

Rural Women and HIV/AIDS Information Exchange in Canada

Authors:

Tiffany Veinot
Faculty of Information and Media Studies
The University of Western Ontario
London, Ontario CANADA
tveinot@uwo.ca

Roma Harris
Professor
Faculty of Information and Media Studies
The University of Western Ontario
London, Ontario CANADA
harris@uwo.ca

Key Words: HIV; Rural Population; Information Dissemination; Canada; Women

Introduction

People with HIV/AIDS (PHAs) face special challenges if they live in rural parts of Canada. The presence of the disease is often unrecognized by members of rural communities and, given the preponderance of conservative values in some areas, PHAs may be reluctant to reveal their health status to avoid being stigmatized. Rural communities may also have limited capacity to provide HIV-related health care, services and support. Rural women with HIV/AIDS face particular challenges due to invisibility of women in the epidemic and their roles as caregivers of their family members, often regardless of their own health status (1, 2). As a result, rural-dwelling women with HIV/AIDS and women caregivers may have unique needs with respect to locating and receiving relevant information and help, particularly since women are often key intermediaries for health information on behalf of other members in their family/social networks.

HIV/AIDS treatment information is a critical resource for people living with HIV/AIDS and their caregivers (3-5). It is used for health decision-making, providing care, support and treatment to PHAs, patient education, treatment advocacy, and other community-based activities. (3-6) Additionally, information about HIV transmission is an important factor in decision-making with respect to potential risk behaviours. (7, 8) The purpose of the research described in this paper is to explore how information related to HIV/AIDS is exchanged in, and affects, rural communities in Ontario. Central to this is consideration of the role of women with respect to health information exchange within rural community networks. The results of the study will be discussed with respect to the roles that libraries could play in facilitating HIV/AIDS information exchange, particularly with respect to IT and other potential intermediary functions that would improve the capacity of rural communities to support PHAs and their caregivers. Supporting community HIV/AIDS information exchange will be important in mobilizing effective responses to the HIV/AIDS epidemic.

Literature Review

HIV/AIDS in Canada

In 2002, there were an estimated 56,000 people living with HIV/AIDS (PHAs) in Canada (9). HIV/AIDS primarily affects men who have sex with men, injection drug users, and, increasingly, women, Black Canadians and Aboriginal people (9). New drug therapies have revolutionized the treatment of HIV/AIDS and reduced AIDS-

associated morbidity and mortality (10-13). (4) However, these drug therapies are not a cure, and PHAs face increasingly complexities in managing HIV/AIDS, such as side effects of medications and co-morbidities such as Hepatitis C, addictions and mental health issues (14). In addition, the epidemic shows no signs of abating, with approximately 2,800-5,200 new infections per year in Canada (15).

Health Issues in Canadian Rural Communities

Understanding and responding to the health concerns of rural residents is a pressing issue. Indeed, there is considerable evidence to suggest that the smaller the size of a community, the lower its health status (16). In comparison with their urban counterparts, people who live in rural areas have shorter life expectancies and higher disability rates (16). Rural communities also face special challenges with regard to health care, including geographic isolation, lack of services, lack of anonymity, and a necessity to travel for health care. In Canada's most populous province, Ontario, there are 142 communities, most of which are rural and/or northern, that are designated to be "under-serviced" with respect to general/family physicians. (17) Furthermore, rural residents are less likely than those living in urban centres to use other types of health services, such as advice nurses who staff telephone hotlines (18, 19).

HIV/AIDS in Rural Areas

To date, there has been very limited study of HIV/AIDS issues in rural areas of Canada and the presence of the disease in these areas remains largely invisible. In contrast, in the United States, the high burden of HIV/AIDS in the rural Southeast – particularly amongst African American women (20, 21) and amongst migrant farm workers (22) has garnered more attention. As a result, this review of the literature relies heavily on American data.

Migration to rural areas is an important factor in the rural HIV/AIDS epidemic. In Canada, the high mobility of Aboriginal persons between inner cities and rural areas increase the risk of HIV in "even the most remote Aboriginal community" (23). Consultations in Ontario also indicate that early in the epidemic, many PHAs "came home" to rural areas for health reasons. Similar trends were noted early in the epidemic in the rural United States (24-28), particularly among men who have sex with men (25). Currently in the United States, migration to rural areas by PHAs is still common (29), and is particularly noted amongst PHAs with a history of injection drug use (28, 30, 31). However, while they comprise a smaller proportion of the total population of infected individuals in rural communities, some rural-dwelling PHAs in the US report that they were infected locally (27, 28, 30).

