



# "You Have to be Positive." Social Support Processes of an Online Support Group for Men Living with HIV

Jennifer L. Peterson

To cite this article: Jennifer L. Peterson (2009) "You Have to be Positive." Social Support Processes of an Online Support Group for Men Living with HIV, *Communication Studies*, 60:5, 526-541, DOI: [10.1080/10510970903260368](https://doi.org/10.1080/10510970903260368)

To link to this article: <http://dx.doi.org/10.1080/10510970903260368>



Published online: 27 Oct 2009.



Submit your article to this journal [↗](#)



Article views: 193



View related articles [↗](#)



Citing articles: 12 View citing articles [↗](#)

# "You Have to be Positive." Social Support Processes of an Online Support Group for Men Living with HIV

Jennifer L. Peterson

*Over the past decade, improved treatments have helped people with AIDS enjoy a state of restored health and greater hope for long-term survival. Because of these changes, social support is an even more important resource for those battling HIV/AIDS. One source for social support is a support group, which offers social and emotional resources to meet the needs of its members. The online support group investigated in this study serves gay men with HIV/AIDS and requires that they talk only about positive aspects of life. To understand the implications this rule has for support processes, a thematic analysis was conducted to determine how this group constructs social support. Rules and resources aimed at the group goal of positivity help develop a unique speech community. Implications for social support, support groups, and the Internet are discussed.*

*Keywords:* Gay Men; HIV/AIDS; Internet; Social Groups; Social Support

First reported in the early 1980s, HIV and AIDS became the center of the most publicized epidemic in the world. Although much more is known about the disease today, there is still no effective cure. With new treatments, people living with HIV/AIDS have enjoyed a state of somewhat restored health and a hope that they might survive (Harris & Alderson, 2007), although they still experience uncertainty

---

Jennifer L. Peterson (PhD, University of Illinois) is an Assistant Professor in the Department of Communication at the University of Wisconsin—Milwaukee. Earlier versions of this article were presented at the National Communication Association annual convention in Miami, FL, 2003 as well as at Internet 1.0: The State of the Interdiscipline in Lawrence, KS, 2000. Correspondence to: Jennifer L. Peterson, Department of Communication, P.O. Box 413, Milwaukee, WI 53201. E-mail: [jenlpet@uwm.edu](mailto:jenlpet@uwm.edu)

and anxiety about their long-term prognosis and about the effect of HIV on their personal and social lives (Brashers et al., 1999).

Social support is a valuable resource for those battling HIV/AIDS. Social support generally has been defined as "an interpersonal transaction involving one or more of the following: emotional concerns, instrumental aid, information, or appraisal" (Cutrona, Suhr, & MacFarlane, 1990, p. 30). People living with HIV/AIDS have complex needs for informational and psychosocial support (Brashers, Neidig, & Goldsmith, 2004). Researchers have found that social support is critical to adherence to treatment regimens and the health of persons living with HIV/AIDS (e.g., Simoni, Frick, & Huang, 2006). Others have found that more stress and less social support may accelerate the course of HIV disease progression (Leserman et al., 1999) and that persons living with HIV/AIDS who are satisfied with their support are less likely to be depressed and therefore possibly less likely to experience symptoms or disease progression (e.g., Hays, Turner, & Coates, 1992). Social support also has been found to have a positive association with effective coping strategies (Green, McVinney, & Adams, 1993) as well as emotional health and social functioning (Jia et al., 2004).

There are many sources for social support; however, research indicates that peers (i.e., others with the illness) often are perceived as the most beneficial source of help for people living with HIV (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003), and they frequently benefit from participating in support groups (Sandstrom, 1996). In fact, support groups have been identified as perhaps the single most important and available intervention for people infected with HIV (Peterson, Brashers, Rintamaki, Goldsmith, & Neidig, 2009). This study investigates an online peer support group for gay men living with HIV ("AIDStired"). This group is unique because its primary stated purpose is to share positive communication. The first part of this paper overviews research on support groups in general, and on online support groups more specifically. Methods and qualitative analysis procedures for investigating the group follow. Finally, results of the analysis are reported, along with theoretical and practical implications.

### *Support Groups*

Over the last few decades, people increasingly have turned to support groups for coping with physical illnesses, addictions, and mental health problems (see Cline, 1999). Research suggests that information about one person's stressful event can enable another person to use his or her own coping styles more effectively, to help reduce stress, and to allow for a more accurate appraisal of the stressful event (Taylor, 1983). Support groups provide interaction with people in similar situations with an emphasis on personal participation, a common purpose, and emotional support (Yalom, 1985).

