

Social Supports, Informal Caregiving and HIV/AIDS: A Community-Based Study

December 2011



Javier Mignone, (University of Manitoba)
Carla Pindera (Nine Circles Community Health Centre)
Jennifer Davis (Nine Circles Community Health Centre)
Paula Migliardi (Nine Circles Community Health Centre)
Carol Harvey (University of Manitoba)
Melissa Bendig (Regina)
Kim McKay-McNabb (First Nations University of Canada)
Lawrence Elliot (University of Manitoba)

Final Report

This project was carried out in partnership between the Department of Family Social Sciences at the University of Manitoba, Nine Circles Community Health Centre in Winnipeg, Manitoba, the AIDS Programs South Saskatchewan, the All Nations Hope AIDS network in Regina, and the First Nations University of Canada, in Regina.

Research Team Members

- Carla Pindera, co-principal investigator (Nine Circles Community Health Centre).
- Javier Mignone, co-principal investigator (Department of Family Social Sciences, University of Manitoba)

Winnipeg Research Team Members

- Jennifer Davis (Nine Circles Community Health Centre)
- Paula Migliardi (Prairie HIV Community-Based Research Program, Nine Circles Community Health Centre)
- Carol Harvey (Department of Family Social Sciences, University of Manitoba)
- Lawrence Elliot (Department of Community Health Sciences, University of Manitoba).

Regina Research Team Members

- Kim McKay-McNabb (First Nations University of Canada)
- Chris Smith (All Nations Hope AIDS Network, Regina)
- Melissa Bendig (Research Assistant)

Report Editor

- Lucia Madariaga-Vignudo

The research team is particularly grateful to the project participants for their commitment to this study and for their willingness to share personal aspects of their lives.

***Project funded by the Canadian Institutes of Health Research (CIHR) HIV
Community-Based Research Program***

TABLE OF CONTENTS

Part 1 - Background and Project Goal	5
Part 2 - Literature Review	7
HIV/AIDS: From an Acute to a Chronic Illness	7
Conceptualizing “Social Support” and “Caregivers”	7
Caregivers: Who are they? And who do they care for?	9
Caregiving: Its Positive and Negative Aspects	10
Part 3 - HIV/AIDS: A Demographic Snapshot	12
Part 4 - Research Methodology	16
Photovoice Overview	16
Recruiting Project Participants	17
Information and Training Sessions	19
Individual Interviews with Community Participants	20
Individual Interviews with Formal Caregivers	22
Retaining Community Participants throughout the Study	23
Dilemmas in the Field: Dealing with the Sensitive Nature of the Research	24
Analyzing the Data	25
Part 5 - Profile of Community Participants	26
Part 6 - Findings	30
Caregiving and its Different Interpretations	30
Lack of Sustained Relationships with Friends, Partners & Family Members.....	30
Peer-to-Peer Network of Care	32
Non Human Sources of Support	33
Heavy or Exclusive Reliance on Formal Caregivers, Among PLWHAs	38

Service Providers' Views on their Caregiving Roles.....	40
Formal Caregivers: Occupying an Essential Role in their Clients' Lives	42
Blurred Professional Boundaries.....	42
Developing Professional Boundaries.....	44
Caring for the Caregivers: The Provision of Organizational Support	45
Part 7 - Conclusion and Recommendations	47
Part 8 - To Disseminate is to Act	50
Part 9 - References	52

PART 1

Background and Project Goal

From 1985 to the end of 2009, a total of 69,844 positive HIV test reports were reported in Canada.¹ Currently, the highest proportion of HIV cases is found in Canada's most heavily populated provinces, such as Ontario, Québec and British Columbia. However, statistics indicate that smaller Prairie provinces are being affected as well. In Manitoba the number of new positive HIV cases increased from 75 in 2007 to 105 in 2009.² In the neighbouring province of Saskatchewan, new confirmed cases rose from 124 in 2007 to 195 in 2009.³ Moreover, as of 2010, Saskatchewan had the highest HIV/AIDS rate in Canada, with 20.8 cases per 100,000 people, compared to the national average of 9.3 per 100,000 people.⁴

Certain groups such as Aboriginal Peoples, Black Canadians and injection drug users are at high risk of HIV infection.⁵ The virus disproportionately affects poor and stigmatized communities, placing great emotional and material strains on those living with HIV/AIDS and the people who care for them. The role and extent to which social support and informal care networks influence the lives of people living with HIV/AIDS have been largely unexplored, particularly in medium-sized Canadian cities with significant per capita Aboriginal and immigrant populations. Little data exists on this topic resulting in a significant lack of understanding of the issue.

¹ Public Health Agency of Canada (2010). HIV and AIDS in Canada. Surveillance Report to December 31, 2009. Ottawa 2010. Retrieved from <http://www.phac-aspc.gc.ca/aids-sida/publication/survreport/2009/dec/index-eng.php>

² Ibid

³ Ibid

⁴ Saskatchewan Ministry of health (2010) Saskatchewan's HIV strategy 2010-2014. Retrieved from <http://www.health.gov.sk.ca/hiv-strategy-2010-2014>

⁵ Public Health Agency of Canada, 2010.

The goal of this project was to describe and understand the care experiences (that of receiving and providing care) of persons living with HIV/AIDS (PLWHAs) and their support networks, in the Canadian cities of Winnipeg and Regina. The research team also sought to increase knowledge of the lived experiences related to social support among PLWHAs, with a focus on low income and/or stigmatized communities, such as drug users, homeless persons, newcomer refugees and Aboriginal People.

Through the use of qualitative research methods, such as photographs taken and interpreted by project participants, as well as in depth interviews, the research team sought to answer the following questions:

- ❖ What types of caregiving networks do people living with HIV/AIDS in Winnipeg and Regina rely on?
- ❖ Who belongs to these networks?
- ❖ What are the roles of informal caregivers in the lives of PLWHASs?
- ❖ How do caregiving networks affect the quality of life of both the caregiver and care recipient?