Initial consultations in rural communities in Ontario reveal important challenges in responding to HIV/AIDS-related concerns. For instance, community representatives highlight both the invisibility and stigma associated with HIV/AIDS. Similarly, American researchers report high levels of stigma experienced by PHAs in rural areas (32-37), with some studies suggesting that this is a more significant problem in rural than in urban areas (33, 35, 36). Conservatism in some rural communities in both Canada and the United States isolates people with HIV (38, 39) and at-risk populations, such as gay men (40-42) and injection drug users. HIV-related stigma has been associated with personal stress (32) and heightened fear that others will learn about PHAs HIV status (36). Stigma also affects parental caregivers of adult children in rural areas (43, 44).

Consultations leading up to the present study also revealed that confidentiality is a major concern for PHAs in rural Ontario, especially in small communities where it is difficult for PHAs to obtain confidential services. American research also suggests that tightly woven social networks (45) and familiarity with health and service personnel make it difficult for rural-based PHAs to use local services (45-47). In order to avoid these problems, rural women may travel elsewhere for services, or not seek services at all (45).

Community consultations also suggest that members of rural communities in Ontario may deny that HIV/AIDS is a local issue. A number of American studies reveal significant risk behaviour in rural areas, suggesting that this denial may result in people putting themselves at risk for HIV infection. For instance, several studies of rural women in the US found that many did not perceive themselves to be at risk for HIV (48-50), and did not use condoms (48, 50-52).

At the same time, high rates of concurrent sexual partnerships have been documented in rural communities in the Southern US (53). High rates of risky sexual behaviour have also been documented among rural-dwelling HIV-positive men and women in the US (54). Injection drug use is also a problem in rural areas. In the US, injection drug use has been found to be a significant contributor to HIV in rural areas (31, 55, 56).

Ready access to anonymous HIV testing is particularly important to people living in rural areas. In Ontario, however, most small communities do not provide anonymous testing. Because young people and those with low income may have little opportunity to travel to anonymous testing sites in larger cities, they may not be tested for HIV despite known risks, such as co-infection with other sexually transmitted infections. In the United States, rural residence has been significantly negatively associated with HIV testing (57) and, in one study it was reported that 21% of rural PHAs who participated in a survey traveled from rural areas to urban areas for their initial diagnosis of HIV (29), suggesting that rural residents may travel elsewhere for HIV testing when they do seek it.

Access to HIV/AIDS information may also be limited in rural areas. In Canada, significant barriers to information include lack of access to a health care provider and reluctance on the part of rural residents to use local AIDS Service Organization (ASO) services (3). As a result, there may be few local routes to HIV/AIDS information (3) for rural-dwellers. Furthermore, proportionately fewer people who live in rural areas have Internet access at home and public Internet access sites located in settings such as small public libraries seldom afford the privacy necessary when community members are in search of sensitive health information.

Lack of locally-accessible information can also affect health care providers. For instance, in rural settings, physicians may have so few PHA patients that their knowledge of HIV treatment is limited. A number of American studies suggest that rural physicians may lack HIV training or experience (33, 35, 45), notably in care for rural women PHAs (47). There may also be limited uptake of universal HIV screening of pregnant women among rural physicians (58). Physicians from rural areas in the U.S. identify challenges in providing care for PHAs, such as having low HIV patient loads and a lack of specialty back-up support (59), as well as a lack of knowledge about when to refer HIV/AIDS cases to specialists (59).

Rural-dwelling PHAs may have to travel to urban centers for specialty medical care. , According to one American study, almost three-quarters of rural PHAs received their care in urban areas (60). As a result, rural PHAs had substantially longer travel times for health care than their urban counterparts (60). In one study, the average time it took rural PHAs to travel for health care was nearly 2 hours. The distance to obtain care may result in delays in obtaining services. In one American study, more than 25% of rural PHAs had delayed obtaining care in the past 6 months because they did not have a way to get to their care provider (60). Indeed, the requirement to travel for treatment may pose such great challenges that PHAs may be forced relocate to urban areas (61).

Having to travel for health services can be a considerable barrier to care for individuals without access to transportation (47). For instance, an American study suggests that as many as one-third of PHAs living in rural areas do not have access to personal or public transportation (62). . This can be a particular issue for rural women who might rely on others for transportation, particularly if they have an abusive partner (25).

Living with HIV in rural areas can also be an isolating experience. Compared with urban residents, rural PHAs report a significantly lower satisfaction with life, lower perceptions of social support from family members and friends and higher levels of loneliness (36). Social isolation has been associated with perceptions of poor perceived health status amongst rural PHAs (63).