There is evidence that support groups are particularly useful for people living with stigmatized illnesses. For example, people living with AIDS are "250 times more likely to participate in a support group than hypertension patients" (Davison, Pennebaker, & Dickerson, 2000, p. 209). Involvement in a support group enables many people with HIV to bolster their coping skills, social networks, and self-esteem (Sandstrom,

1990). Early in the history of HIV, support groups focused on issues such as the transmittal of the disease, social stigma, terminality of the illness, the care from doctors, homosexuality, and trust (Newmark, 1984). Stewart and Gregory (1996) later found that the themes of a long-term support group for gay men with HIV/AIDS included topics such as marginality, making choices, coping with the emotional roller coaster, premature confrontation of life issues, living with a chronic illness versus dying with a terminal disease, and death and dying.

Despite the fact that support groups can be helpful, many people do not attend them. Barroso (1997) found that people living with HIV reported not attending support groups because they outlived their usefulness, did not want to be around others who are more ill, and the groups tended to rehash the same subjects. Leaders of support groups report that irregular attendance at meetings as well as members being at different stages of dealing with their illnesses are challenges to positive support group experiences (Galinsky & Schopler, 1994). An additional concern is that group members may feel pressure to conform to coping strategies or treatment methods favored by the group (Galinsky & Schopler, 1994). Group conflicts can lead to additional tension and stress for an individual already struggling to cope (Paulus, Baum, & Andersen, 2001).

Support groups also can be difficult to maintain as group members become ill or die (Brashers et al., 2004; Sandstrom, 1996). Some people living with HIV do not attend support groups for fear of seeing others in more advanced stages of the illness or seeing possibilities for their own future. Seeing the condition of people in the group can make it difficult to create and maintain positive illusions and coping strategies (Brashers et al., 2004). Conversely, a potential problem with support group experiences is that individuals may make upward comparisons with those who are healthier, with those coping more effectively, or with those who are more experienced with the illness leading to increased anxiety (Paulus et al., 2001).

With the rise of technology and computer-mediated support groups, an alternative to face-to-face groups is available to patients and their families. Online groups provide members with an opportunity to share their stories, to find emotional support for dealing with issues, to provide a sense of empowerment, and to offer advice and opinions on how to deal with situations from other individuals with the same issue (Alexander, Peterson, & Hollingshead, 2003; Barak, Boniel-Nissim, & Suler, 2008; Weinberg, Uken, Schmale, & Adamek, 1995). Support is readily available 24 hours a day and for those patients or families who are affected by stigmatized conditions such as HIV, the computer provides them with anonymity, or privacy, without preventing participation in a support group (Im et al., 2007).

Preliminary evidence suggests that the same social support resources present in face-to-face support groups are also available in their online counterparts; although the evidence is somewhat mixed as to how these groups function (see Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). Some researchers have found high amounts of informational and emotional support in online support groups for depression and people with disabling conditions; however, research comparing multiple online support groups demonstrated that these groups can have very different styles of providing support and relating to their environment (Braithwaite, Waldron, & Finn,

1999; Coulson, 2005). Alexander et al. (2003) found that four online support groups in their study all focused on health issues, but they functioned quite differently and served different purposes for their members. Each group developed its own working conception of social support to meet the needs of its members.

The unique form of community building that is enabled online (e.g., around specific social support needs) serves as an impetus for this study. The community of interest is "AIDStired," an asynchronous online group for gay men with HIV/AIDS. This group is unique because its primary purpose is to "talk about the good things in life, share pictures, and meet new POSITIVE (both in virus and mental status) friends." (AIDStired, 2001, emphasis in original). I investigate this group as a form of speech community (Hymes, 1972), which Goldsmith (2004, p. 42) described as a "group that shares not only a language but also ideas about how language may be (and should be) used to accomplish various social purposes." To learn about how this group delivers *positive* social support and builds community, I asked the following research questions:

- RQ1: How do members of AIDStired regulate social support messages in their group?
- RQ2: What types of messages constitute positive social support in this group?

## Methods

AIDStired was founded in October of 1999 to provide support for gay men living with HIV who were tired of other people living with the virus who were "moaning and crying about how bad their life is" (see [www.groups.yahoo.com/group/AIDStired](http://www.groups.yahoo.com/group/AIDStired)). A list owner or moderator controls who is allowed into the group: Membership is limited to men who have tested positive for HIV, and who have agreed to be fair to other members, to promote positive ideas and feedback, and to never be rude or hateful to another member of the list. A person must fill out a questionnaire to join the group. If accepted, he is sent a message with introductory material including the group rules and directions for posting messages. Group proceedings are available in a daily digested listserv or via an archive through the Web page.

## Procedure

I contacted the list owner for permission to access the group. He provided the group with my research proposal and allowed the members to determine whether or not I could observe. The group voted to allow me to move forward and my request was again posted to the group with the notification that their proceedings were being monitored for research purposes. Any new member who joined the group during that period was sent a copy of my original message with the notice that the group was being monitored, along with the introductory material about the group. I observed AIDStired for a period of two months. There were 1205 messages in the first month and 665 messages in the second month, and the membership grew from 38 to 50 members.