PART 2

Literature Review

HIV/AIDS: From an Acute to a Chronic Illness

An HIV positive diagnosis was once considered fatal, giving a diagnosed person relatively little time to prepare themselves for death. In Canada, persons living with HIV/AIDS (PLWHAs) now have access to effective medications and more information about healthy living with the illness. For the most part, PLWHAs are living longer and healthier lives; this not only affects them, but also the persons who care for them as well. With the advent of new medications, HIV/AIDS is more frequently defined as a chronic illness that often requires vigilant and ongoing home care.⁶ In many aspects, HIV/AIDS caregiving has begun to more closely resemble the protracted time line associated with chronic care of elderly family members.⁷ A major trend in the treatment of PLWHAs has been the shifting of their care away from hospitals or clinics into the home.⁸ In this light, Wrubel and Folkman (1997) argued that the responsibility assigned to informal caregivers such as family members and friends would undoubtedly increase.⁹

Conceptualizing “Social Support” and “Caregivers”

Social support is generally understood intuitively, as the help from other people in a difficult life situation. This concept can also be thought of as the perceived availability of people whom a person trusts and who make one feel cared for and valued as a person. Social support is closely related to the concept of a social network, or the ties to family, friends, neighbours, and others of significance to a person. Evidence suggests that social support can produce health-related benefits^{10 11 12}

⁶ Land, H., and Hudson, S. (2002). HIV serostatus and factors related to mental and physical well-being in Latina family AIDS caregivers. *Social Science and Medicine*, 54 (1): 147–159.

⁷ Wight, R. G. (2000). Precursive depression among HIV infected AIDS caregivers over time. *Social Science and Medicine*, 51(5): 759–770.

⁸ Wrubel J, and Folkman, S. (1997). What informal caregivers actually do: The caregiving skills of partners of men with AIDS, *AIDS CARE* 9(6): 691-706.

⁹ Ibid

¹⁰ Leserman, K., Perkins DO, and Evans DL. (1992). Coping with the threat of AIDS: the role of social support. *American Journal of Psychiatry*, 149(11): 1514-1520.

¹¹ Friedland, J., Renwick, R. and McColl, M. (1996). Coping and social supports as determinants of quality of life in HIV/AIDS. *AIDS Care*, 8(1): 15-31.

Caregivers can be great sources of social support. Within the context of this particular study, a caregiver is a person who acts as a primary and/or significant provider of care to a PLWHA. A caregiver may or may not be a PLWHA. Care towards PLWHAs can include, but may not be limited to assistance in the emotional, social, physical and spiritual realms. Care can consist of social support, food preparation and hands-on care, such as helping the partner move, preparing comfortable beds with cushions and pillows. Caregivers can also spend significant amount of time advocating on behalf of PLWHAs, in hospitals and other administrative offices. The diagram below offers further examples of informal caregiving tasks.



Much of the literature on caregiving focuses on the tasks of caregivers, such as personal care or domestic work. However, focusing only on the tasks that caregivers perform does not take into account the *context of the illness*, including the *nature of the relationship* between the caregiver and care recipient.¹³ Factors, such as the clinical course of the illness and the income and lifestyles of the PLWHAs are often neglected.

¹² Gonzales JS, et al. (2004). Social support, positive states of mind, and HIV treatment adherence in men and women living with HIV/AIDS. *Health Psychology* 23 (4):413-418.

¹³ Wrubel and Folkman, 1997.

Existing literature defines informal caregivers as persons who voluntarily provide assistance during an illness.¹⁴ Informal care towards affected persons can be provided by a friend, a neighbour, a family member or a partner, for example. The caregiver is considered informal because the relationship between the caregiver and the person in care is not established or regulated by any organization or employer. Likewise, the parameters for the care relationship may change regularly and indefinitely. In contrast to informal caregiving, formal caregiving is more official in nature. Formal caregivers may be employees or volunteers in organizations that serve PLWHAs; or, they may be employed directly by PLWHAs and/or their family members and friends.

Caregivers: Who are they? And who do they care for?

Research on informal caregiving has tended to focus on self-selected, middle class caregivers of elderly recipients who are not HIV/AIDS positive. Very few studies have examined informal caregiving among low income persons with HIV/AIDS for whom supportive ties may be limited or dysfunctional. Data suggest that, in some circumstances, informal caregivers come from the same ethnic, cultural and socioeconomic milieu as the PLWHAs whom they offer care for. In 2003, for example, a study found that among a group of low-income African American PLWHAs and their caregivers, there was no significant difference in regard to race, educational and income levels, or hospitalization rates.¹⁵ This suggests that persons who belong to stigmatized communities and are affected by HIV/AIDS may be heavily reliant on similarly disadvantaged persons.

In general, women (e.g., mothers, sisters, aunts, girlfriends) are more likely than men to be the primary caregivers to PLWHAs, and to commit themselves to the very end.^{16 17} Although there seems to be agreement that caregivers of PLWHAs are predominantly women, such data apply primarily to heterosexual PLWHAs who do not use intravenous drugs. Differences in the lifestyles of low income persons from stigmatized communities may affect the availability of informal care when confronted with HIV/AIDS. Persons

¹⁴ For example, see: Knowlton AR, et al. (2011). Informal care and reciprocity of support are associated with HAART adherence among men in Baltimore, MD, USA. *AIDS Behaviour*, 15(7):1429-36.

¹⁵ Knowlton, AR. (2003) Informal HIV caregiving in a vulnerable population: toward a network resource framework. *Social Science & Medicine*, 56(6): 1307-1320.

¹⁶ Amaratunga, C., and Gahagan, J. (2002) Striking to the Heart of the Matter - Selected Readings on Gender and HIV. Atlantic Centre of Excellence for Women's Health. Retrieved from http://www.acewh.dal.ca/pdf/Striking_to_the_Heart_of_the_Matter.pdf

¹⁷ Ward D, and Brown, MA (1994) Labour and cost in AIDS family caregiving. *Western Journal of Nursing Research* 16(1): 10-25.

may be reluctant to aid those with stigmatizing conditions who are deemed personally responsible for their conditions. Moreover, a lack of basic resources, such as food and money, as well as prior commitments have been found to contribute to the refusal of family members to provide informal care to PLWHAs.¹⁸

Persons who are poor, depressed or using illicit drugs are not only more likely to be HIV/AIDS positive and in need of support; they also tend to have more conflictive, less consistent sources of support, and less likely to reciprocate support.¹⁹ Family members of PLWHAs can have health problems of their own, thereby sometimes compromising this potential source of care.