Understanding Information Seeking

Understanding how people look for information is crucial to delivering relevant health and social services, yet this process is rarely understood in the design of these services. Research in the field of library and information science

yields some useful insights in this regard. For instance, it is well-documented that: (1) information needs arise from personal contexts; (2) information seekers rely on sources that are readily accessible (often regardless of quality), especially interpersonal sources; and (3) information seekers expect emotional support to be wrapped into the delivery of information, regardless of the type of problem for which help is sought. (64) Common barriers or obstacles to successful information searches have also been identified. For instance, the information necessary to resolve a problem may not exist. Those in search of help may be unsure about what information is needed to solve a problem or they may not know where to locate the information they need. They may also be unaware that information relevant to the problem actually exists. Literacy and language barriers pose additional barriers, especially when information relevant to the searcher's problem is particularly complex or technical in nature. (64) When it comes to facilitating information seeking, there are two critical factors: (1) there must be a common understanding between the information-seeker and provider about the problem situation and the type of information being sought and (2) 'helpers' must be perceived by the information-seeker to be concerned, respectful and supportive (64).

Many of these general observations about information searching are relevant to the experience of PHAs. For instance, it has been reported that PHAs prefer personalized treatment information relevant to their particular circumstances (6) and that patients, including PHAs, prefer to receive health information from someone with whom they have a personal relationship, particularly their physician. (3, 65-69) PHAs also regard their peers as an important source of treatment information (6) and express a desire for emotional and spiritual support when making decisions about the course of their treatment. (3) With respect to obstacles that interfere with successful information searches, PHAs and staff members in community-based AIDS organizations may be unaware of many of the sources of information that are available or may be concerned about bias on the part of some sources of information, especially drug companies (3). PHAs have also expressed a desire for help in understanding what they should know in order to make treatment decisions (3). Some PHAs may find it difficult to obtain treatment information in an accessible format or an appropriate literacy level. (3) Additionally, PHAs, workers in AIDS service organizations, and health care providers may experience significant problems with information overload (3, 4, 6) resulting in concerns about whether the best or most current sources are being used or if all information relevant to a particular concern has been located.

As well as information that is purposefully sought to cope with challenging situations, information acquired on an incidental basis, through conversation, reading or media exposure, can play a significant role in decision-making. (70, 71) In addition, the "passive" monitoring of everyday life helps to orient us to our environments and keeps our mental models of the world around us up to date. For PHAs, informal learning and peer observation in day-to-day living are important avenues for obtaining HIV/AIDS treatment information (6). This process, which takes place through extended networks of PHAs, friends, and AIDS Service Organizations, may occur through conversation, word-of-mouth, or observing the physical appearance of other PHAs (72).

Given the importance of context, whether for the active search of information, or the passive absorbing of information that might, at some time, be relevant, it seems likely that living in a rural community has a considerable impact on the information worlds of PHAs. If communities are silent, conservative and/or possess limited or incorrect information about issues related to HIV/AIDS, PHAs and their caregivers will be affected both in the active search for information and in the passive acquisition of information that might, at some time be relevant.

Research conducted in minority communities reveals a significant role for gatekeepers who act as community links and filters for information gathering and dissemination. (73-75) In Canada, HIV/AIDS treatment information is exchanged by diverse individuals and groups, including AIDS Service Organizations, PHAs and their networks, physicians, nurses and other health care providers, HIV clinics, community health centers, informal caregivers, support workers and volunteers. (3, 4, 6) The degree of access PHAs have to these sources is likely a strong determinant of their level of access to HIV/AIDS treatment information. It has also been reported that, in some

communities, volunteer treatment information experts, often PHAs themselves, are an important source of treatment information for other PHAs (3). These volunteers are critical to AIDS Service Organizations in Canada (3) but little is known about how such gatekeepers operate in rural areas.

To understand more about how information exchange systems work in rural communities, social network analysis provides an excellent framework (76-81). For instance, Haythornwaite argues that social networks can either facilitate or constrain information exchange by affecting who actors can make contact with, what information their contacts can provide, and the contacts that the actor has to whom they can forward information (80). Positions in a social network reveal who controls, inhibits or facilitates information flow, and who has similar needs and uses. Network structures can expose how information flows through the whole environment (80). This approach is a promising way of studying HIV/AIDS information exchange in communities.

