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## How individuals coping with HIV/AIDS use the Internet

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### Abstract

**Although identified 20 years ago, HIV/AIDS remains among the most serious disease epidemics of modern times. Because of the stigmatization associated with infection, no health crisis has rivaled HIV/AIDS in underscoring the need for emotional, informational and instrumental support. The critical role that support plays in coping with HIV/AIDS is well documented. Adults with HIV/AIDS have utilized traditional means of support—family, friends and community-based service organizations—in coping with their illness. Recently, however, the Internet has been recognized as a potential avenue for support. Although the Internet may prove promising, little is known about how the wide array of resources available via the Internet is used. The purpose of this study was to investigate how individuals with HIV/AIDS use the Internet in coping with their illness. This research study employed a descriptive qualitative design that used in-depth, semi-structured, face-to-face interviews for data collection. The sample of 10 purposefully selected individuals living with HIV/AIDS reflected diversity in gender, age, race, education, employment, number of years living with HIV/AIDS and Internet use. Data analysis guided by the constant comparative method revealed four themes. Individuals with HIV/AIDS use the Internet for finding information, making social connections, advocating and escaping.**

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### Introduction

Although two decades have transpired since HIV was first identified, this incurable virus and precursor of AIDS remains among the most serious infectious disease epidemics the world has ever known. The most recent statistics from UNAIDS reveal that 33.6 million individuals worldwide are infected with HIV/AIDS, 920 000 of whom reside in North America (UNAIDS, 2000). Yet as startling as these numbers are, they conservatively reflect the true extent of infection, since several years often elapse between the time of infection and diagnosis.

During the early years of the epidemic, news of a virus associated with certain death among homosexuals and minorities such as Haitians generated a morbid curiosity. On 2 October 1985 newspapers around the world trumpeted the news: 'Rock Hudson Dead of AIDS'. Before this startling announcement, AIDS had been a mysterious disease, the 'misfortune of people who fit into rather distinct classes of outcasts and social pariahs' [(Shilts, 1988), p. xxi]. The sobering reality, however, contrasted sharply with this widely held belief. On the day Rock Hudson died, some 12 000 Americans were already dead or dying of AIDS and hundreds of thousands more were infected with HIV. However, it took a move beyond the boundaries of the gay community and the death of a celebrity before AIDS received serious attention from the American public, and the political community was no quicker in its response. It was not until the late 1980s, at the end of his tenure as President of the US, that Ronald Reagan publicly acknowledged the health dangers posed by HIV

infection. This delay in public support and political recognition was not without serious repercussions. Opportunities to fund AIDS research before the illness reached epidemic proportions were forfeited, as were educational opportunities to stem its tide. According to Adam and Sears, AIDS quickly became 'part of a highly charged sociopolitical milieu which shaped its trajectory and meanings over the ensuing years' [(Adam and Sears, 1996), p. vx]. It took the endangerment of populations previously considered 'safe' to ignite the outrage essential to battle this deadly disease.

If any comforting news can be found in this tragedy it is that the outrage continues, fueling efforts to improve the quality of life for individuals living with HIV/AIDS until a cure can be found. Health care professionals and educators alike have an abiding interest in discovering ways to alleviate stress and nurture the adaptive coping efforts of individuals diagnosed with HIV/AIDS. It may be that the vast resources available on the Internet will offer promise in this regard.

While often viewed as a relatively recent phenomenon, the Internet has actually been in existence for about 25 years. Begun as ARPANET, it was the exclusive domain of research scientists in the early days; most were affiliated with large universities and many also worked for the Department of Defense (Moore, 1995). However, innovations in computer and network technology led to rapid growth and access beyond academic and military environs. Today, any person with a computer, modem and a gateway for access can tap into the services offered through the Internet.

The Internet is widely used for many purposes with information, communication and commerce being among the most common. The health resources available on the Internet may be especially endowed with life-changing potential since they 'can help us build our self-confidence and develop the coping skills we need to manage our own health problems' [(Ferguson, 1996), p. 42]. Despite the benefits that may be afforded by online health resources, few studies have

looked at how they are used by individuals coping with health problems, including HIV/AIDS. The studies (Brennan and Ripich, 1994; Gustafson *et al.*, 1994; Boberg *et al.*, 1995; Chan, 1995; Taylor, 1995; Pingree *et al.*, 1996; Smaglik *et al.*, 1998) that have been conducted involved the use of ComputerLink or Comprehensive Health Enhancement Support System (CHESS)—computer-based health systems that offer a variety of resources including information, decision support and social support. However, the ability of these computer-based systems to advance our understanding of how individuals with HIV/AIDS use the Internet is constrained in two significant ways [(Reeves, 2000), p. 49]:

- (1) These systems are often not operating on the Internet and when they are, they are not available to the public at large, requiring membership and a password.
- (2) The resources offered by these computer-based systems reflect the design decisions of their developers. In other words, while these systems offer many resource options, the selection is not unlimited.

