Improving Access to HIV Information in Rural Canada

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Summary

Information on HIV is not always easily accessible, especially in rural communities in Canada. This can lead to special challenges for people with HIV/AIDS (PHAs) who live in rural areas. This article will help to explain the barriers to accessing information that people in rural communities face and possible solutions. These barriers and solutions have important implications for the design and development of programs that facilitate the exchange of information on HIV in rural Canada.

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Setting the Stage

Rural Canada

In 2006, approximately 31.6 million people lived in Canada and, of these, 20% or roughly 6 million Canadians lived in small towns and rural areas. The number of Canadians residing in rural areas in Canada declined by 0.4% from 1996 to 2001; however, the most recent Census shows that the rural population grew by 1% from 2001 to 2006.

HIV in Canada

HIV continues to be a major health issue in Canada: it is estimated that 65,000 people were living with HIV and that there were an estimated 2,300 to 4,300 new infections in 2008. Due to limitations in the way information is collected when people go for testing and due to the mobility of PHAs, we do not know how many PHAs live in rural areas. If the percentage of PHAs in rural areas is similar to the percentage of PHAs in the country as a whole (20%), then approximately 13,000 PHAs live in rural Canada. However, this may be an over-estimate since some PHAs choose to live in urban centres so they can access the care of specialists more readily.

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HIV Information in Rural Canada

HIV information needs

Since the advent of highly active antiretroviral therapy (HAART) in 1996, the care and treatment of PHAs has become far more effective but also increasingly complex. This is, in part, due to the development of new HIV drugs, the potential for drug resistance and side effects, longer life expectancies and the potential for co-infection (having HIV as well as another condition, such as hepatitis C).
Due to these complexities, access to accurate, up-to-date information on HIV care and treatment is essential for PHAs and their care providers. Reliable information allows PHAs to make more informed decisions and it helps ensure that care providers offer optimal treatment, care and support.

PHAs need information about their illness, their treatment options and how to live with HIV. Friends and family of people with HIV need information on treatment, how to prevent HIV transmission and how to provide emotional and social support.

**Sources of HIV information**

Due to lower levels of knowledge about HIV in rural communities and a lack of widespread discussion about HIV, people living in rural communities are unlikely to receive useful information about HIV by “accident.” A 2005 survey of three rural Canadian communities found that 45% of the people surveyed never talked to anyone about HIV or related topics, and 83% of those who had talked to others about the disease did so infrequently. These survey results also revealed that people living in rural areas were significantly less likely than their urban counterparts to have ever discussed the disease and were less likely to be very knowledgeable about how the disease is transmitted and diagnosed.

People living in rural areas typically obtain HIV-related information by purposely looking for it, unless they know someone who is knowledgeable about HIV, such as a PHA. Common sources of information include healthcare providers, service providers, print materials (such as pamphlets) and websites.

PHAs in rural communities report looking to other PHAs (also known as peers) as important sources of information and help. From peers, PHAs learn how to ‘live with’ HIV—for example, strategies for dealing with HIV practically, emotionally and spiritually; information on how to find support services and how to disclose HIV status; information on self-care, complementary therapies, nutrition and how to deal with side effects, among other things. Many PHAs in rural areas describe the experience of learning from peers as a positive and emotionally rewarding experience.

In rural Canada, knowledge of HIV generally appears to be a kind of specialized knowledge that is largely concentrated among PHAs, their caregivers, healthcare providers and some service providers. It is through these networks that rural PHAs learn about their illness and how to manage it. Knowing how these networks work is important to understanding how to facilitate the exchange of information in rural settings.

**Finding HIV information through personal networks**

In a 2005 study, rural PHAs in Canada and the people who make up their support systems were asked about the size and membership of their information networks. The size of personal networks through which HIV information travels in rural Canadian communities was quite small—on average, about seven to 10 people. Rural PHAs expressed concern about their reliance on such small networks. This is because information and support networks can be devastated due to staff turnover and/or unreliable funding that can result in the loss of key network members. Most of the friends and family members of PHAs had even smaller networks of only three to five people.