Due in part to the stigma associated with drug use and societal gender role expectations, which dissuade men from caregiving, one study found that women with HIV/AIDS who used drugs appeared to be frequently abandoned by lovers and family members. The women's drug and substance abuse histories contributed to their small and/or unsupportive social networks.²⁰ Another study found that women living with HIV/AIDS relied on children and friends for support more than men did. This same study found that male injection drug users and gay men relied on friends and traditional family almost equally for support.²¹

Caregiving: Its Positive and Negative Aspects

In order for effective caregiving to occur, there must be an element of trust, acceptance and communication between the caregiver and the person requiring care. When these are present, caregiving support can be very beneficial to PLWHAs. Research suggests that social support is a positive predictor of returning for HIV test results.²² Moreover, a strong caregiving network has been found to help PLWHAs adhere to a medication regime,^{23 24} and to reduce depressive symptoms.²⁵ Caregiving can also play a key role in

¹⁸ Knowlton, 2003.

¹⁹ As cited in Knowlton et al., 2011

²⁰ Ciambone, D. (2002) Informal networks among women with HIV/AIDS: present support and future prospects. *Qualitative Health Research* 12(7): 876-896.

²¹ Smith, M and B Rapkin (1996)."Social Support and Barriers to family involvement in caregiving for persons with AIDS: implications for patient education." *Patient Education and Counselling* 27(1): 85-94.

²² Stein, J. A. and A Nyamathi (2000) Gender differences in behavioural and psychosocial predictors of HIV testing and return for test results in a high-risk population. *AIDS Care* 12(3): 343-56.

²³ Catz, SL, Kelley J, Bogart L, Benotsch E, McAuliffe T (2000). Patterns, Correlates, and Barriers to Medication Adherence Among Persons Prescribed New Treatments for HIV Disease. *Health Psychology* 19(2): 124-33.

²⁴ Knowlton et al., 2011

helping PLWHAs to find meaning in their lives, gain a sense of control and restore self-esteem.²⁶ As mentioned earlier on in this report, HIV/AIDS disproportionately affects economically disadvantaged and stigmatized communities. Informal caregiving often constrains already limited economic and material resources and health status.²⁷ Promoting the provision of care in the home may be a cost-effective strategy for governments and the private sector, but gives little consideration to the physical, emotional and economic costs to informal caregivers who take on caregiving tasks.

Like in other health areas, those caring for PLWHAs encounter numerous caregiving-related stressors including emotional stress, isolation and depression.^{28 29 30 31} Caregiving is particularly stressful if the caregiver is also impoverished, ill, or if the care recipient has a stigmatizing condition or exhibits disruptive behaviour, such as substance abuse.³² The burden of caring for PLWHAs can also be exacerbated by the stigma that surrounds the illness and its association with homosexual, promiscuous and/or drug using life styles.

Even though caregiving is associated with a number of stressors, it can also bring about positive effects for caregivers. One qualitative study, which examined the experiences of 64 HIV/AIDS caregivers revealed the following positive side-effects of providing assistance: the perception of personal growth, a positive change in personality, an increased understanding of people with HIV/AIDS, the development of new relationships, the consolidation of existing relationships, feelings of achievement and self-satisfaction, and a change in life's priorities and personal goals.³³ In a similar qualitative study, caregivers of PLWHAs described how caregiving made them feel effective; they also felt that the work they undertook was meaningful.³⁴ These findings demonstrate that both positive and negative aspects of caregiving can occur simultaneously, suggesting that HIV/AIDS caregiving is a somewhat complex experience.

²⁵ Simoni, J. M and N. A. Cooperman (2000) "Stressors and strengths among women living with HIV/AIDS in New York City." *AIDS Care* 12(3): 291-97.

²⁶ Ciambrone, 2002.

²⁷ As quoted in Knowlton et al., 2011

²⁸ Wrubel and Folkman, 1997.

²⁹ Knowlton et al., 2011

³⁰ McCausland, J. and K. I. Pakenham (2003). Investigation of the benefits of HIV/AIDS caregiving and relations among caregiving adjustment, benefit finding, and stress and coping variables. *AIDS Care* 15(6): 853-69

³¹ Ship, J. and Norton, L. (2001). HIV/AIDS and Aboriginal women in Canada. *Canadian Women Studies*, 21(2): 25-31.

³² Knowlton et al., 2011.

³³ Mccausland and Pakenham, 2003.

³⁴ Wrubel and Folkman, 1997.

PART 3

HIV/AIDS: A Demographic Snapshot

Aside from the change in the course of the illness from terminal to chronic, the demographics of PLWHAs have shifted. Early in the evolution of the virus, in the 1980's, the MSM (Men who have Sex with Men) population group was the largest affected, accounting for over 80% of all cases.³⁵ Although MSM is still the predominant exposure category, the proportion has diminished significantly over the years. In 2009 in Canada, 41.8% of all positive HIV cases with known exposure category were attributed to MSM.³⁶

Poverty, inadequate housing, racism and marginalization affect the likelihood of contracting the virus. People with low incomes, for example, are more likely than those with higher incomes to be at risk of infection, to have (and to succumb to) AIDS more quickly.

In the two cities where this study was based - Winnipeg and Regina - little disaggregated information about HIV/AIDS exists. Data is generated on a provincial instead of a municipal level. As a result, the following information on rates of HIV/AIDS refers to the provinces of Manitoba and Saskatchewan, where Winnipeg and Regina are situated.



Between November 1, 1985 and December 31 2009, 1,634 HIV positive cases were reported in Manitoba and 1,187 in Saskatchewan.³⁷ Furthermore, in the year 2009, 105 newly positive HIV cases were reported Manitoba and 197 in Saskatchewan.³⁸ In 2010, Saskatchewan had the highest HIV/AIDS rate

³⁵ Public Health Agency of Canada, 2010.