Rural HIV/AIDS Information Networks Study

In order to increase understanding of HIV/AIDS in rural Canada, the Rural HIV/AIDS Information Networks study received funding from the Canadian Institutes for Health Research's HIV/AIDS Community Based Research program. This funding supports a two-year study of HIV/AIDS information exchange in three rural areas of Canada, including Ontario. Interviews began in Summer 2005, and will continue until Spring 2006. This research is guided by the following questions.

Research Questions

1. How do rural-dwelling people with HIV/AIDS (PHAs) and their caregivers locate and use HIV/AIDS information?
2. What networks exist in rural communities for HIV/AIDS information exchange and how do they work?
3. What features of these information networks enhance or inhibit access to useful HIV/AIDS information?
4. What strengths and barriers exist in rural communities with respect to HIV/AIDS information exchange?
5. How can information technology (IT) be used to support HIV/AIDS information exchange in rural areas?
6. What is the impact of IT on social isolation experienced by rural-dwelling PHAs and their caregivers?

Methodology

The Ontario portion of this study will be centered in two sparsely populated, rural, agricultural counties in Ontario, Canada. The overall study will take place in two phases. The phases of the project are as follows:

Phase One. Interviews with PHAs and caregivers: 35-50 individual, in-depth, semi-structured interviews will be conducted with members of rural communities in Ontario. Participants will be recruited through health and social services, and using snowball methods. Particular efforts will be made to recruit women participants. Interviews are expected to last from 1-3 hours. Interviewees will include: PHAs, their friends and family members, health care providers, as well as staff and volunteers in community agencies. Interviews will address: people's experiences with HIV/AIDS, how they locate and use HIV/AIDS information, networks for HIV/AIDS information exchange, and how information technology affects exchange of HIV/AIDS information and interviewees' sense of social isolation. Interviews will be audio-taped (with permission) and the tapes will be transcribed to facilitate analysis.

Phase Two. Population survey: A telephone survey will be conducted with a representative, random sample drawn from the wider population. Questions posed in the survey will assess general knowledge about HIV/AIDS, its causes and treatment, specific knowledge about the presence of HIV/AIDS in the local community, and awareness of sources of help and support available in the community. The goal of the survey is to identify community strengths and assets, as well as barriers to HIV/AIDS information exchange and support. These data will provide a community context for the analysis of interview data from Phase One.

Of particular interest in the analysis of data from the two phases of the study will be common themes that emerge about the experience of living with HIV/AIDS in rural areas, women's roles in information exchange, the role of communities in facilitating HIV/AIDS information exchange, and the role or potential role of information technology. The findings will provide a base from which to pursue further investigations of approaches to building community capacity, especially through e-health, library or IT-based strategies.

Preliminary Results

To date, three interviews have been conducted with rural women as a part of this study, including two service providers and one PHA. The service providers who were interviewed explained that the HIV/AIDS landscape in the community was challenging; one described it as "very low key". As she states it, "people are not really too worried about it because they don't think it's a threat here". Another service provider identified that from the vantage point of a rural AIDS-service organization (ASO), they struggle with communication issues, geographical isolation and confidentiality issues. All of these issues act as barriers to connecting with the HIV community. In contrast, a rural woman PHA who has chosen to be public about her diagnosis identified considerable support within the community:

"Actually, the community came to [me], and they were truly amazing. There were a few boneheads around, but [I] found out after the fact about a lot of it, because people would say something, and then somebody in the community would challenge it...and they would take the initiative to get the information to those people...these weren't necessarily even friends that were doing this...they were just people that knew [me]..."

However, in another region, a service provider noted that loneliness and isolation were pronounced among rural PHA clients who are unlikely to attend local support groups for fear of loss of confidentiality.

Consistent with what has been reported in other studies of women's roles in health information exchange, the rural women interviewed to date in this study have acted as intermediaries for HIV/AIDS information in their communities. One woman PHA speaks regularly about HIV/AIDS in schools, service clubs, religious organizations and other groups in the area. She has also made many referrals to other PHAs in the area and provides emotional support for newly diagnosed individuals. One of the service providers interviewed provides information about disease transmission, as well as treatment information. She also assists clients to understand their lab results, and provides legal information, as well as referrals to mental health, health care, palliative care, and a range of other services. In addition, she provides her clients with publications from AIDS Service Organizations. Another service provider provides referrals to support and health care services for newly diagnosed PHAs and educates clients about various testing options.