When asked who makes up their information networks, PHAs mentioned primarily their healthcare and social service providers, family members and close friends. Most PHAs had at least one other PHA in their information network—in many cases, someone who they had met through their local AIDS service organization or through volunteer work. Most PHAs had very few friends or acquaintances within their information networks, often because of a wish to protect their privacy and because of fears of stigma and discrimination. The networks that the friends and family members of PHAs turn to for information comprised other family members, close friends and the PHA in their lives. Friends and family members reported that they often obtained information from PHAs without looking for it, such as when PHAs told them things about the disease or the topic ‘came up’ in conversation. Notably, according to the 2006 survey of the general population of three rural Canadian communities, knowing at least one PHA personally significantly predicted knowing more about HIV/AIDS.

Rural healthcare and service providers also reported having small networks they turn to for information—on average, their networks comprise four to six people. These tended to be professional colleagues that worked for other organizations, such as staff members and volunteers at AIDS service organizations and/or public health nurses. Staff at AIDS service organizations and public health nurses were seen by many as the only obvious source of HIV-related expertise in their communities.
Barriers to Accessing HIV Information in Rural Canada

Misinformation

Misinformation is the unintentional spread of inaccurate or false information. There is evidence that misinformation does travel within HIV information networks in rural areas and pass into the larger community. Misinformation may not originate in rural communities and its spread can be facilitated by the ease of accessing information on the internet.

Misinformation in rural communities tends to fall into three categories: (1) information that challenges the local existence of HIV; (2) mistaken notions about how HIV is transmitted; and (3) unsubstantiated claims about treatment and cures.

In a 2006 survey, one in four rural Canadians believed that HIV/AIDS could be, or might be, transmitted by sharing a glass of water with a PHA. Misinformation can be damaging not only to PHAs but also to their networks and the broader community. Misinformation can endanger PHAs who accept false or unsubstantiated medical information. Misinformation about transmission is also detrimental as it can misrepresent PHAs as people to be avoided or feared. This can cause rifts between PHAs and others in their family and community—generating feelings of hurt, isolation and rejection.

Many rural PHAs try to avoid passing on information of questionable value while others have worked very hard in their communities to challenge misinformation and misunderstandings about HIV.

Barriers to accessing healthcare

Some rural PHAs obtain HIV-related information from healthcare providers while others find it difficult to find local healthcare providers with experience and expertise in HIV. Because most HIV specialists work in urban areas, most rural dwellers have to travel long distances for specialized care. In rural areas, primary care physicians are the other option; however, only about 5% of primary care physicians in Canada provide care for people with advanced HIV. Therefore, it may be difficult for primary care physicians to be the source for HIV-related information, which is becoming increasingly complex. Indeed, a recent study of PHAs in three rural Canadian communities showed that rural PHAs are often unable to get the information they are looking for from their family physicians and that they may (often with some frustration) try to educate their own physicians.

Rural PHAs also report getting HIV-related information from service providers, such as those at AIDS service organizations. However, these types of services and agencies are not available in all rural locations, and even if available, AIDS service organizations may have limited resources and high turnover of staff and volunteers, which curbs their ability to act as a stable source of information and support for PHAs. For example, in the three years after the aforementioned study was completed, 10 of 15 key healthcare and service providers in the networks of rural PHAs left their positions and two rural AIDS service organizations closed. Some AIDS service organizations may also be reluctant to provide information on HIV treatment due to both the complexities of this information and their possible lack of up-to-date information on HIV treatment.

Unreliable internet access

The internet can be a valuable source for information for people living in remote and rural areas; however, internet access can be slow or sporadic in some communities, and not all healthcare and service providers communicate with their clients or patients by e-mail.

Confidentiality

Within rural communities there is a greater chance for a breach of confidentiality due to overlapping relationships within smaller communities. For example, a service provider at a local agency could also be a relative or friend of the family. The potential for a breach of confidentiality can affect a person’s willingness to access needed services and information. To protect themselves, rural dwellers may choose to obtain services and information about HIV only in
distant locations.

**Stigma and discrimination**

Stigma is a form of prejudice that discredits or rejects an individual or group of people because they are seen to be different from ourselves or from the “norm.” When people act on their prejudice, stigma turns into discrimination. HIV-related stigma arises mostly from fear and ignorance about the disease and/or hostility and existing prejudices about the groups most affected by it (e.g. gay men or people who inject drugs).