Because the goal of this research was to examine how members within a unique speech community exchange support, this study employed a qualitative grounded

theory approach (Corbin & Strauss, 2007). Over the two-month period, I collected 1,870 messages. I took the following steps for analysis: (a) read through the messages to form a basic impression of the group, (b) re-read messages to look for specific themes and issues, (c) grouped themes under larger categories, (d) reviewed major categories for repetition to combine duplicates and (e) presented the categories to the members of AIDStired in a posted message for verification and feedback. Upon completion of a draft of the entire paper, I shared it a second time through a post with the members of AIDStired for participant verification. Although the coding procedures were completed by only the author, the findings were verified with the group on two separate occasions: as initial results and as a complete report. Feedback was uniformly positive about my portrayal of AIDStired.

## Results

Messages exchanged in AIDStired were categorized into three major themes. The first included messages about utilizing group norms for positive interaction. Themes in this category focused on messages by the moderator, group management messages, and introductions and welcomes. The second included messages about seeking support in the context of positive interaction. The third included messages about providing social support. All names have been changed to protect the identity of the group members.

### *Utilizing Group Norms for Positive Interaction*

Group norms are recurrent “patterns of behavior or thinking that come to be accepted in a group as the usual way of doing things” (Scheerhorn & Geist, 1997, p. 92). They are considered regulators of group members’ behavior because they shape their beliefs, attitudes, and interactions. Norms can develop from explicit statements made by group leaders, from critical events that establish precedents, from repetitive behavioral patterns that emerge in a group, or from other group experiences imported into the group by its members (Keyton, 1999). The group norm of positivity was the predominant influence on interaction for AIDStired. This norm was invoked through (a) moderator oversight, (b) group management messages, and (c) norm-reinforcing introductions and welcomes.

### *Moderator oversight*

As a closed group, AIDStired has a moderator. This was a unique aspect of the group that served to enforce group norms. The moderator monitored group membership by evaluating prospective members’ questionnaire responses, as well as administering the group. The group includes this statement of purpose:

A different kind of support group for HIV+ Gay Men. We share pictures, cartoons, jokes, treatment info, etc. We are a fun bunch of HIV+ guys living life and making the most of it. Every gay HIV+ man is encouraged to join BUT, no bitching between members is allowed and is enforced by the moderators (AIDStired, 2001).

The moderator did not actually monitor or edit group members' postings. He was only responsible for the affirming membership of the group and administrative matters; however, his control of membership and described role in the mission statement undoubtedly led to a more homogeneous group (e.g., the declaration that "no bitching allowed" would be enforced by moderators). During the time that data was being collected, there was not a posting that would be considered negative.

#### *Management messages*

Messages in this category included announcements about events such as a face-to-face get together, changes in the Web domain that hosted the group, and changes to membership rules. The enforcement of rules, as a group activity, helped keep the norm of positivity forefronted in members' conception of the group. For example, during the two months of observation, the group discussed whether to accept the request for membership by someone with a questionable screen name. A prospective member with the screen name "AIDSisaMYTH" attempted to join the group. The name referenced debates about whether HIV causes AIDS, and whether AIDS is simply a result of toxic medications being forced on people living with HIV. Group members feared that this person could bring negativity and criticism to the group interaction. During this incident, the requirements for membership and the membership questionnaire were discussed and a poll was taken to determine the future direction of the group. The overwhelming response from the group was to deny this person membership to keep the group from disintegrating into conflict. These actions during a period of a perceived external threat to the group both heightened and justified sensitivity to group norms and goals.

#### *Normative introductions and welcomes*

Another thread in AIDStired was the process of welcoming new members. Each time a member was added to the list, the list owner introduced the new group member with a simple message such as, "Please welcome Mitch *msmith@apl.com* from Oregon to the group!" These messages were sometimes closely followed by the person introducing himself, for example:

Just wanted to say a quick hello . . . My name is Mitch, I live in Seattle, Washington. I was diagnosed HIV+ on August 24th. At the moment I am TERRIFIED—but my feelings seem to come and go, as I'm sure you all well can imagine. I don't have insurance and that makes it even scarier. I am waiting for my initial blood work to come back. That's it for now, take care everyone. :) Mitch

These introductions commonly included information about when the person was diagnosed, what treatment he was participating in, and something about his life (e.g., where he lived or what kind of family or friends he had). To complete this process, these introductions were met by positive and affirming messages from current members welcoming the new member to the group. These messages frequently reflected the kind of information offered in the introduction. For example, if a new member

offered treatment information, many of the current members reciprocated with similar information in their welcome.

### *Seeking Social Support*

The second theme involved messages seeking support. These messages were categorized as either indirect or direct support-seeking statements.