The Internet, in contrast to these 'closed' computer-based systems of support, provides a limitless array of resource possibilities for individuals with HIV/AIDS and it can be accessed by anyone. Yet, little is known as to how individuals with HIV/AIDS who do not have access to systems such as ComputerLink and CHESS—individuals who are 'on their own'—use the Internet in coping with their illness.

Knowledge of how the Internet is being used by persons living with HIV/AIDS may inform the coping efforts of individuals who have been diagnosed with any number of chronic illnesses. It is also likely that this information would be particularly useful for those who are isolated from traditional means of support (e.g. family, friends, community-based organizations) due to geographical or medical circumstances. The purpose of this study was to investigate how individuals with HIV/AIDS use the Internet in coping with their illness.

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## Method

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This study employed a descriptive qualitative design to investigate how individuals with HIV/AIDS use the Internet in coping with their illness. A qualitative design facilitates understanding of an experience or phenomenon from the perspectives of the individuals who have 'lived' it. It accomplishes this by using the participants' own words, rather than numbers, to convey meaning.

A purposeful sample of HIV-positive individuals was located through the assistance of a large AIDS service organization (ASO) in a southeastern state of the US. Each participant was given \$50; several donated this gift to the ASO. To reflect the diversity characteristic of individuals with HIV/AIDS, a mix was sought in terms of gender, age, race, education, employment, number of years living with HIV and Internet use. Participation in the study was limited to individuals who: (1) were at least 21 years of age; (2) had been seropositive for HIV for at least 6 months; (3) had utilized the Internet in coping with HIV/AIDS for at least 6 months and were using it in this manner at the time of the study; (4) were at a sufficient level of cognitive functioning to recall and articulate how they use the Internet, and the impact of its use on their ability to cope with HIV/AIDS; (5) were at a sufficient level of physical functioning to comfortably endure a 90–120 min, face-to-face interview and agreed to a brief follow-up interview (by phone or E-mail) if a review of the data revealed a need for clarification; and (6) lived within the southeastern US.

The final sample consisted of 10 adults, six men and four women, whose ages spanned a 20-year period (ages 27–47). Eight are Caucasian, one is African-American and one is Hispanic. Level of educational attainment ranged from some post-secondary education to completion of a Master's degree. Two participants were employed full-time and the remaining eight were on disability. Participants had been living with HIV from 4 to 20 years. One was homebound and another, who lived within 1 h of a large metropolitan city, considered herself a resident of a rural area. Participants had been

using the Internet for HIV-related purposes from 1 to 10 years.

Data collection consisted of 90–120 min, semi-structured interviews; a semi-structured format is recommended for investigating the 'personal significance of what has transpired in the lives of respondents' [(Coyne and Gottlieb, 1996), p. 985]. Areas explored included participants' history of Internet use, how they use the Internet for purposes related to their illness and general coping strategies. The interviews were audio-taped and transcribed verbatim.

Data were analyzed inductively using the constant comparative method (Glaser and Strauss, 1967), although the intent of the study was not to build grounded theory. According to this method, data analysis proceeds simultaneously with data collection. I compared a particular incident from an interview with another incident in the same set of data or in another set. A rough classification scheme emerged from this comparison. Further analysis of the data transformed this classification scheme into categories and properties that were exhaustive, mutually exclusive, conceptually clear and sensitizing (Merriam, 1998). This process resulted in findings that represent my interpretation of how participants use the Internet in coping with their illness.

To ensure the trustworthiness of this research, I employed data source triangulation. In addition, I shared the findings with three of the participants, a member check, to see if my perceptions 'rang true'. I also shared the findings with two colleagues. Finally, I kept a detailed account of the decisions that guided the research, also known as an audit trail, in order to facilitate replication of the study.