³⁶ Ibid

³⁷ Ibid

³⁸ Ibid

in the country with 20.8 cases per 100,000 people, compared to the national average of 9.3 per 100,000 people.³⁹ While injection drug use has declined overall nationally, Saskatchewan has experienced a significant increase in the number of intravenous drug attributed HIV cases.⁴⁰

The number of females testing HIV positive has been steadily increasing in both provinces. For example, in 1999 in Manitoba, 28.2% of persons affected by HIV/AIDS were female. This figure increased to 45.3% ten years later, the largest percentage of female cases ever reported in one year in that province.⁴¹ In Saskatchewan, 69% of the female HIV cases reported since 1984 were identified between 2004 and 2009. In 2004, the number of female cases in Saskatchewan began to increase, surpassing the number of male cases in 2005 and 2006.⁴²

In Canada, Aboriginal Peoples and people of African heritage are vulnerable to HIV/AIDS infection because of structural and systemic inequities that result in economic and social exclusion. In 2006, it was estimated that approximately 7-10% of all HIV infections in Canada were attributed to people of African heritage, even though they represented only 2.2% of the Canadian population.⁴³ Stigma, racism, unemployment, lack of access to culturally appropriate health services and loss of support from extended families in home countries for those who recently moved to Canada, contribute to newcomers' vulnerability to HIV/AIDS.

The infection rate among immigrants from regions where HIV/AIDS is widespread (e.g., sub-Saharan Africa and parts of the Caribbean) was estimated to "be 12.6 times higher than among other Canadians in 2005".⁴⁴ In Ontario, approximately 40% of infections among immigrants and refugees from sub-Saharan African and the Caribbean occurred *after* arrival in Canada despite the popular belief that the virus is brought into Canada during migration.⁴⁵

³⁹ Saskatchewan Ministry of Health, 2010

⁴⁰ Public Health Agency of Canada, 2010.

⁴¹ Manitoba Health (n.d.) Statistical Update: HIV and AIDS – Report to December 31, 2009. Retrieved from <http://www.gov.mb.ca/health/publichealth/surveillance/hivaids/dec2009.pdf>

⁴² Saskatchewan Ministry of Health (2009). HIV and AIDS in Saskatchewan 2009. Retrieved from <http://www.health.gov.sk.ca/hiv-aids-annual-report-2009>

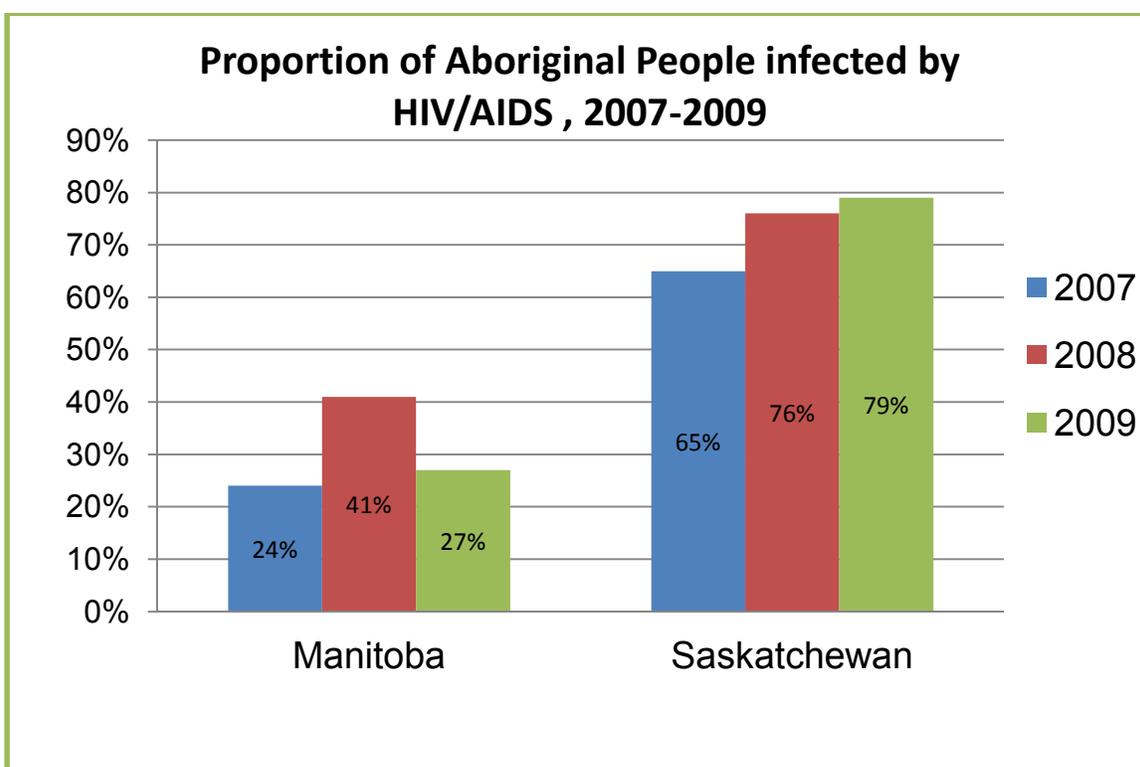
⁴³ Interagency coalition in AIDS and development (2006). "HIV/AIDS in African Diaspora Communities Living in Canada." Retrieved from http://www.icad-cisd.com/pdf/HIV-AIDS_AfricanDiaspora_EN.pdf

⁴⁴ Public Health Agency of Canada (n.d.) Population Specific HIV/AIDS Status Report – Fact Sheet. Retrieved from <http://www.phac-aspc.gc.ca/aids-sida/publication/ps-pd/pdf/factsheet-info-eng.pdf>

⁴⁵ Winnipeg Regional Health Authority. (2009). Working with Immigrant Communities: A Guide for Service Providers: The Improving Access Project.

