**R R  Rapid Response Service**

# Online counseling and support groups for people living with or affected by HIV/AIDS

**OHTN**

## Questions

- What are best practices in providing online counselling and facilitating support groups for individuals living with or affected by HIV/AIDS?
- What are the ethical issues in providing online counselling and facilitating support groups for individuals living with or affected by HIV/AIDS?
- Are there any other organizations providing online counselling and support for people living with or affected by HIV/AIDS?
- What is the safest and most ethical way of conducting cyber-counselling?

## Key Take-Home Messages

- Given the importance of counselling and support groups in maintaining the well-being of HIV-positive individuals (1;2), it is important to consider providing these services online which can reduce barriers related to mobility, scheduling constraints and stigma (3).
- There is interest in online HIV/AIDS counselling by people living with HIV/AIDS(8;9); however, at the time of this review, the peer-reviewed literature on best practices and ethical issues of HIV/AIDS online support groups and counselling was limited
- Users of HIV/AIDS online support groups tend to be younger, female, not in relationships, newly diagnosed or in advanced, symptomatic stages of the disease (4).
- Online support interventions appear to be effective. Those who actively participated in online HIV/AIDS support groups experienced a greater sense of empowerment through receiving social support and information, and helping others (3;5); they also experienced higher levels of adaptive coping (6) and better psychological health outcomes than those who participated less frequently (7).
- Existing HIV/AIDS online counselling services tend to be in more static formats, such as online informational materials, and question and answer forums. However, there are live examples of online counselling in psycho-therapy treatments. Online support groups often involved peer-to-peer discussions in forums hosted by AIDS service organizations.

## EVIDENCE INTO ACTION

The OHTN Rapid Response Service offers HIV/AIDS programs and services in Ontario quick access to research evidence to help inform decision making, service delivery and advocacy.

In response to a question from the field, the Rapid Response Team reviews the scientific and grey literature, consults with experts, and prepares a brief fact sheet summarizing the current evidence and its implications for policy and practice.

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# The Issue and Why It's Important

HIV counselling and support group services are fundamental in HIV prevention and support. They can help people reduce risk of transmission and support people living with HIV in maintain their health, particularly their psychological well-being (2). Counselling aims to prevent HIV transmission, and support those directly and indirectly affected by HIV/AIDS (2). HIV/AIDS support groups also enable people living with HIV to connect with one another and share experiences. Providing support for people living with HIV has several measurable physical and mental health benefits, including stronger immune function, better disease management, better quality of life, and improved psychological well-being (3). However, several barriers may prevent people living with HIV from receiving face-to-face social support, such as the lack of family members close by, the loss of friends to AIDS, HIV stigma, difficulty accepting one's status, non-disclosure of one's HIV status, mobility challenges and geographic isolation (3).

The increasing use of computers and the Internet are providing new ways to meet the social support needs of people living with HIV. Recent studies found that people with HIV who are frequently online, generally have better knowledge about HIV and more social support; they are more engaged in information-seeking and active coping than those who are not online (11;12).

Many websites provide access to information about HIV testing and treatment; however, the internet also has the potential to deliver counselling and support services for people affected by HIV/AIDS (1;12). Access to the Internet can vary by age, race, income and education levels (1) so, when developing online support services, it's important to consider the most effective and ethical ways in which to provide these services.

# What We Found

Peer-reviewed literature on HIV/AIDS online counselling and support groups was limited. We did not find any best practice guidelines or articles focusing on the ethical issues of providing online counselling and support groups to those affected by or living with HIV. The peer-reviewed literature on online HIV/AIDS support groups generally focuses on characterizing the people who use online services and the benefits they receive. Few studies explore the challenges of implementing online counselling sessions.

### HIV/AIDS Online Support Groups

Online support groups are forums where people affected by HIV can connect and communicate with others in a similar situation. A content analysis (5) of an online HIV/AIDS support group found that the most frequent type of social support exchanged in online groups was factual information followed by offering advice, redefining a negative situation in a positive perspective and sharing one's own experience (5). Online support group users commonly discussed content related to illness management, symptom interpretation, drug treatment, and psychosocial and political issues (5).

Who uses online support groups and what are their benefits?
A 2010 study of 640 people living with HIV found that online support group users were more likely to be younger and female, single (i.e. not in relationships) and recently diagnosed (4). People in advanced stages of the disease were more likely than those who were asymptomatic to access online support groups, and frequent users appeared to be experiencing poorer physical and social functioning (4).

Using online support groups is associated with positive outcomes for people with chronic health conditions:

- A study of 528 online support group users with breast cancer, fibromyalgia or arthritis found that individuals felt empowered through online participation in groups (13).
- The level of engagement in an online group can affect its benefits. For example, a study of 340 people living with (3) found that people who actively posted messages experienced more empowering processes such as receiving social support, receiving information and helping others, compared to those who only read online posts who experienced less empowering processes. An additional analysis showed that receiving social support and helping others was related to greater self-care and self-efficacy which, in turn, was related to higher levels of adaptive coping and lower levels of maladaptive coping (6). A final analysis showed that online support group users who actively participated had better psychological health than those with lower levels of participation (7).
- A U.S.-based qualitative study of 10 purposively selected HIV-positive internet users had similar findings: internet use encouraged empowerment, social support and helping others (10).