Stigma and discrimination are major challenges to Canadians with HIV. According to a national study conducted in 2006, almost three in 10 Canadians reported a moderate or high level or stigma directed towards PHAs. This stigma can lead to discrimination, which can affect the willingness of PHAs to seek information about HIV.

While stigma and discrimination are pervasive in communities of all sizes, these issues may be exacerbated in rural communities for a few reasons. Religious conservatism in some rural communities may negatively influence the thoughts and beliefs of people towards PHAs and/or the groups most affected by it. Also, due to the general lack of knowledge and discussion about HIV in rural communities, there may be misconceptions and fears of PHAs within their community.

Since open discussion and the distribution of information on HIV are limited in many rural communities, there may be little chance for people to encounter ‘incidental’ information about HIV in these communities. Yet, people who have ever discussed the disease or who know a PHA personally are more likely to be knowledgeable about the disease. Therefore, efforts to enhance knowledge and to encourage dialogue, particularly involving PHAs, may be an important way to reduce HIV stigma and improve access to HIV information in rural communities.

**How to Improve Access to HIV Information in Rural Canada**

**Building information networks**

Since it may be difficult for people living in rural areas to find the information they need, and finding information ‘by accident’ doesn’t occur very often, building personal networks may be an important way to facilitate and improve access to HIV information in rural Canada.

There are several ways that information networks could potentially be enhanced within rural communities. Firstly, PHAs emphasize the importance of connecting with others like themselves and they, along with their friends and family members, stress the value of having access to knowledgeable people who show concern and compassion while providing sound information and advice. Supporting the important role that PHAs and service providers can play in informing and supporting others may lead to growing networks that facilitate the exchange of information.

In rural areas where information networks are small, when staff and volunteers leave their positions within medical facilities and community-based agencies, these networks can become unstable. It is important that AIDS service organizations and other agencies try to engage more people in activities related to HIV information exchange, in order to stabilize their information networks. These activities could include opportunities for PHAs to meet one another and to form relationships, for example, through ‘buddy’ programs; or support programs for the family members of PHAs who often feel isolated and stigmatized and don’t know where to look for information.

It is also key that people within networks be knowledgeable about treatment and the other information needs of PHAs. This can be accomplished through materials and workshops that teach service providers and other PHAs the information they need to know to facilitate knowledge exchange. It could also include programming through frontline agencies aimed at increasing the skills of PHAs to provide peer-based information within the community. The benefit of this approach is the use of peers to provide not only information but also a shared experience and a common understanding of the issues faced by PHAs.

Information technology, such as toll-free phone lines and email, can help people overcome geographical barriers to accessing HIV information. For PHAs, toll-free phone lines and email can be used to communicate with ASOs, their healthcare providers and national HIV organizations. However, these are not always available. Agencies and medical
facilities should review their policies and investigate how these simple measures can help people access information.

Reducing misinformation

Rural PHAs obtain information from a variety of sources. There is the potential for PHAs to come into contact with inaccurate information. For example, it is impossible to control the quality of health information on the web, which can result in the easy and rapid dissemination of misinformation. Because it may be difficult to equip PHAs with the skills needed to evaluate the legitimacy of online health information themselves, it is important that the networks of PHAs include people who are sufficiently knowledgeable to help them verify the credibility of any information they have found.

Building community knowledge of HIV

HIV stigma affects PHAs and their friends and family members. When members of a rural community hold stigmatizing beliefs about the disease, are unaware it exists in their community, and exchange little information about it through local networks, PHAs may be reluctant to disclose their status or use local services. Anti-stigma campaigns are important in rural communities to ensure PHAs are comfortable seeking the information they need. These campaigns as well as any other initiatives should work on educating the community since we know that stigma is connected with a lack of awareness and understanding.

Reducing the stigma of HIV in a community may also have an added benefit. Fears of stigma and discrimination can lead PHAs to conceal their status, which makes it difficult for PHAs to find and connect with one another. Reducing the stigma and discrimination experienced by members of a community could lead to better connections among peers and expanded information networks.

References


16. Veinot TC. 'We have a lot of information to share with each other': Understanding the Value of Peer-Based Health Information Exchange. Information Research (in press).


**Disclaimer**

Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV- and hepatitis C-related illness and the treatments in question.

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