Gathering data on the ethnicity of affected persons is important since this information supports targeted program planning and resource allocation.⁴⁶ In 2009, 18% of newly diagnosed cases of HIV in Manitoba were self-reported as African/African American.⁴⁷ No comparable data exists for Saskatchewan, where epidemiologists appear to gather data on an Aboriginal/non Aboriginal basis.⁴⁸

Aboriginal Peoples have experienced an alarming rise of HIV infections in Canada. In 2009 in Manitoba, 27% of persons affected by the virus identified themselves as Aboriginal.⁴⁹ That same year in Saskatchewan, 79% of new cases were of Aboriginal origin.⁵⁰ What is more, in Saskatchewan, Aboriginal origin comprised 65% of all cases in 2007 and 76% in 2008⁵¹



⁴⁶ Saskatchewan Ministry of Health, 2009

⁴⁷ Manitoba Health (n.d.) Statistical Update: HIV and AIDS – Report to December 31, 2009. Retrieved from <http://www.gov.mb.ca/health/publichealth/surveillance/hivaids/dec2009.pdf>

⁴⁸ See, for example: Saskatchewan Ministry of Health, 2010.

⁴⁹ Manitoba Health (n.d.) Statistical Update: HIV and AIDS – Report to December 31, 2009.

⁵⁰ Saskatchewan Ministry of Health, 2009.

⁵¹ Ibid.

On a national level, Aboriginal Peoples in 2009 had the highest proportion of HIV infections attributed to injection drug use (60.3%).⁵² If the intersecting categories of gender (female) and ethnicity (Aboriginal) are analyzed together, the figures are even more concerning. In Saskatchewan in 2009, Aboriginal women accounted for a disproportionate number (93%) of the reported female cases of HIV under the age of thirty.⁵³ The legacy of European colonization continues to negatively impact on the physical, mental-emotional, social and spiritual health of Aboriginal Peoples. Residential schools, multigenerational abuse, forced assimilation, and a loss of culture have given rise to a range of pressing social problems that include alcoholism, substance abuse, high suicide rates and violence.⁵⁴ Aboriginal Peoples bear a disproportionate burden of ill health compared to the general Canadian population, and have a particularly high risk of acquiring HIV infection due to the above mentioned intersecting risk factors.

⁵² Public Health Agency of Canada, 2010.

⁵³ Saskatchewan Ministry of Health, 2010.

⁵⁴ Ship, J. and Norton, L. (2001). HIV/AIDS and Aboriginal women in Canada. *Canadian Women Studies* 21(2), 25-31.

PART 4

Research Methodology

This section describes the methods used during various stages of this study. We have deliberately expanded this section in order to shed light on processes, reflections and lessons learned when using a variation of Photovoice methodology (see below) with low income, homeless and/or stigmatized PLWHAs.

Photovoice Overview

The research team used a variation of Photovoice methodology to gather data from participants. Photovoice entails providing project participants with cameras so that they can photograph *their every day realities*. Photovoice is a research method that puts cameras into the hands of people in order to address issues from their visual point-of-view. This unique and participatory methodology is based on the beliefs:

- That images teach
- That pictures can influence policy, and
- That community members should participate in creating and defining images that shape healthful public policy.⁵⁵



With Photovoice methodology, the meaning of photographs is elicited through interviews or storytelling circles with the persons who have taken the photos. The power of images engages participants, researchers, program planners and policy makers in a dialogue that may result in individual and social change. Photovoice methodology has been used to explore a wide range of health issues and has been modified to reflect research questions, community dynamics and project participants' needs. In this particular study, we adapted Photovoice to meet the specific goals of the project. As such, participants in this study took photos in order to reflect, depict and narrate their social support and caregiving and receiving experiences.

⁵⁵ Wang, Caroline C (2006). Youth Participation in Photovoice as a Strategy for Community Change. *Journal of Community Practice* 14(1): 147-161.

Recruiting Project Participants

Recruitment of project participants began in December of 2007. After receiving formal Ethics Approval from the Health Research Ethics Board at the University of Manitoba, a research coordinator in Winnipeg and a research assistant in Regina were hired. Both of these staff members had experience working with potential participants to the study through work in AIDS service organizations, research and sexuality education. For the recruitment process in Winnipeg, another research assistant was hired. She was particularly well connected to the community members we were trying to access and was an excellent bridge for connecting members of the research team with many of the participants.

As similar recruitment and data collection activities were to take place in both cities, we determined that Winnipeg would lead the process and Regina would follow a few months behind, allowing one set of activities to be completed in Winnipeg, before they began in Regina.

Since the research team was large and the project was based in two different provinces, a strong communication system was necessary. Using a combination of telephone, Skype, e-mail and standard post, we were able to keep inter-city travel to a minimum while maximizing the connection and communication between the various team members who were working not only in two cities, but in various sites in both of those cities.

In general, the research team recruited participants through various AIDS service organizations and other organizations that work with vulnerable and stigmatized people. We created and distributed posters to many agencies in Winnipeg and Regina, and we contacted service providers to help us find people willing to be part of the study. Careful attention was paid to prevent potential participants from feeling the need to satisfy the request from service providers to participate (e.g., assurance of voluntary nature of participation and clear and sufficient written materials available to the potential participant). As time went on, word-of-mouth among project participants and service providers became an important means of recruitment.

Our efforts were concentrated on finding persons who were using drugs, were on social assistance (i.e., welfare), with low or no income and/or with no fixed address. Our aim was to recruit PLWHAs or their informal caregivers. In order to avoid potential selection

Promising Practice

Hired a trusted community member to act as a bridge and help connect the potential participants to members of the research team.

bias towards PLWHAs and caregivers who had positive relationships, we did not actively recruit pairs of relationships of PLWAs and their caregivers. Although we were able to recruit community participants who were Aboriginal, low income, using drugs, and/or homeless, it proved difficult to engage persons from the immigrant and refugee newcomer community, a population cohort that, along with Aboriginals, is vulnerable to HIV/AIDS risk infection.