The findings of this study are limited by the fact that the participants are articulate, motivated, well-educated individuals who do not accurately represent the HIV population worldwide, or even in the US. A second limitation of this study (as in most qualitative research) is the small size of the sample, which limits the ability to generalize the findings in a statistical sense. This study also may be limited by a lack of candor on the part of the participants. Not being seropositive for HIV, I am an outsider

in the HIV/AIDS community. Although the ASO endorsed my legitimacy as an ethically responsible researcher, participants' feelings about my 'right' to engage in HIV/AIDS-related research may have influenced their willingness, or ability, to be candid with me.

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## Results

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The results were derived inductively from the analysis of interview transcripts of 10 HIV-positive individuals. Each participant is represented below by a pseudonym. The purpose of this study was to investigate how individuals with HIV/AIDS use the Internet in coping with their illness. Four themes emerged to reveal that participants use the Internet for finding information, making social connections, advocating and escaping.

### Finding information

All 10 participants underscored the value of finding information on the Internet in coping with their illness and many considered it to be their primary use of the Internet. The importance of information obtained through the Internet was well expressed by Quint, the one Hispanic participant in the study. Quint's assessment exemplified the position of the other participants:

I read publications, especially journals, on the Internet. I really don't believe in the paper media anymore. Journals prolong my life. I mean, the simple fact that my last regimen, medication regimen, I got the interest thanks to the Internet. So the Internet is not just for communication, it [information from Internet] is directly tied to the length of your life.

Within the theme of 'finding information', three dimensions were particularly noteworthy. (1) A range of information, from general to specific, can be obtained on the Internet. (2) The Internet serves as the best source for up-to-date information. (3) Information on the Internet is easily accessible.

#### *Range of information*

Participants described using the Internet for both general and specific information. Interestingly, over

time, there was a shift in the type of information sought by participants, with general information being of greater interest for most during their first few weeks and months of Internet use. Vicky, the rural resident among the participants, described her early days of Internet use as 'looking up AIDS, AIDS, AIDS, anything pretty much'. Similarly, Rheta, a recent, yet enthusiastic Internet user who now maintains the web page for an ASO, noted, 'I was just surfing and looking at all kinds of different things'. Over time, there was a shift in focus from general to specific information. Many participants commented that this movement paralleled their perception of what they, personally, needed to know at various stages of their illness. For example, a newly diagnosed person will perform what Jack, who at age 35 is completing his college degree, describes as 'wildly generic searches' in an effort to learn as much as possible about HIV/AIDS. Laughing while recounting the incident, Jack talked about the first time he tried to locate HIV-related information through newsgroups:

I went through and pulled a list of anything that had to do with HIV. And so I went through each newsgroup and I literally—this is kind of embarrassing—I sat there for 3 days and I read every single post. There were 2476 of them [laughs]. I read them all.

As participants realized that it is not necessary to know everything about HIV and that, in fact, it is impossible to do so, the search for information became more focused. Today, Beth, a female peer counselor at an ASO, describes her approach to seeking information on the Internet as one that 'lets you individualize it to you'.

#### *Up-to-date information*

Participants also underscored the need for up-to-date information. Robert, who is homebound and has been living with HIV for 20 years, described the Internet as 'really the only way to stay on the cutting edge of anything'. Many saw the need for up-to-date material especially critical for individuals dealing with an illness such as HIV/AIDS,

where having access to information regarding new medications can influence treatment decisions that can directly govern one's prognosis. Ike, the editor of a newsletter for HIV-positive individuals, clearly emphasized the importance of having access to the most current information:

Information can change real fast...the face of AIDS has changed a lot in the last couple of years. It's very easy for information to become stale. You really need a tool that can change rapidly with it and the Net works really well for that.

Cal, a resource specialist at an ASO, provided a specific instance of just how up-to-date some of the information on the Internet can be:

Every work day, the Centers for Disease Control puts out on the Internet probably a dozen hot topics about new things that are going on. They could be treatment-related, social-related, or legal-related, but they're all going to be related to AIDS in some respect. And it's brand new information *that* day...I don't know of any print media for AIDS that has that ability.

#### *Easily accessible information*

Many participants noted the ease of access to information afforded by the Internet, indicating that their awareness and appreciation of this characteristic has grown through observing others' situations as well as through their own experiences. Ike emphasized how important easily accessible information, provided courtesy of the Internet, can be to individuals who are disabled: 'In situations where you can't do a lot of walking and getting out and stuff, having a terminal can be a life saver because you can get information and services without making a lot of effort...endangering your health'. Leslie, who at 27 was the youngest participant and an African-American, cited a personal example of a time when ease of access to information on the Internet was especially helpful to her:

I was real, real sick and I was desperate for information. Driving was out of the question. I

did get to the point where I could get off that couch right there [points to the couch] and get to the computer. And I was able to get what I needed off the Internet.