#### *Seeking support indirectly*

Members of AIDStired frequently elicited support indirectly by sharing personal updates or changes in their condition. This included messages as simple as revealing what had happened that day, or something as complicated as disclosure to family and friends, personal health status, or experiences with various drugs and treatments. These messages often were met with informational and emotional support. For example, the following message was interpreted as an indirect request for support about starting medication:

I got the results of my initial blood work in today  
Cd4: 513  
Viral load: 76,400  
The doctor said I could start meds, but I've decided NOT to do so yet : /  
Very distressed over all this actually : (  
Mike

The response to this posting was reassurance about the decision not to start medications and support about the results of the blood work, indicating an understanding that this message was seeking support even though it does not request a specific response. Instances in which negative news was shared were often about a person's health and typically only appeared once in the group proceedings. Responses were offered with comfort and advice; however, because the group values harmony, they avoided clashing about their opinions or advice. Although many messages focused on health status, there were also others that dealt with more personal or relational issues. For example, relationships with partners were frequent topics for discussion:

Actually Mark, today was the day I divulged my status to Tim. He was extremely supportive even more than I thought he would be. You know that divulging your status is not an easy thing and people have different views on this matter . . .

Likewise, one member wrote that he would not be participating much in the group because he had to look for a new place to live which was going to be a difficult task. Group members interpreted this as an indirect call for social support and responded with emotionally supportive messages.

#### *Seeking support directly*

Members of AIDStired also simply asked direct questions to elicit support. Many of these direct requests focused on health-related information and decision making. For



example, messages that asked for information about people’s experiences with a specific medication were fairly common:

Does anyone have experience on using Paxil? I would like your thoughts on it if you have any. A friend of mine is starting to use and wants to know what people think of it. I take Zoloft, and I believe Paxil is basically the same thing.

Members also directly requested emotional support, asking for thoughts and prayers at times when they were waiting for test results or when they were facing a challenge.

### *Providing Social Support*

Messages categorized in this theme were of four types: providing emotional support, providing informational support, offering humor and inspiration, or delivering political activism messages. Each was offered in the tone of supportive, rather than critical or conflictual, messages.

### *Providing emotional support*

Emotional support focuses on feelings and includes such things as sympathy, empathy, prayer, or physical affection. These messages made it apparent that the group was very cohesive and/or caring. For example, one member had not posted anything for a long period of time and messages were posted asking if he was still around or if anyone knew if something had happened. Whenever a group member expressed feelings of anxiety or depression or shared a troubling experience, there were multiple replies with encouragement and esteem-building sentiments, as well as expressions of caring and love, such as:

Life always brings changes. Being positive is another aspect of living. One only realizes that when life can be taken from you that if you meet someone you want to be with, you must take that opportunity with both hands. Being positive does have an influence on who you are and how you think and what you want. But it will still be stressful. Live life to the fullest. Good luck.

Sometimes a trying experience was met with praise and encouragement from other group members. A member living in South Africa had taken in a boy who had lost all of his family members to AIDS. After a touching story about the boy, group members responded with messages such as:

You are truly a wonderful man! The new family you have formed will certainly be a blessing for each of you. One can only hope that your love and kindness will spread to others around you—and I DO believe that it will.

In response to the member who was forced to look for new housing mentioned above, group members posted messages such as:

I can only say that I hope it’s not health related, and that everything will soon be OK in your life! You will be sorely missed by the group and I hope to hear from you again in the future.

Sending you love and big bear hugs.

These messages provided members with encouragement, emotional support, and a sense of the importance of their role in the group interaction.

### *Providing informational support*

Members of AIDStired frequently shared information they found from other sources with the group. For example, articles such as “Cardiac Risk Needs to be Monitored in Patients on HAART” and “Preventing Infections from Pets” appeared in group proceedings. Other topic areas included a computer notification system for hospital patients, announcements about drug trials, vaccine research, and treatment regimens.

If a group member posted information on his health status, other members responded with similar information to help teach someone who might be struggling to understand his health status. For example, in response to the message reporting blood counts that I labeled an indirect request for support, this message was posted:

Actually Mike, starting meds is a very personal decision that you and only you can make and your doctor should be behind you. He can help you with the thinking process. Your CD4 count is quite good and very close to normal which is anywhere between 600 and 1200. The higher the number indicates that your body will be able to fight any possible diseases/viruses.

Your viral load is an indication of the amount of virus in your bloodstream. If it's any consolation, my viral load used to be 774,000. You have to look at the global picture. Do you feel healthy? Have you suffered any OI s [opportunistic infections] such as PCP, meningitis?...