Numerous service providers who worked with newcomers told us that their clients are terrified of identifying themselves as being HIV/AIDS positive. Congruent with existing literature, we learned that the stigma of HIV is so overwhelming in newcomers' home cultures that the fear of disclosing HIV/AIDS status is too high for them to overcome.^{56 57} With this in mind, we were able to engage two newcomer participants for the project, both of whom migrated to Canada from Africa. These two participants chose to carry out their interviews in French rather than their dialect, for fear of being identified by someone from their own cultural background. One of them would not participate in the interview if the interpreter was Black. This project participant wanted the interviewer to be someone who was indisputably a Caucasian "Canadian" disconnected from her/his ethno-cultural community.

Lesson Learned

Research with immigrants and refugees who are affected by HIV/AIDS requires very high levels of sensitivity and attention to anonymity and confidentiality.

Information and training sessions about the project preceded the photo taking and interview stages. At the first information and training session, 40 potential community participants were present. This proved to be somewhat disruptive as there were too many people in the room to have a meaningful discussion or to ask and answer questions. Subsequent recruitment in Winnipeg and Regina followed a different pattern, in which we invited potential community participants to have a short one-on-one discussion with the project coordinator to discuss their willingness to be a part of the project. If potential participants showed motivation and belonged to our target participant groups, we invited them to a more intense information and training session with no more than two or three potential participants at a time.

⁵⁶ Tharao, E. and Massaquoi, N. (2001). Black Women and HIV/AIDS Contextualizing Their Realities. *Canadian Woman Studies* 21(2): 72 -80.

⁵⁷ Worth, H., Denholm, N. and Bannister, J. (2003). HIV/AIDS and the African Refugee Education Program in New Zealand. *AIDS Education and Prevention* 15(4):346-56.

Information and Training Sessions

During the information and training sessions, which were held in Winnipeg and Regina, we gave those in attendance an overview of the study, and discussed their potential involvement in it. After that, consent forms were signed which - among other details - indicated that persons were willing to be project participants and that they were prepared to take photos and be interviewed by a member of the project team.

After the consent forms were completed, each community participant was given a disposable camera and offered tips on how to effectively use it, such as how to use the flash function and how to focus on subjects. We asked community participants to take photos of anything that provided a support for them in their lives. We also discussed caregiving and the role of caregivers in the lives of people living with HIV/AIDS. We defined “caregiving” as “anything or anyone that offers support.”

Community participants asked many questions about what objects or scenarios they were allowed to photograph. The only restrictions that we placed on what types of photos were permitted were legal ones. Therefore, participants could not take photos of:

- Anyone buying or selling drugs
- Anyone in the act of using drugs
- Anyone acting violent or abusing children, or
- Anyone actively engaged in illegal activity.

On the other hand, we told community participants that they could photograph:

- Objects
- People
- Places
- Pets

For ethical reasons, we trained community participants on how to administer release forms when taking photographs of human subjects. If they wished to take photos of other people, we told them that they needed to:

- Ask the person/people first
- Get the person/people to sign a photo release form, and
- Bring the release form back to the project coordinator, along with the photo.

Photovoice Instructions

We Asked Participants to take photos of anything that provided a support for them in their lives...We defined caregiving as “anything or anyone that offers support.

We also let participants know that photos of people could be taken without having them sign a release form:

- If the person(s) were not recognizable in the photo (e.g., they were too far away or their back was to the camera)
- If persons were at a public event where there was a reasonable expectation of publicity.

We confirmed that everyone at the information and training session understood these directions. Close to the end of each session we asked community participants to return the camera to the research coordinator when they were finished taking photos. Throughout the sessions, we encouraged community participants to ask us questions as well as voice comments or concerns. The proceedings during these discussions were analyzed in the same manner as other forms of qualitative data, such as individual interviews; thus, all information and training sessions were, with the consent of participants, audio taped. An honorarium of \$20 was provided to each participant for their time spent during the session. Bus tickets were also provided to cover transportation costs.

Individual Interviews with Community Participants

When the cameras were returned, usually 2-3 weeks later, the research coordinators in both cities took charge of developing the photos and scheduling a personal interview with each participant. The in-depth personal interviews were held at agencies where participants indicated feeling comfortable, such as a private room in an AIDS service organization where they received support.

The interviews began by giving community participants an unopened package of their developed photos. They were asked to open the package and remove any photos they did not want to be part of the research. Only two out of the 31 community participants removed some photos from their packages. The project coordinator conducted the interview with one set of photos and the community participant kept the other set. A disc of electronic copies was also kept for analytical and reporting purposes.

Data for this project consisted of photos as well as training session and interview proceedings. Unlike the traditional photovoice approach where participants are asked to select a limited number of photographs and follow a series of questions to tell their stories, the interviews in this project were loosely structured. Community participants took the lead in the telling of the stories behind each photograph. During the interviews, the project coordinator maintained a focus on the topics of social supports and

caregiving while remaining as open as possible to whatever that might mean to the participant.

With Photovoice methodology, the interview discussions are centred on the photographs taken by the participants. For a few participants of this study, the photos created more of a wall than a window or a door into their experiences. Some had photos that were taken during a single event, such as a concert or a party. One person took almost an entire set of self-portraits in different poses. In these situations, it was difficult to expand the conversation outside of the event or self-portraits. Given the open style of the interviews and the reliance on the photos to spark the conversation, it became difficult with some individuals to explore issues more fully, especially if they were shy or reserved. Moreover, community participants with many and varied photos would occasionally shorten the oral interview process in order to return to the photos. Where the interview might have moved to a very interesting and pertinent aspect of the research, the individual's desire to "get through" the stack of photos would sometimes take them out of their train of thought and they would insist that the interviewer move on to discussing the next photo in the stack.

Nonetheless, in general, as the photos were reviewed a window would open into the lives of many of the community participants. Some community participants clearly appreciated the opportunity to take photos and share their life stories and experiences. Others were happy to have a set of photos that they could take with them and share with others. Two individuals had never held a camera before and were quite moved by the experience.