In their intermediary roles, the study participants rely extensively on information sources that are not located in their own communities. Service providers are linked to networks of similar providers, including those outside of the region. They rely on known individuals in these professional networks when they had questions about HIV/AIDS, and use print resources provided by the networks when they are available. In addition, specialist medical care in a nearby urban area was a very popular information source for medical information, or, in the case of a rural PHA participant, for personalized treatment information. Provincial and national HIV/AIDS information providers were also mentioned frequently as sources of information for various matters including treatment, prevention and psychosocial issues. Services providers mentioned using the Internet, but most relied on known sources of information in order to manage concerns about information quality.

For some issues, such as mental health and support services, local resources were perceived as adequate and were used as needed. And, where needed, local referrals were easy to provide, "because we're small, we really do know what exists in this community and what doesn't, so it's not like we have to struggle to find out whether a

service is available or not". However, one provider remarked that she does not refer to local general practitioners (GPs), as she is not aware of HIV-knowledgeable GPs in the region.

Conclusion

HIV/AIDS in rural Canada remains a largely unstudied phenomenon. Little is known about the role of rural communities in Canada in limiting, or enabling access to HIV/AIDS information. In particular, the dynamics of health information seeking in rural settings are not well understood nor do we have much information about the role of the community environment in facilitating incidental information acquisition. Findings from this study should therefore prove useful to other rural regions in Canada, and to other developed countries, such as Australia and the United States.

Although social network analysis has proven to be a fruitful strategy for study of information exchange and of HIV/AIDS issues, little is known about the role of social networks in facilitating or enhancing access to HIV/AIDS information. As such, our findings should yield some useful insights into the dynamics of community-based health information exchange in general, and HIV/AIDS information exchange in particular.

To a large extent, decision-making about preventing, managing or treating HIV/AIDS is social in nature, that is, it is influenced by people's relationships, such as those with health care and other service providers, peers, friends and family members, and by the information that is exchanged in these relationships. Information is also shared and used in a community context. Since specific challenges face rural communities, such as geographic isolation, lack of services and lack of anonymity, understanding this social context may suggest a rethinking of some of the ways that HIV/AIDS information provision has been approached in the past. Of interest will be consideration of the roles that rural women can play in HIV/AIDS information provision in rural communities. Initial research results show that rural women act as intermediaries for HIV/AIDS information in their communities, accessing resources from outside of the community in order to do this.

The results of the study will be discussed with respect to the roles that libraries could play in facilitating HIV/AIDS information exchange, particularly with respect to IT and other potential intermediary functions that would improve the capacity of rural communities, especially to women intermediaries who may be informational 'hubs' in local community network, to improve support to PHAs and their caregivers. Enabling community HIV/AIDS information exchange will be important in mobilizing effective responses to the HIV/AIDS epidemic

Acknowledgements

Funding for this study has been provided by the Canadian Institutes for Health Research under the Federal Initiative to address HIV/AIDS in Canada.

We gratefully acknowledge funding from the Research Chair in Rural Women's Health, The University of Western Ontario for travel funds to support this presentation.

References

1. Hackl KL, Somlai AM, Kelly JA. Women living with HIV/AIDS: the dual challenge of being a patient and caregiver. *Health & Social Work* 1997;22:53-62.
2. Stein MD, Crystal S, Cunningham WE. Delays in seeking HIV care due to competing caregiver responsibilities. *Am J Public Health* 2000;90 (7):1138-40.
3. Health Canada. National HIV/AIDS Treatment Information Environmental Scan. Ottawa: Health Canada; 2000.