Here advice is offered without a specific opinion on how to proceed but provides several considerations about the decision. Much of the advice is given in terms of general information about the situation. Other group members shared their own personal experience as well as advice. For example, this message was posted in a response to a direct request for information about a medication:

I have been on Paxil for about a year now. It has been very good for me. The doc wasn't sure how to handle some problems I was having. She couldn't diagnose anything specific, but suspected depression. I was sure she was wrong, but agreed to try Paxil. Well, she was right. It is pretty mild and subtle. I definitely improved both mentally and physically. As I am sure you know depression is as much physiological as it is psychological.

Anyway, I recommend trying it. I had no adverse side effects at all. Hope this helps.

Messages such as these that shared information about personal experiences and advice were common responses to requests for support.

### *Offering humor and inspiration*

It was not surprising to find a large number of the messages exchanged in AIDStired providing support through humor. Humorous messages contained jokes, quotations, funny stories, and even humorous chain letters such as the “Discouraged Gay Men Chain Letter.” Jokes varied widely in subject matter from dating to politics such as:

FROM THE WHITE HOUSE. . .

Democrats announced today that they are changing their emblem from a donkey to a condom because it more clearly reflects their party's political stance. A condom stands up to inflation, halts production, discourages cooperation, protects a bunch of dicks and gives a sense of security while screwing others.

A frequent source of humor was various lists such as popular bumper stickers, how to speak about men and be politically correct, anagrams, and notes from a doctor's chart notes.

Inspirational messages included quotations, prayers, and stories. Quotations came from a number of sources and usually shared a common theme. For example, on the subject of "giving" a quotation was, "Give to the world the best you have and the best will come back to you. Madeline Bridges," and on the subject of consistency, "Consistency is the last refuge of the unimaginative. Oscar Wilde." There were also electronic greeting cards and pictures that typically were humorous or inspirational.

#### *Discussing political activist issues*

Messages in this category tended to be news articles, transcripts of radio shows, or announcements. There were a number of different topics that varied from positive or enlightening events to disturbing or tragic events. A frequent topic was President Mbeki of South Africa and his declaration that he did not believe that HIV causes AIDS at the International AIDS Conference. This was of particular interest to the group because a number of its members reside in South Africa. Same-sex marriage and the new laws in Amsterdam as well as the controversy surrounding Dr. Laura's television show were also popular topics. Members also shared news of hate crimes that were committed against gay men, as well as a discussion of the major political candidates' views on hate crime legislation. These messages can be seen as supportive, not only because they provide members with information but also because they empower group members to be involved in the debate of important issues.

#### **Discussion**

Results from this analysis of AIDStired messages show that members can maintain positivity through their use of normative messages and the tenor of their informational and emotional support statements. Communication that enacts social support serves to develop and sustain norms for this speech community. In the discussion that follows, theoretical and practical implications of these findings are discussed. These results suggest rethinking how support groups and their members are most effectively linked. They also provide evidence for the role of group membership restriction in online support groups and how that process can lead to positive outcomes.

#### *Linking Support Groups and Members*

Past research indicates that one important consideration to support group interventions is that we may need to provide different support groups for different illness

stages (Barroso, 1997); however, this study suggests another way of linking support groups and people with support needs. Common communicative preferences or similar attitudes (e.g., positivity) may be an important factor in individual choice of communal relations. Lieberman, Wizlenberg, Golant, and Di Minno (2005, p. 239) found that support group cohesion (i.e., commitment and attraction) included “(a) the frequency of hope, positive feelings and thoughts, and affection linked to group as a target and (b) the frequency of ‘we,’ ‘our,’ and other words of inclusion.” These elements of positive and communal interaction were associated with positive changes in support groups over time.

Data from Lieberman et al. (2005) and the current study suggest that we should look at elements of support group interaction that have previously been overlooked. Goldsmith (2004, p. 86) noted that the “common research practice of attending only to functional types of support (ignoring their content, form, and style) severely limits our ability to understand how effective enacted support is fitted to the problem for which it is offered.” In the case of AIDStired, the group has negotiated the process of positive social support as a core group value to meet members’ needs. These communicative preferences for positivity were identified clearly by members as well as the group’s manifest documents and behavior. Actions that helped maintain group positivity and cohesion included norm-enforcing behaviors, such as the use of a moderator, the overt discussion of group rules, and the use of introductions as a group-building device. Support seeking was often indirect, which may be more face-saving. When support seeking was direct, it was often asking for others to share their personal experiences. Messages included typical informational and emotional support, but characteristics such as humor and political activism were themes that seem to influence the connections between group members.

Overt actions toward developing positive community perhaps are intended to overcome a potential “downside” of support groups—that is, focusing primarily on sharing negative emotions. Despite the fact that support groups often are seen as helpful, people in support groups are potentially overwhelmed by both the quantity and negativity of information (Brashers et al., 2004). Members of support groups may find open communication threatening and can be overwhelmed and depressed by stressful group sessions (Galinsky & Schopler, 1994), and providing support to others can sometimes lead to reliving negative experiences, uncertainty, or affect (Brashers et al., 2000). In response to these experiences, the members of AIDStired created a unique speech community to meet their needs.

