0.006% of total messages) posted by a unique member on different sub-boards were observed. Future content analysis studies need to consider the sampling techniques for duplicate messages. From one perspective, the inclusion of duplicate messages would result in an accurate reflection of cumulative online support activities; however, such sampling would result in a false representation of unique member activity of social support exchanges. Given the very small number of such occurrences in this study, duplicate messages were included in the data analysis. Another consideration is whether the sampling method should be based on a random selection of messages by threads or batches of postings. While our method of sampling batches offered the benefit of random message selection from the entire message pool, a random selection of threads would result in analyzing complete communication exchanges and placing the content of each message in context.

Future research should measure the impact of CMSH groups by surveying or interviewing members in order to have a better understanding of the role and significance of CMSH HIV/AIDS groups in their coping processes. The impact may be reflected in, but not be limited to, members’ lifestyles, psychological wellbeing, health status, etc. Moreover, in this study, members’ profiles were found to contain little information and thus were difficult to examine, due to the fact that it was optional for them to provide personal information when creating their account. Future studies should take this factor into consideration when selecting a specific group from which to collect data. The efficacy of CMSH groups would be better revealed if the demographic and health related personal information of participants is known.

Moreover, social interactions in a virtual environment are becoming increasingly complex, a phenomenon apparent in this study as well. Upon closer inspection, it was found that, while the majority, 87%, of the messages conveyed only one type of social support, 12% of the messages expressed two types, while another 1% of messages expressed three types of social support (in agreement with earlier observations, the most frequent combination of social support types in a single message was information and emotional support). Thus, while CMSH groups may appear to resemble offline ones in terms of message richness, this presents another area that warrants further investigation.

In conclusion, CMSH HIV/AIDS groups are promising sources of HIV-related information and emotional support for people with such concerns, and they also have important advantages compared to offline groups with the same purpose. In the present study a group member wrote, “I can’t even tell my best friends because of fear of how they might react. Maybe someday, hopefully in our lifetime, there won’t be such a stigma attached to HIV/AIDS.” We believe that the numerous CMSH groups can be a solution for people with stigmatizing diseases, such as AIDS.

References