Perhaps Robert's experience most poignantly describes how ease of access to information on the Internet has affected his life: 'The Internet has connected me to information and people I couldn't otherwise connect with. I really don't believe I would still be alive without it'.

#### **Making social connections**

Making social connections, a second use of the Internet by individuals living with HIV/AIDS, occurred both in group settings, such as chat rooms and on a one-to-one basis. Interestingly, the salient feature of online connection was that it linked participants with other individuals living with HIV/AIDS. Ike described it like this: 'The neat thing about the Internet is that you can actually hook up with people that have gone through the same experiences, that *do* understand what you're talking about, that *have* been there'. For Quint, making social connections on the Internet allows him to 'receive input or feedback from people that are in a very similar situation...people living with AIDS, but that have had different experiences with doctors, with treatments, and things like that'. Ivan, a counselor at a wellness clinic, found that making social connections over the Internet generates what he called an 'encouraging effect' because 'it puts me in contact with men and women who have become infected and who've somehow decided to take that on as a challenge, instead of some kind of personal embarrassment or defeat'.

Regardless of whether the social connections were forged in a group setting or one-to-one, the participants described these efforts as fostering a sense of community with others coping with HIV/AIDS. Rheta explained it like this: 'I mean, you have a community there [on the Internet]. It's not a community of folks you see or that you would even necessarily recognize if you did run into them, but the community is still present'. Leslie similarly phrased this observation:

On the Internet, I connect with individuals I know and individuals I don't know...There are friendships and camaraderie that you get *from* the Internet. There's a community of us who are *always* on the Internet. Nine times out of 10, I'm closest to people who are on the Internet.

In many ways, Ivan's simple statement exemplifies the belief expressed by most: 'I really believe there is a community...there is this world called cyberspace...where we can extend ourselves beyond what we usually consider to be our customary boundaries'.

### **Advocating**

The use of the Internet for advocating struck a particularly passionate chord with several participants. Jack, for example, remarked, 'It [Internet] gets me excited sometimes, especially if I'm doing advocacy work. I know there are other people out there and we can get something done'. For Jack, 'the first part of advocacy is education. You have to be informed in order to care...and education sort of leads into the next part of advocacy—the part where you try to effect change'. Jack went on to describe advocating as 'making my voice heard', words also used by Rheta and Quint, who see their Internet activities as being largely concerned with advocacy issues. According to Rheta, 'advocating is letting your voice be heard on a particular issue' and she finds the Internet a particularly efficient forum for advocating:

You can do this stuff [alert members about imminent legislative votes] over the Internet. You could do it over the phone, but not as timely. And when you phone, you may even get an answering machine. You can leave a message, but they [individuals] may be gone. But people take their laptops with them when they're away from home, so they can get E-mails and act quickly.

Quint also viewed advocating as 'getting involved and having my voice heard'. It means 'speaking up, raising concerns, raising questions and being noticed as a person that has concerns that are

important not just for you, but for a group that you are a member of'. Quint's advocacy efforts have recently focused on the creation of his own web page which, he maintains, is 'my way to contribute to the educational process of society in general and people with AIDS. It now defines me in many respects'.

Robert, like Quint, clearly sees his position as an AIDS advocate as integral to the way he defines himself. Throughout the interview, he used the words 'advocate' and 'activist' synonymously. From the moment he lost his job due to his HIV-positive diagnosis, helping himself has been associated with educating others and demanding non-discriminatory treatment for persons with HIV/AIDS. 'The two are tied, are twins. From that point in my life on, they were intertwined'.

### **Escaping**

Escaping is the final way the participants used the Internet in coping with their illness. Ivan noted the potential for the Internet to be 'more than a place where you can get information. It can also allow for a certain amount of escapism and believe me, when you're taking 20–30 medications a day, you want to escape!'