The AIDStired online support group is an example of a speech community that intentionally addresses the problematic circumstances under which groups sometimes operate. When I began monitoring their interactions, many of the members posted messages that explained to me why they had joined the group and how they felt about the group. Many of these men had attended other support groups and had not found what they needed. Many men said they joined AIDStired because they felt that people in those other groups were negative all the time. To those members, the only thing these groups accomplished was a cycle that perpetuated the negativity or the tribulations of living with HIV. Group members generally seemed quite satisfied with the support and

companionship they found in AIDStired. One member characterized the group this way, "it's about individuals who feel they need the companionship and support of like-minded people." The tone of messages and responses to messages in AIDStired never focused on dying or terminality, but on how to overcome hurdles and live on.

The relatively small size of the group and the fact that it was cohesive was important to many members as well. In particular, the fact that no one criticized anyone else was extremely important. The high value that this group places on harmony is part of what allows the group to remain positive. Although opinions are welcome, it is clear that conflict is not. This lack of conflict and the conviction to keep it that way is one important aspect of keeping the tone of the group positive. Social support only serves as an effective buffer if it meets the needs of the people receiving it (Cohen & Wills, 1985; Goldsmith, 2004). This diligent focus on keeping the tone of the group positive is what the members of this group need. By meeting those needs, the support group is both successful at supporting one another and building strong camaraderie. This provides an opportunity for group or community members to engage in communal coping, which involves the pooling of resources and efforts of several people to confront shared adversity (Lyons, Mickelson, Sullivan, & Coyne, 1998). Members of the speech community may therefore cope communally—participating in solutions for joint benefit (Goldsmith, 2004).

The major difference between the groups that these men experienced is accounted for by AIDStired's demand for positive support. Although three of the six themes that Stewart and Gregory (1996) found focused on death-related issues, none of the themes present in AIDStired focus on death or dying in any way. This is an extremely important difference for the members of AIDStired. Many important health issues, both encouraging and discouraging, are shared in the group; however, the tone used to present messages and responses to messages is never focused on dying or terminality, but on how to overcome the hurdles and live on. This tone is one key to the positive environment of the group. Humor, for example, was used to keep the group from becoming too gloomy. One member noted:

The one aspect of this group that I really like is that we can talk about something really serious one moment, and pass around some very helpful information without fear of being chastised, and the next moment a great joke comes through!

This focus on keeping the tone of the group positive is what group members feel they need. By meeting those needs, the support group is both successful at providing support and building camaraderie. It is important to note, however, that members of AIDStired do share discouraging news and experiences with one another, which would seem to go against their desire to maintain a positive attitude. After group members have offered responses, references to the negative event typically do not reappear unless something further develops. This process avoids the cycle that perpetuates the negativity that many of these men found in other support groups. It appears that this is the fundamental difference between the self-disclosures allowed in AIDStired and the constant focus on negative events AIDStired members found in other support groups and referred to as "whining."

These findings suggest that communicative preferences, alone or in conjunction with other factors, can play a vital role in how individuals with illnesses select and maintain membership in online support groups. Still it must be noted that keeping the tone of the group positive could negatively impact, or even exclude, some members. People may experience uncertainty about the appropriateness of their thoughts and feelings, especially when a dominant group perspective may inhibit the sharing of different thoughts and feelings (Paulus et al., 2001). The dominant group perspective of positive interaction may inhibit members from expressing negative feelings or concerns. There is the chance, for example, that incorrect information could go unchallenged because a group member fears debating the posting of another member. The pressure to keep the tone positive may keep group members from seeking the support they need because they cannot find a positive way to approach a stressor or contradict what they believe is bad advice.

This study also highlights an important aspect of the Internet for social support—the power to restrict access. The Internet is referred to as the information superhighway with endless possibilities and infinite resources. In the case of online support groups, there are thousands of groups available anytime day or night; however, researchers largely have ignored the power of the Internet to restrict access and to discriminate. Expanded Internet capabilities allow people to exclude those who do not share similar needs or beliefs. AIDStired limits its members as well as the types of support allowed, practices that might not be deemed acceptable in most face-to-face support group situations. In essence, the power of the Internet is doubled because it not only provides us with the power to expand opportunities for access, but it also provides us with the power to limit membership.

### *Limitations and Directions for Future Research*

The most obvious limitation to this study is the short duration of data collection. Although 1,870 messages is a fairly large sample, it is a very limited view of these men and their support group. In addition, as with many studies of online support groups this study was conducted by observing the group solely through its messages. Although this type of research is important and provides us with some indication of how complex social support processes work, it does not provide us with important information that can only be gained by exploring the viewpoints of the group members.