4. Canadian AIDS Treatment Information Exchange. *Many Voices: Report on Stakeholder Consultations*. Toronto: Canadian AIDS Treatment Information Exchange; 2003.
5. Huber JT, Cruz JM. Information needs and information-seeking behaviors of HIV positive men and women. *Med Ref Serv Q* 2000;19 (3):39-48.
6. Taylor D. Synthesizing information about HIV/AIDS and its treatment. In: Group MCVW, editor. *Making care visible: antiretroviral therapy and the health work of people living with HIV/AIDS*. Toronto: Making Care Visible Working Group; 2002. p. 105-121.
7. Coleman LM, Ford NJ. An extensive literature review of the evaluation of HIV prevention programmes. *Health Educ Res* 1996;11 (3):327-38.
8. Johnson BT, Carey MP, Marsh KL, Levin KD, Scott-Sheldon LA. Interventions to reduce sexual risk for the human immunodeficiency virus in adolescents, 1985-2000: a research synthesis. *Arch Pediatr Adolesc Med* 2003;157 (4):381-8.
9. Health Canada. *HIV and AIDS in Canada: Surveillance Report to December 31, 2004 [April 2005]*. In. Ottawa: Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control, Health Canada; 2004.
10. Mocroft A, Vella S, Benfield T. Changing patterns of mortality across Europe in patients infected with HIV-1. EuroSIDA Study Group. *Lancet* 1998;352 (9142):1725-30.
11. Palella FJ, Delaney K, Moorman A. Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. HIV Outpatient Study Investigators. *N Engl J Med* 1998;338 (13):853-60.
12. Vittinghoff E, Scheer S, O'Malley P. Combination antiretroviral therapy and recent declines in AIDS incidence and mortality. *J Infect Dis* 1999;179 (3):717-20.
13. Schanzer D. HIV/AIDS mortality in trends in Canada, 1987-1998. *Can J Public Health* 2003;94 (2):135-9.
14. Canadian AIDS Treatment Information Exchange. *Strategic Plan*. Toronto: CATIE; 2003.
15. Public Health Agency of Canada. *Estimates of HIV Prevalence and Incidence in Canada, 2002*. *CCDR* 2003;29 (23).
16. Sutherns R, McPhedran M, Haworth-Brockman M. *Rural, Remote and Northern Women's Health: Policy and Research Directions. Final Summary Report*. In. Winnipeg: Centres of Excellence for Women's Health; 2004.
17. Ontario Ministry of Health and Long-Term Care. *List of Areas Designated as Underserved for General/Family Practitioners: October/November/December 2004*. In. Sudbury, ON: Ontario Ministry of Health and Long-Term Care; 2004.
18. Hibbard JH, Greenlick M, Jimison H, Kunkel L, Tusler M. Prevalence and predictors of the use of self-care resources. *Eval Health Prof* 1999;22:107-122.
19. Wagner TH, Hibbard JH. Who uses self-care books, advice nurses, and computers for health information? *Int J Technol Assess Health Care* 2001;17:590-600.
20. Holmes R, Fawal H, Moon TD, Cheeks J, Coleman J, Woernle C, et al. Acquired immunodeficiency syndrome in Alabama: Special concerns for black women. *Southern Medical Journal* 1997;90 (7):697-701.
21. Wasser SC, Gwinn M, Fleming P. Urban-nonurban distribution of HIV infection in childbearing women in the United States. *JAIDS* 1993;6 (9):1035-1042.
22. Fitzgerald K, Chakraborty J, Shah T, Khuder S, Duggan J. HIV/AIDS Knowledge Among Female Migrant Farm Workers in the Midwest. *Journal of Immigrant Health* 2003;5 (1):29-36.
23. Public Health Agency of Canada. *HIV/AIDS Among Aboriginal Persons in Canada: A Continuing Concern*. In. Ottawa, ON: Public Health Agency of Canada; 2003.
24. Davis K, Stapleton J. Migration to rural areas by HIV patients: impact on HIV-related healthcare use. *Infection Control & Hospital Epidemiology* 1991;12 (9):540-543.
25. Castaneda D. HIV/AIDS-related services for women and the rural community context. *AIDS Care* 2000;12 (5):549.
26. Davis K, Ferguson K, Stapleton J. Moving home to live: migration of HIV-infected persons to rural states. *JANAC* 1992;3 (4):42-7.
27. Rumley RL, Shappley NC, Waivers LE, Esinhart JD. AIDS in rural eastern North Carolina--patient migration: a rural AIDS burden. *AIDS* 1991;5 (11):1373-1378.
28. Cohn SE, Klein JD, Mohr JE, van der Horst CM, Weber DJ. The geography of AIDS: patterns of urban and rural migration. *Southern medical journal* 1994;87 (6):599-606.
29. Mainous AG, 3rd, Matheny SC. Rural human immunodeficiency virus health service provision. Indications of rural-urban travel for care.[see comment]. *Arch Fam Med* 1996;5 (8):469-473.
30. Lansky A, Nakashima AK, Diaz T, Fann SA, Conti L, Herr M, et al. Human immunodeficiency virus infection in rural areas and small cities of the Southeast: Contributions of migration and behavior. *Journal of Rural Health* 2000;16 (1):20-30.
31. Grace C, Richardson-Nassif K, Rolley L-A. Injection drug use (IDU) related human immunodeficiency virus infection in rural Vermont: a comparison with non-IDU related infections. *Drugs & Society* 2000;16 (1/2):223-35.

