



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

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### ABSTRACT

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.

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### 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,

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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?

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