This investigation examined how the members of AIDStired exchanged support by examining the messages. Future studies of this group should include the group members' interpretations of their experiences with AIDStired. This research could also focus on how this unique group norm of positive support impacts the possible negative experiences support groups members can encounter. Enactment of positive support might be an additional factor to consider in the design of support interventions (see Goldsmith & Brashers, 2008 for a general discussion of support interventions). Moreover, despite the potential for negative messages to be posted to the group, none appeared during this time period. Future research should look for instances in which negative messages are posted and study how the group deals with

violations of their most important norm. Another aspect that merits further attention is the membership of the group. AIDStired was a group only for gay men, it is unclear whether a group with heterogeneous membership would be able to create and/or benefit from a similar speech community. As for the technological focus for future research, it would be useful to know if particular features of the Internet make being positive more or less difficult for the members of AIDStired. In addition, the technology may also have an impact on the potential negative experiences support group members can encounter. For example, the anonymity and lack of self-awareness (Matheson & Zanna, 1988) that a computer provides may diminish the effect of upward or downward comparison.

## Conclusion

As medicine has advanced and people with HIV/AIDS have begun to live longer, their need for social support has changed. The Internet has enabled people to create their own support groups utilizing their own accepted forms of social support. AIDStired has established itself as an important source of information and support for its members, while deviating from what previous research has found to be common themes for the same type of group. This group does not focus on death and dying, but on living and growing. By using the Internet's power to limit, these men have created a closed community, in which living is the focus and HIV/AIDS is simply part of life. This shared belief is what makes the group helpful, if not vital, to its members. By defining and enacting support as strictly positive interaction, AIDStired preserves a strong sense of harmony. This sense of harmony seems to be what brings this group together and keeps them positive—in more ways than one.

## References

- AIDStired. (2001). Retrieved from <http://groups.yahoo.com/group/AIDStired>.
- Alexander, S. C., Peterson, J. L., & Hollingshead, A. B. (2003). Help at your keyboard: Support groups on the Internet. In L. Frey (Ed.), *Group communication in context: Studies of bona fide groups* (pp. 309–344). Mahwah, NJ: Lawrence Erlbaum.
- Barak, A., Boniel-Nissim, M., & Suler, J. (2008). Fostering empowerment in online support groups. *Computers in Human Behavior*, 24, 1867–1883.
- Barroso, J. (1997). Social support and long-term survivors of AIDS. *Western Journal of Nursing Research*, 19, 554–582.
- Braithwaite, D. O., Waldron, V. R., & Finn, J. (1999). Communication of social support in computer-mediated groups for people with disabilities. *Health Communication*, 11, 123–151.
- Brashers, D. E., Neidig, J. L., Cardillo, L. W., Dobbs, L. K., Russell, J. A., & Haas, S. M. (1999). "In an important way, I did die": Uncertainty and revival in persons living with HIV/AIDS. *AIDS Care*, 11, 201–219.
- Brashers, D. E., Neidig, J. L., & Goldsmith, D. J. (2004). Social support and the management of uncertainty for people living with HIV/AIDS. *Health Communication*, 16, 305–331.
- Brashers, D. E., Neidig, J. L., Haas, S. M., Dobbs, L. K., Cardillo, L. W., & Russell, J. A. (2000). Communication in the management of uncertainty: The case of persons living with HIV/AIDS. *Communication Monographs*, 67, 63–84.