For some of the participants, escaping was an intentional act that permitted respite from the stress of living with a potentially life-threatening illness. These individuals were cognizant that they used the Internet to relieve the pressures associated with their illness and they articulated this awareness. Some, like Ivan, escaped to HIV-related web sites like [Gaytoday.badpuppy.com/HIV-AIDS.htm](http://Gaytoday.badpuppy.com/HIV-AIDS.htm) that are 'more of a leisurely kind of thing than a serious inquiry'. Others, like Vicky and Rheta, used non HIV-related web sites for escapism. Vicky noted that 'through the Internet I can look at things like gardening and meditation, fun things that are basically escaping...lowering stress. Things that don't *matter*'. Rheta also found that visiting a web site for a particular television program that she enjoys allows her to escape from a life immersed in HIV-related activities:

Using the Internet is like letting off steam. I can only have the intense realities in my face

for so long, whether it's going to a doctor's appointment, going to see somebody in a hospital that I know that's dying from AIDS...that kind of thing. So much of that is like in your face, and I can't do that 24 hours a day. I mean, there's got to be some place where I can forget about it for a little while...So the Internet is kind of an escape which always allows me to mentally unwind.

Other participants used the Internet for escaping, but they did not immediately connect their escapism via the Internet with the need to retreat from the stress associated with HIV infection. It was only after some probing on my part that they made this link. When one participant, Beth, did make the connection, it was with more than a hint of exasperation:

I mean, God, you get tired of AIDS, AIDS, AIDS. I mean, you can't sit there for hours and read everything about AIDS. You have to take a break or something to kind of escape from it, and I go to web sites with pictures of Antarctic stations and Australia because they fascinate me.

Similarly, Robert revealed that he often went online 'to play games' and added:

I use the Internet for escapism from time to time and it's fun to do. It's not so much escaping from HIV, I've come to terms with it and sort of consider it my sidekick nowadays—my buddy that's beside me all the time. What I'm escaping from is the boredom, the lack of interpersonal relations that are a result of being homebound.

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## Discussion

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The participants in this study revealed four uses of the Internet in coping with HIV/AIDS. Two, finding information and making social connections, were not surprising and support the findings of previous research regarding Internet use. However, the remaining two uses, advocating and escaping, were unexpected and represent novel uses not previously reported in the literature.

At the conference, 'The Internet and Society', *finding information* was highlighted as the most pressing need of individuals living with HIV/AIDS. Ferguson noted that survey data from people living with HIV/AIDS indicate that access to treatment information, in particular, is their greatest need (Ferguson, 1997). The Internet, in offering unparalleled entrée to a universe of information, can be a powerful ally for individuals battling HIV/AIDS. As Jack so eloquently noted in discussing the events that prompted his Internet use, 'And what better or what more compelling reason to want to get information than finding out you're HIV-positive? That's the one time when you need all the information you can get'.

Not only does the Internet serve as a robust source of both general and specific information, it also permits access to the most current information and with considerable ease. Treatment opportunities for individuals with HIV/AIDS are expanding at a terrific pace. So fast, in fact, that the medical community has difficulty keeping up with what Kiyoshi Kuromiya, Director and Founder of Critical Path AIDS Project, refers to as 'bleeding edge' news (Kuromiya, 1997). This was certainly the case for Cal, who indicated that interest in getting the most up-to-date information is not only a function of his work as a resource specialist at an ASO, it is also tied to his commitment to 'save my own life'. Kuromiya in underscoring the capacity of the Internet to provide the most current treatment information [(Kuromiya, 1997), p. 229], noted that:

...by the time AIDS research and treatment information is published in a book, it is historic; some would say ancient. Even with the new bending of rules by such peer review journals as the *New England Journal of Medicine*, by the time a journal publishes AIDS research findings, the data is 6 months to a year old...This year, we have seen the future of AIDS information on the Internet.

Sofka also commented on the Internet's ability to provide access to the most up-to-date treatment information and considered it an 'adjunct resource to be used in conjunction with the advice and

guidance of a physician' [(Sofka, 1997), p. 557]. The participants in this study shared numerous examples of times when treatment decisions stemmed from coupling information obtained from the Internet with advice from their physicians. Rheta, for instance, had been on medications for so long that she had 'always been right up to the point of needing another drug just as something else was coming out'. When she shared new drug information obtained from the Internet with her doctor, he told her, 'I don't want to use just this medication'. Together, they made the decision to delay changing her medication regimen until a certain combination of drugs became available—something, Rheta said, 'I can keep my eye out for now on the Internet'.