## Online Counselling

We found two articles on the efficacy of online counselling -- both were focused on psychological conditions:

- A study in the Netherlands exploring the effectiveness of Internet therapy for post-traumatic stress (14) randomized participants into the experimental condition or a wait list control (14). During the intervention, the experimental group received online contact with a therapist and psycho-education about post-traumatic stress. In addition they described their traumatic experience and completed structured writing assignments (14). The experimental group showed significantly greater improvement than the control group in trauma-related symptoms and general psychopathology (14).
- A UK-based study exploring the effectiveness of therapist-delivered internet psychotherapy for depression (15) randomized participants into either an online cognitive-behavioral therapy intervention with usual care or to usual care while on a wait-list for the intervention (15). Participants in the experimental arm completed ten, 55-minute cognitive-behavioral therapy sessions with a therapist online in real time. At eight month follow-up, 42% of participants in the experimental arm recovered from depression compared to 26% of participants in the control group (15).

Only two peer reviewed articles discussed implementing an online counselling intervention for people affected by HIV/AIDS:
- A US-based exploratory study (8), which sought the views of women with HIV about implementing an online behavioural HIV prevention intervention, highlighted some of the logistical and ethical issues in online interventions. In this study, 27 women who had completed *Healthy-Relationships*, a face-to-face, group-based behavioural program for women living with HIV, participated in focus groups to discuss their views on participating in the program through a video-group format (8). Overall, women supported the video-group format (8); however, they had many concerns about program logistics, and safety and confidentiality. In general, they believed there would be fewer breaches in privacy with a video-phone than with computers and webcams (8). They also thought video-phones were more user-friendly

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and familiar than computers (8). They were concerned that taking part in the video-groups at home could lead to unintended serostatus disclosure to family members (8). Some women were also concerned about their ability to consistently access computers or the internet at home; however, they thought it would be acceptable to access group sessions through computers located in safe spaces within their communities (8).

- The same researchers then pilot tested the delivery of *Healthy-Relationships* through video-groups among women living with HIV (9). The online counselling session consisted of six two-hour video-conferencing- sessions led by two facilitators who used structured activities and video-clips to build disclosure and safe-sex skills (9). Four minority women with HIV received counselling at four different community-based sites.  Each woman was in a private room equipped with a video-phone and a desktop computer to complete individual assessments (9). Almost all participants reported they would choose the video-group format over the in-person format. The facilitators had mostly positive experiences with the video-group; however, they did report difficulties with equipment, and being able to speak privately with group members. Other challenges included connection interruptions and video pixilation (9).

With respect to user guides, the University of Toronto's Factor-Inwentash Faculty of Social Work created *A Manual on Cyber Counselling with Children and Youth* (16) for providing psychological counselling. The how-to manual provides information on forming therapeutic alliances with clients, conducting assessments and terminating sessions with online clients. It also provides a guide to culture and gender, and ethical and legal aspects of providing online counselling (16). Although focused on psychological counselling, the principles can be applied to counselling people affected by HIV.

### Organizations Providing Online Counselling and Support Group Services

The following are examples of North American organizations that provide either online counselling or support group services. In general, online HIV counselling services are in static formats -- such as online informational materials, and question and answer forums -- rather than in live formats – such as Skype, video-groups and online chats. However, we did find examples of live online counselling for psychotherapy. In general, online support groups were often peer -to-peer discussions in forums hosted by HIV/AIDS organizations.

CATIE (http://www.catie.ca/en/about/work/resources)
A Canadian-based source of information about HIV and hepatitis C, CATIE aims to link people living with HIV or hepatitis C, at-risk communities, health care providers and community organizations with knowledge and expertise to reduce transmission and improve quality of life (17). On its website, CATIE has compiled a compendium of resources (18), including books, pamphlets and e-resources such as webinars that, in addition to providing basic information about HIV and hepatitis C, also provide multiple practical guides to living with and managing one's condition.

TheBody.com (http://www.thebody.com/)
TheBody.com is a US-based online resource centre that uses the internet to lower barriers between patients and clinicians; demystify HIV and its treatment; improve the quality of life for people living with HIV; and foster community (19). The website provides general information about HIV, and also provides online counselling through an "Ask the Experts" forum which provides answers to questions that users post about living with HIV, treatment, disease complications and prevention. Through its "connect" tab, the website also hosts a peer-to-peer online support and discussion group which serves to link people

living with HIV/AIDS.

Thunder Bay Online Counselling Centre (http://www.tbaycounselling.com/counselling/online-counselling/)
This organization is a diverse group of community members and counselling professionals working together to provide responsive mental health services in Northern Ontario (20). Clients interested in seeking online counselling first contact the Centre to see if online counselling is right for them. Clients are then provided with a website where they can securely register and log into their own confidential email account to communicate freely with a counselor (20).

LivePerson (http://www.liveperson.com/lp/online-therapy)
Individual accredited counselors provide online mental health counselling services via email and Skype; however, these services are not free.

HIV/AIDStribe (http://www.hivaidstribe.com/)
HIV/AIDStribe is a U.S.-based online HIV/AIDS support community that strives to link those living with HIV. Online members get free access to general information on HIV, online blogs of those living with HIV, and interest groups and forums led by those with HIV.

# Factors That May Affect Local Applicability

All studies included in this summary were conducted in high income countries that have similar HIV epidemics as Canada. Peer-reviewed literature on online counselling and support groups was limited. No best practice guidelines, or articles focusing on the ethical issues on providing online counselling and support groups to those affected by, or living with HIV/AIDS were found.

# What We Did

We searched Medline, Embase, PsychINFO for articles using a combination of text terms [HIV] in the titles AND text terms [(skype) or (online counsel*) or (internet counsel*) or (web counsel*) or (cyber counsel*) or (online support) or (internet support) or (web-based support) or (cyber support) or (video)] in the titles. The search was limited to articles published since 1996 onwards, in English. We also conducted appropriate searches on Google to identify organizations that provide online counselling and support group services.