Members of the research team were deliberately flexible and willing to modify processes based on unexpected findings, research goals and needs of the participants. Most of the interviews lasted an hour. Some interviews were carried out with one community participant, whereas others took place with couples, including a PLHWA and his/her partner. With the exception of two interviews, which were carried out in French, all of the interviews were conducted in English. The participants' identities have been protected in all articles, presentations, and other dissemination activities.

A few of the community participants appeared to be under the influence of drugs during the interview. However, no interviews were stopped because of drugs. The project coordinator was not prepared to alienate the individual with a suggestion that they were "high." The research team decided to stop the interview only if someone was aggressively "high" or exhibiting inappropriate behaviour.

During the initial stages of this study, the research team was specifically concerned about PLWHAs who were receiving “informal” care; that is, that the care they were receiving was not connected to any organization and they were not employing the caregiver in any way for their services. Early on during the research, it became apparent that our notion of informal caregiving was not only limited; it was also not entirely relevant to the project participants. In fact, the term caregiving seemed alien to many of them who said, “I can take care of myself.” If PLWHAs depended on others for help, we discovered that the majority of them relied heavily on what we conceptualized as “formal” caregivers. The fact that so many of the project participants affected by HIV/AIDS relied on staff members from formal organizations and on peer groups for support led us to negate the need to recruit a specific number of informal caregivers. Instead, we adapted our methodology and coordinated a series of interviews with “formal” caregivers in Winnipeg and Regina. Henceforth, the phrase “community participant” refers *only* to PLWHAs or their informal caregivers, who were recruited from disadvantaged and stigmatized communities and who participated in the study. The phrase “formal caregivers,” on the other hand, refers to the participants who were employed in formal organizations, and who were interviewed for this study.

Individual Interviews with “Formal Caregivers”

“Formal” caregivers were recruited through open e-mail requests. Those who replied and were willing to be part of the project were interviewed. A couple of the members on the research team were employed as program managers in AIDS service organizations. Since some of the “formal” caregivers whom we interviewed were under their direct supervision, and the interview was focused on work dynamics, an extra effort was made to protect the identity of those “formal” caregivers who were willing to participate. “Formal” caregivers were asked a pre-determined set of questions. In total, 17 “formal” caregivers from five different AIDS Service Organizations were interviewed on an individual basis; three of them worked in Regina and 14 worked in Winnipeg. Of the 17 formal caregivers:

- 5 were medical staff members (e.g., doctors or nurses)
- 3 worked in the area of support for clients (e.g., social workers)
- 7 worked in the area of community outreach and/or education (e.g., outreach workers)
- 1 was a board member of an Aids serving organization
- 1 was a front line receptionist in an AIDS service organization

Retaining Community Participants throughout the Study

The use of Photovoice requires that participants be involved in a project for a period of time over several weeks or even months. Attracting and retaining participants for this project proved to be challenging. In Winnipeg, for example, 40 people attended an initial information and training session about the project, with 16 becoming project participants. Considering the vulnerability of the population with which we were working, this seemed a reasonably high participation rate. Many of these persons had no permanent address and were living on the streets, couch/floor surfing or living in shelters. Alcohol and drugs such as crack, crystal meth, and solvents were having an impact on their lives and their ability to participate in the project.

The lifestyles that many of the project participants led did not lend itself well to the needs of a project that required a degree of forethought and planning. Participants needed to get a camera; keep it safe from loss, theft, spillage or other damage; take photos of people, animals, plants or objects; keep, complete and return the photo release forms (in the case of photos including people); and return the cameras to the project coordinator. Completion of this process assumes that the person cares enough about the project to do all of this work and return for an interview. Simply because we as researchers cared about the results did not mean that participants did.

For many individuals in vulnerable situations, money in hand is worth more than the potential for some abstract information in the distant future. A few scenarios that the research team encountered highlighted this point. In one case, a participant sold the camera and bus tickets that were given to him. Another person called the project coordinator to say that he had dropped the camera in the toilet and needed a new one. Yet another person had his camera stolen minutes after the information and training session. These situations were handled on a case-by-case basis by the project coordinator, who tried to find a balance between unlimited access to cameras and replacing legitimately lost or stolen cameras.

The harshness of the streets was also a factor affecting participation. A number of street involved people died in Winnipeg early in 2008. While none of them were study participants, these deaths affected many who were involved in the project. The grieving process and the effects of the loss, violence and difficulties of the time prevented a few community participants from continuing. In addition, because some of the participants had no phone numbers or addresses, we were unable to locate them to schedule a personal interview.

Although retaining participants throughout the different project phases proved to be a challenge, it became obvious to us that some of them took the research very seriously. A number of them kept a scrap of paper for weeks with the date and time of their interview. They regarded their involvement in the project as a job with the \$20 honorarium being payment for that job. These participants usually felt a clear responsibility to document their lives properly, present issues appropriately, or become a voice for all persons with HIV/AIDS and similar concerns and struggles.

Promising Indicator

Some [participants] took the research very seriously...and kept a scrap of paper for weeks with the date and the time of the interview. They regarded their involvement in the project as a job with the honorarium being payment for that job.

Dilemmas in the field: dealing with the sensitive nature of the research

Research on sensitive subjects has the potential to impact all of the people who are involved in it, including members of the research team.⁵⁸ About six months into the project, the project coordinator in Winnipeg, who was responsible for conducting interviews with community participants, indicated being isolated and somewhat overwhelmed. In order to be a good listener, a person needs to be actively listening and engaged in the interview process. Hearing story after story of isolation, abuse, violence and discrimination produced emotional distress for the project coordinator.

The transcription process was an additional weight for the project coordinator, who chose to transcribe the first few interviews, but soon realized that it was far more difficult to hear the stories again than it was to be actively involved in the interview in the first place. This situation is not unusual. Research has found that participating in and transcribing interviews on sensitive topics can be an emotional distressing experience.⁵⁹

In response to the project coordinator's concerns, another individual, who did not form part of the research team, and therefore had some level of emotional distance from the project participants' lives, was hired to transcribe the interviews. Moreover, a small team was set up to support the project coordinator and frequent meetings were arranged to discuss and debrief about the project. This process worked well and provided a much-

⁵⁸ Dickson-Swift, V., James E.L., Kippen, S., and Liamputtong, P. (2009). Researching sensitive topics: qualitative research as emotion work. *Qualitative Research* (9)1: 61-79.