32. Heckman TG, Miller J, Kochman A, Kalichman SC, Carlson B, Silverthorn M. Thoughts of suicide among HIV-infected rural persons enrolled in a telephone-delivered mental health intervention. *Annals of Behavioral Medicine* 2002;24 (2):141-148.
33. Reif S, Golin CE, Smith SR. Barriers to accessing HIV/AIDS care in North Carolina: Rural and urban differences. *AIDS Care* 2005;17 (5):558-565.
34. Sowell RL, Lowenstein A, Moneyham L, Demi A, Mizuno Y, Seals BF. Resources, stigma, and patterns of disclosure in rural women with HIV infection. *Public Health Nursing* 1997;14 (5):302-312.
35. Heckman TG, Somlai AM, Peters J, Walker J, Otto-Salaj L, Galdabini CA, et al. Barriers to Care among Persons Living with HIV/AIDS in Urban and Rural Areas. *AIDS Care* 1998;10 (3):365-375.
36. Heckman T, Somlai A, Kalichman S, Franzoi S, Kelly J. Psychosocial differences between urban and rural people living with HIV/AIDS. *J Rural Health* 1998;14 (2):138-45.
37. Black BP, Miles MS. Calculating the risks and benefits of disclosure in African American women who have HIV. *JOGNN* 2002;31 (6):688-697.
38. Carwein VL, Sabo CE, Berry DE. HIV infection in traditional rural communities. *Nursing Clinics of North America* 1993;28 (1):231-239.
39. Yoder RE, Preston DB, Forti EM. Rural school nurses' attitudes about AIDS and homosexuality. *Journal of School Health* 1997;67 (8):341-347.
40. Marchand R. Gay Men Building Local Knowledge: CBR in HIV prevention and health promotion. In. Vancouver: Community Based Research Centre; 2001.
41. Williams M, AM B, Horvath K. The social/sexual environment of gay men residing in a rural frontier state: implications for the development of HIV prevention programs. *J Rural Health* 2005;21 (1):48-55.
42. Ullrich PM, Lutgendorf SK, Stapleton JT. Social constraints and depression in HIV infection: Effects of sexual orientation and area of residence. *Journal of Social and Clinical Psychology* 2002;21 (1):46-66.
43. McGinn F. The plight of rural parents caring for adult children with HIV. *Families in Society-the Journal of Contemporary Human Services* 1996;77 (5):269-278.
44. Boyle JS, Ferrell JA, Hodnicki DR. Patterns of resistance: African American mothers and adult children with HIV illness. *Scholarly Inquiry for Nursing Practice* 1999;13 (2):135-9.
45. Ingram Fogel C, Belyea M. The Lives of Incarcerated Women: Violence, Substance Abuse, and at Risk for HIV. *JANAC* 1999;10 (6):66.
46. McKinney MM. Variations in rural AIDS epidemiology and service delivery models in the United States. *Journal of Rural Health* 2002;18 (3):455-466.
47. McKinney MM. Service needs and networks of rural women with HIV/AIDS. *AIDS Patient Care and S T Ds* 1998;12 (6):471-80.
48. Crosby RA, Yarber WL, DiClemente RJ. HIV-associated histories, perceptions, and practices among low-income African American women: does rural residence matter? *Am J Public Health* 2002;92 (4):655-9.
49. Winningham A, Richter D, Corwin S, Gore-Felton C. Perceptions of Vulnerability to HIV among Older African American Women: The Role of Intimate Partners. *Journal of HIV/AIDS & Social Services* 2004;3 (1):25-42.
50. Winningham A, Corwin S, Moore C, Richter D, Sargent R, Gore-Felton C. The changing age of HIV: Sexual risk among older African American women living in rural communities. *Preventive Medicine: An International Journal Devoted to Practice & Theory* 2004;39 (4):809-814.
51. Thomas JC, Lansky A, Weiner DH, Earp JA, Schoenbach VS. Behaviors that facilitate sexual transmission of HIV and STDs in a rural community. *AIDS & Behavior* 1999;3 (4):257-267.
52. Crosby RA, Yarber WL, Meyerson B. Frequency and predictors of condom use and reasons for not using condoms among low-income women. *Journal of Sex Education & Therapy.Special Researching HIV/STD risk behavior: Implications for prevention* 1999;24 (1-2):63-70.
53. Adimora AA, Schoenbach VJ, Martinson F, Donaldson KH, Stancil TR, Fullilove RE. Concurrent sexual partnerships among African Americans in the rural south. *Annals of Epidemiology* 2004;14 (3):155-160.
54. Heckman TG, Silverthorn M, Waltje A, Meyers M, Yarber W. HIV transmission risk practices in rural persons living with HIV disease. *Sexually Transmitted Diseases* 2003;30 (2):134-136.
55. Graham RP, Forrester ML, Wysong JA, Rosenthal TC, James PA. HIV/AIDS in the Rural United States: Epidemiology and Health Services Delivery. *Medical Care Research And Review* 1995;52 (4):435-452.
56. Berry DE. The emerging epidemiology of rural AIDS. [Review] [37 refs]. *Journal of Rural Health* 1993;9 (4):293-304.
57. Mainous AG, 3rd, Neill RA, Matheny SC. Frequency of human immunodeficiency virus testing among rural US residents and why it is done. *Arch Fam Med* 1995;4 (1):41-45.