- Cline, R. J. W. (1999). Communication in social support groups. In L. R. Frey, D. S. Gouran, & M. S. Poole (Eds.), *The handbook of group communication theory and research* (pp. 516–538). Thousand Oaks, CA: Sage.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98, 310–357.
- Coulson, N. S. (2005). Receiving social support online: An analysis of a computer-mediated support group for individuals living with irritable bowel syndrome. *CyberPsychology & Behavior*, 8, 580–584.
- Corbin, J. L., & Strauss, A. C. (2007). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Thousand Oaks, CA: Sage.
- Cutrona, C. E., Suhr, J. A., & MacFarlane, R. (1990). Interpersonal transactions and the psychological sense of support. In S. Duck (Ed.), *Personal relationships and social support* (pp. 30–45). London: Sage.
- Davison, K. P., Pennebaker, J. W., & Dickerson, S. S. (2000). Who talks? The social psychology of illness support groups. *American Psychologist*, 55, 205–217.
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: Systematic review of the effects of online peer to peer interactions. *British Medical Journal*, 328, 1166–1170.
- Galinsky, M. J., & Schopler, J. H. (1994). Negative experiences in support groups. *Social Work in Health Care*, 20, 77–95.
- Goldsmith, D. J. (2004). *Communicating social support*. New York: Cambridge.
- Goldsmith, D. J., & Brashers, D. E. (2008). Communication matters: Developing and testing social support interventions. *Communication Monographs*, 75, 320–330.
- Green, D., McViney, L. D., & Adams, S. (1993). Strengths in transition: Professionally facilitated HIV support groups and the development of client symptomatology. *Social Work with Groups*, 16, 41–54.
- Harris, G. E., & Alderson, K. (2007). An investigation of gay men's experiences with HIV counseling and peer support services. *Canadian Journal of Community Mental Health*, 26, 129–142.
- Hays, R. B., Turner, H., & Coates, T. J. (1992). Social support, AIDS-related symptoms, and depression among gay men. *Journal of Consulting and Clinical Psychology*, 60, 463–469.
- Hymes, D. (1972). Models of the interaction of language and social life. In J. Gumperz & D. Hymes (Eds.), *Directions in socio-linguistics: The ethnography of communication* (pp. 35–71). New York: Holt, Rinehart, & Winston.
- Im, E.-O., Chee, W., Lim, H.-J., Liu, Y., Guevara, E., & Kim, K. S. (2007). Patients' attitudes toward Internet cancer support groups. *Oncology Nursing Forum*, 34, 705–712.
- Jia, H., Uphold, C. R., Wu, S., Reid, K., Findley, K., & Duncan, P. W. (2004). Health-related quality of life among men with HIV infection: Effects of social support, coping, and depression. *AIDS Patient Care and STDs*, 18, 594–603.
- Kalichman, S. C., DiMarco, M., Austin, J., Luke, W., & DiFonzo, K. (2003). Stress, social support, and HIV-status disclosure to family and friends among HIV-positive men and women. *Journal of Behavioral Medicine*, 26, 315–332.
- Keyton, J. (1999). Relational communication in groups. In L. R. Frey, D. S. Gouran, & M. S. Poole (Eds.), *The handbook of group communication theory and research* (pp. 192–222). Thousand Oaks, CA: Sage.
- Leserman, J., Jackson, E. D., Petitto, J. M., Golden, R. N., Silva, S. G., Perkins, D. O., et al. (1999). Progression to AIDS: The effects of stress, depressive symptoms, and social support. *Psychosomatic Medicine*, 61, 397–406.
- Lieberman, M. A., Wizlenberg, A., Golant, M., & Di Minno, M. (2005). The impact of group composition in Internet support groups: Homogeneous versus heterogeneous Parkinson's groups. *Group Dynamics: Theory, Research, and Practice*, 9, 239–250.



- Lyons, R. F., Mickelson, K. D., Sullivan, L., & Coyne, J. C. (1998). Coping as a communal process. *Journal of Social and Personal Relationships, 15*, 579–605.
- Matheson, K., & Zanna, M. P. (1988). The impact of computer-mediated communication on self-awareness. *Computers in Human Behavior, 4*, 221–233.
- Newmark, D. A. (1984). Review of a support group for patients with AIDS. *Topics in Clinical Nursing, 6*, 38–44.
- Paulus, P. B., Baum, A., & Andersen, B. L. (2001). Group processes in therapeutic support groups. In A. Baum & B. L. Andersen (Eds.), *Psychosocial interventions for cancer* (pp. 131–141). Washington, DC: American Psychological Association.
- Peterson, J. L., Brashers, D. E., Rintamaki, L. S., Goldsmith, D. J., & Neidig, J. L. (2009). *Forms and functions of peer social support*. Unpublished manuscript.
- Sandstrom, K. (1990). Confronting deadly disease: The drama of identity construction among gay men with AIDS. *Journal of Contemporary Ethnography, 19*, 271–294.
- Sandstrom, K. (1996). Searching for information, understanding, and self-value: The utilization of peer support groups by gay men with HIV/AIDS. *Social Work in Health Care, 23*, 51–74.
- Scheerhorn, D., & Geist, P. (1997). Social dynamics in groups. In L. Frey & J. K. Barge (Eds.), *Managing group life: Communicating in decision-making groups* (pp. 81–103). Boston: Houghton Mifflin.
- Simoni, J. M., Frick, P. A., & Huang, B. (2006). A longitudinal evaluation of a social support model of medication adherence among HIV-positive men and women on antiretroviral therapy. *Health Psychology, 25*, 74–81.
- Stewart, G. M., & Gregory, B. C. (1996). Themes of a long-term AIDS support group for gay men. *The Counseling Psychologist, 24*, 285–303.
- Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist, 38*, 1161–1173.
- Weinberg, N., Uken, J. S., Schmale, J., & Adamek, M. (1995). Therapeutic factors: Their presence in a computer-mediated support group. *Social Work with Groups, 18*(4), 57–69.
- Yalom, I. D. (1985). *The theory and practice of group psychotherapy* (3rd ed.). New York: Basil.