That individuals with HIV/AIDS use the Internet for *making social connections* was also not a surprising finding of this research. Studies have consistently shown that the Internet's ability to facilitate connections with others accounts for much of its appeal. Anthony Rutkowski, Executive Director of the Internet Society, endorses this viewpoint, stating that the 'greatest value of the public Internet is its connectivity. Virtually everyone understands that' [(Flower, 1997), p. 15]. Porter [(Porter, 1997), p. xii] similarly noted that:

...recent hype about the World Wide Web and Information Superhighway notwithstanding, what continues most powerfully to draw people to the Internet is its power and novelty as a medium of person-to-person communication...People log on [because] they've either got something to say or else an ear to lend to those who do.

Studies of computer-based support systems like ComputerLink and CHES have also highlighted the popularity of the systems' communications/support functions. Brennan and Ripich found that the communications area (particularly E-mail and the support group) of ComputerLink was used most often by the 26 persons living with AIDS (PWAs) in their study (Brennan and Ripich, 1994). Similarly, three studies (Gustafson *et al.*, 1994; Boberg *et al.*, 1995; Pingree *et al.*, 1996) of PWAs

using CHES have consistently revealed that its communication/support function, Discussion Group, is one of the most widely utilized.

HIV infection is often an isolating illness with social ramifications every bit as debilitating as its physical consequences. While it was not particularly astonishing that study participants reported using the Internet for social communication, making connections primarily with other individuals with HIV/AIDS has not been noted elsewhere in the literature. Establishing ties with people similar to oneself can be attributed, Gutierrez (Gutierrez, 1994) asserts, to the perception that like-minded individuals are apt to be more accepting, more capable of supporting the need to ventilate, and better equipped to provide accurate information and advice. She maintains that these beliefs facilitate the coping process. This appeared to be true for all study participants. Quint, for instance, commented on the value of receiving 'input or feedback from people that are in a very similar situation'. Ike likewise noted that it is 'very comforting' to be able to connect with people who 'know about the thing you're talking about'.

Many of the participants commented on the sense of 'community' that online communication frequently engenders. Foster explains that the perception of community is a natural by-product of association with like-minded individuals [(Foster, 1997), p. 29] and notes: 'That which holds a virtual community intact is the subjective criterion of togetherness, a feeling of connectedness that confers a sense of belonging'. Porter also supports this connection [(Porter, 1997), p. xii], adding that sustained interactions on the Internet 'can give rise to a unique and intriguing form of social space, and one that will continue to provoke assessments of the fundamental nature of 'community' itself'.

Although participants in this study reported that communicating online produced positive outcomes, a well-publicized study by Kraut *et al.* of individuals who use the Internet primarily for communication revealed the opposite (Kraut *et al.*, 1998). (It should be noted that these individuals were not living with HIV/AIDS or any other chronic illness.) The researchers found that greater



use of the Internet was associated with 'declines in participants' communication with family members in the household, declines in the size of their social circle, and increases in depression and loneliness' [(Kraut *et al.*, 1998), p. 1017]. In a challenge to the findings of this study, Shapiro states that it 'suffers from a serious methodological flaw' and notes that the researchers selected participants whose social contacts were likely to decline even without Internet access [(Shapiro, 1999), p. 782]. She goes on to add that because participants with the greatest loss of social contacts might occupy their time by using the Internet, 'the observed negative correlation between social contact and Internet usage might indicate that isolation leads to Internet usage—a causal relationship opposite to that posited by the researchers' [(Shapiro, 1999), p. 782]. It is beyond the scope of this research to suggest a causal relationship between isolation and Internet usage. However, it is reasonable to speculate that loneliness may result from the stigmatization associated with HIV infection or from progression of the disease itself, as was the case in Robert's situation. In instances such as these, Internet use might provide a way to assuage loneliness by filling the empty hours.

That study participants employed the Internet for *advocating*, a third use, was an unanticipated and intriguing finding of this research, given that there is scant reference to this use in the research literature. It was also a use of the Internet that stirred considerable feeling among the participants. Although the HIV/AIDS community has a proud and successful history of advocacy and activism, serving as a model for other illness populations, the context of these efforts is often associated with some of the more politically oriented branches of the AIDS movement, such as ACT-UP. Images of the Internet as a forum for activism do not come to mind as readily as its use for informational and social purposes.

Since the 1960s there has been a marked decline in participation in such organizations as the PTA, labor unions and political parties (Putnam, 1995). Healy, in viewing activism as collective action, noted that the 'Internet has not countered a trend in

American civic life toward less activism' [(Healy, 1997), p. 63]. The participants in this study, however, provide a different perspective. They found the Internet to be an especially fertile venue for advocacy, largely because of the speed and broad access that it affords.