58. Duggan J, Khuder S, Sinha N, Chakraborty J. Survey of physician attitudes toward HIV testing in pregnant women in Ohio. *AIDS Patient Care & STDs* 2003;17 (3):121-127.
59. Samuels ME, Shi L, Stoskopf CH, Richter DL, Baker SL, Sy FS. Rural physicians: a survey analysis of HIV/AIDS patient management. *AIDS Patient Care* 1995;9 (6):281-289.
60. Schur C, Berk M, Dunbar J, Shapiro M, Cohn S, Bozzette S. Where to seek care: an examination of people in rural areas with HIV/AIDS. *J Rural Health* 2002;18 (2):337-47.
61. Van Cleef V. Listen Up! Women are talking about... Women's Health Research Project Report on Phases 3 and 4. In: Vancouver: Positive Women's Network; 2003.
62. Heckman TG, Somlai AM, Otto-Salai L. Rural persons living with HIV/AIDS: reducing barriers and improving quality of life. *AIDS Patient Care & STDs* 1996;10 (1):37-43.
63. Stewart KE, Cianfrini LR, Walker JF. Stress, social support and housing are related to health status among HIV-positive persons in the Deep South of the United States. *AIDS Care* 2005;17 (3):350-358.
64. Harris RM, Dewdney P. Barriers To Information: How Formal Help Systems Fail Battered Women. Westport, Conn.: Greenwood Press; 1994.
65. Decter MB. Four strong winds: understanding the growing challenges to health care. Toronto: Stoddart; 2000.
66. Raynor DK, Savage I, Knapp P, Henley J. We are the experts: people with asthma talk about their medicine information needs. *Patient Educ Couns* 2004;53 (2):167-74.
67. Raupach JC, Hiller JE. Information and support for women following the primary treatment of breast cancer. *Health Expect* 2002;5 (4):289-301.
68. Chen X, Siu LL. Impact of the Media and the Internet on Oncology: Survey of Cancer Patients and Oncologists in Canada. *J Clin Oncol* 2001;19 (23):4291-4297.
69. Silliman RA, Dukes KA, Sullivan LM, Kaplan SH. Breast cancer care in older women: sources of information, social support, and emotional health outcomes. *Cancer* 1998;83 (4):706-11.
70. Williamson K. Discovered by chance: The role of incidental information acquisition in an ecological model of information use. *LISR* 1998;20 (1):23-40.
71. Ross CS. Finding without seeking: the information encounter in the context of reading for pleasure. *Information Processing & Management* 1999;35:783-799.
72. Bresalier M, Gillis L, McClure C, McCoy L, Mykhalovskiy E, Taylor D, et al. Making Care Visible: Antiretroviral Therapy and the Health Work of People living with HIV/AIDS. Toronto: Making Care Visible Work Group; 2002.
73. Metoyer-Duran C. Information gatekeepers. In: *Annual Review of Information Science and Technology (ARIST)*. Medford, NJ: Learned Information Inc.; 1993. p. 111-150.
74. Metoyer-Duran C. The information and referral process in culturally diverse communities. *RQ* 1993;32:359-371.
75. Agada J. Inner-city gatekeepers: An exploratory survey of their information use environment. *JASIS* 1999;50:74-85.
76. Degenne A, Forsé M. *Introducing Social Networks*. London: Sage; 1999.
77. Wasserman S, Faust K. *Social Network Analysis: Methods and Applications*. Cambridge: Cambridge University Press; 1994.
78. Scott J. *Social Network Analysis: A Handbook*. London: Sage; 1991.
79. Moontz M. Attitudes towards health in social networks of chronic patients. In: Knipscheer KCPM, Antonucci TC, editors. *Social Network Research: Substantive Issues and Methodological Questions*. Amsterdam: Swets and Zeitlinger; 1990. p. 41-53.
80. Haythornwaite C. Social network analysis: an approach and technique for the study of information exchange. *LISR* 1996;18:323-342.
81. Otte E. Social network analysis: a powerful strategy, also for the information sciences. *Journal of Information Science* 2002;28 (6):441-453.