The words 'advocating', 'advocacy' and 'activism' were used interchangeably by the study participants. These words are often used synonymously in the literature as well. Lefley, for example, employs both 'advocacy' and 'activism' in depicting an action that enhances the 'collective potential for knowledge building, systems planning, and social policy change' [(Lefley, 1996), p. 218]. Moreover, she considers it a 'proactive coping mechanism' [(Lefley, 1996), p. 218]. Rheta, who updates the web page at the ASO where she volunteers, noted that the Internet serves as a particularly efficient tool for advocacy since individuals could be notified quickly of impending HIV/AIDS-related information. In fact, Rheta stated that use of the Internet for advocating has been so effective at this particular ASO that the 'list of folks that get the advocacy alert is probably double what it was last year when we started'. Nancy Marks, Public Policy Manager at AIDS Action Committee, similarly underscored the Internet's utility for advocacy [(Marks, 1997), p. 233]:

What do we gain as a movement when we use the Internet as an organizing and advocacy tool? It's clear we gain numbers...And now I can reach people who might never have become active in AIDS public policy had it not been for access to it through the Internet.

The final use of the Internet by individuals with HIV/AIDS, *escaping*, was also unanticipated. This phenomenon has been referenced in the literature in numerous ways, from the elegant phrase, 'a partial bracketing of 'real life'' [(Ito, 1997), p. 94] to the simple word, 'play' (Schafer, 1996). When escaping is intentional, it resembles the adaptive coping strategies of 'balance' (Reeves *et al.*, 1999) and 'suppression' (Vallaint, 1997). Balance entails the conscious act of weighing and dealing with competing life demands. Similarly, suppression

involves deliberately putting aside unacceptable or inappropriate thoughts for a temporary period of time. 'Like Scarlett O'Hara in *Gone With the Wind* we tell ourselves that we will think about it tomorrow, and we generally do' [(Schwebel *et al.*, 1990), p. 170].

For some study participants, escaping was conscious and deliberate. They clearly linked the use of the Internet to the need to escape from lives consumed by HIV/AIDS-related stress. Some, like Ivan, escaped to 'fun' HIV/AIDS web sites, such as [Gaytoday.badpuppy.com/HIV-AIDS.htm](http://Gaytoday.badpuppy.com/HIV-AIDS.htm). For others, like Rheta, escaping entailed visiting non-HIV/AIDS-related web sites. Rheta, in fact, used the word 'balance' to describe how the Internet abets her periodic need for relief: 'The stuff that I do here [at the ASO] I do with a lot of intensity. And then I can do something fun. The Internet kind of allows for a balance between the intensity and then just fantasy'.

Other participants also used the Internet for escaping from HIV/AIDS-related stress. Their actions, however, were not intentional. That is, they did not initially 'make the connection' that visits to sites such as 'Antarctic stations' were prompted by the need to escape from the stress of living with HIV/AIDS.

In conclusion, the participants in this study revealed four ways in which they use the Internet in coping with HIV/AIDS: finding information, making social connections, advocating and escaping. An understanding of and appreciation for the myriad ways that individuals use the Internet in coping with chronic illness is helpful to health educators as they consider Internet applications in planning interventions. Knowing, for example, that the Internet provides a vehicle for advocating and escaping (and that individuals perceive these uses as adaptive coping behaviors) prompts health educators to 'think out of the box'—to consider Internet usage beyond its customary informational and social affordances. Health educators may want to design web pages that include 'forums' for advocacy. These 'forums' could include links to advocacy issues, the names of organizations that sponsor advocacy events and even chat rooms

where health educators host advocacy discussions. Similarly, these web pages could include links that members of illness populations have identified as providing beneficial 'escapes' from the stress of dealing with their disease. What is clear is that 'new and existing technologies can have a major impact on the treatment of clients' [(Karger and Levine, 1999), p. 319] and that we have only just begun to tap the possibilities.

In assisting individuals as they confront the many challenges they will face as a consequence of chronic illness, health care professionals must consider every tool that offers promise. Peter Piot, Executive Director of the Joint United Nations Programme on HIV/AIDS, noted that in the battle being waged against HIV/AIDS, 'the lessons learned—from successes and failures—must be shared' (UNAIDS, 1999). The participants in this study would certainly share their belief that Internet use ranks as a success.

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