⁵⁹ Ibid.

needed outlet for project coordinator. Being in a room with other research team members who had read the same transcripts and were analyzing the same data helped to relieve the project coordinator's emotional discomfort.

Analyzing the data

All interviews were transcribed and any identifying information was removed from each transcript. Data analysis took place with the entire team of project partners and the research team. A series of meetings allowed us to discuss the information and themes emerging from the interviews. At least two research team members were responsible for reading each interview and bringing their thoughts to the larger group. For the interviews that were conducted with “formal” caregivers, transcripts were carefully divided among team members who would not present a potential conflict of interest between supervisors and the service providers⁶⁰ who were interviewed.

Themes and patterns began to arise naturally. The research team kept track of these themes and then went back to the data to analyze them in specific reference to the study's initial research questions. A separate analysis was conducted with the photos that were taken by participants. However, as the interview data and the photos became impossible to separate completely, the main analyses always incorporated elements of both. The images offered by the photos were essential to understanding the participants' commentary, while the context offered for the commentary became integral to the analysis of the photos.

Since we had over 804 photos in our data set, the photo analysis was intense and time consuming. Photovoice methodology traditionally invites project participants to take only a handful of photos, or to choose a few photos to discuss from their larger set. For this project, the research team made the choice to analyze every photo taken. By offering each participant a camera that could take 27 photos, the participants were able to present a “slice of life” that a smaller set of photos may not have yielded.



⁶⁰ For the purposes of this report, we use the words “formal caregiver” and “service provider” interchangeably.

PART 5

Profile of Community Participants

In total the research team engaged 48 project participants, and conducted 53 interviews. We gathered data from two different groups of persons. The first group consisted of 31 community participants, and the second of 17 “formal” caregivers. This section provides a profile of the community participants who took part in the study and shared their stories, experiences and insights with us.⁶¹

Of the 31 community participants who attended an information and training session, took photos, returned cameras and participated in an in-depth interview, only eight (26%) identified themselves strictly as caregivers of a PLWHA. 14 (45%) characterized themselves as a PLWHA and 9 (29%) as *both* a PLWHA and a caregiver.

65% of all community participants were living in Winnipeg and 35% in Regina. However, 87% of them indicated living in a city that was not their original home. The participants ranged in age from 17 to 49 years old, with a mean age of 40. The majority self-identified themselves as Aboriginal (64%) whereas 10% identified themselves as Black and 26% as Caucasian.

Only 10% of the community participants had some level of post secondary education, and many of them indicated dropping out of high school due to external pressures. Their lives were violent and several were expelled from school, or they were drinking or doing drugs which preventing them from completing their studies. Others felt unaccepted in school due to their ethnicity or perceived sexual orientation. And yet others were compelled to drop out of school and work to help support their families. Although the reasons for not completing high school were as varied as the participants, none of them indicated they had quite school as a result of an informed and explicit decision.

Given the strong connection between having formal education and employment, it did not come as a surprise to the research team that many of the community participants were unemployed. At the time they were interviewed, only 6% of the participants pointed to having full time employment; 55% were fully unemployed; 36% worked casually or illegally and one participant went from being unemployed to employed

⁶¹ For information about the “formal” caregivers who were interviewed, please refer to page 22 of this report.

between meetings with the project coordinator. Well over half cited welfare (i.e., social assistance), as their primary source of income.

Due to their impoverished and precarious lifestyles, many of the community participants were susceptible to being pushed out or evicted from rental apartments. Potential or actual homelessness was a common reality. Several of the participants couch/floor surfed from house to house, sleeping where they could. When given cameras, they decided to

show the research team where they slept or had slept: in a city forest surrounded by shrubs (see photo 1); under a bridge near a hospital by the local riverbank (see photo 2) or in a dumpster (see photo 3).



Photo 2: Place To Sleep: Under a Bridge near a Hospital



Photo 3: Place to Sleep: Dumpster



Project participants related histories of violent childhoods; they recalled memories of substance, physical, sexual and emotional abuse, as well as racism and displacement. They made known that the level of abuse had not changed, and that they used drugs or alcohol as a mechanism to cope with the continuing violence. In fact, during the time of the interview, 65% of the community participants indicated that they were regular users of illicit drugs.

Stigma was experienced by virtually all of the participants who talked about feeling discriminated against because of their HIV/AIDS status, culture, race, sexual orientation, drug use and/or low level of education. The reality of death and dying was present throughout the project. Most of the participants spoke of people they knew who had died and some had been very close to death at one point or another in their lives. With this said, it is important to note that very few of the study participants were at the point of their illness where they needed intense physical caregiving.

Despite the precarious situations that participants were living under, the project team was often struck by their resiliency. After offering tales of violence, abuse or other difficulties that most of the research team members would likely never encounter, participants would indicate the desire to keep on going or to face their difficulties head-on. The project team felt their humour and listened to how hard their lives were as participants smiled, joked or spoke with more hope than might be thought possible considering their situation.

PART 6: FINDINGS

Caregiving and Its Different Interpretations

During interviews, the research team realized that its initial understanding of caregiving did not fit with the study population. Responses by community participants led us to realize that the notion of caregiving means different things to different people. Some of this study's community participants viewed caregiving as a helping act by another person when they were sick. Other participants, in line with research by Johnston, Stall & Smith, did not like to ask for help.⁶² They felt that needing care was a sign of weakness and they would do anything to prevent being thought of as weak; and yet other participants talked openly about caring for others, without offering examples of being the recipients of any care.

Most community participants spoke about care in a very tangible and physical sense, such as sharing food, offering someone a place to stay, or giving someone money to use public transportation. This type of care was often associated with basic necessities and usually represented needs from a poverty perspective rather than an HIV/AIDS or illness perspective. Family members, close friends or intimate partners usually take on the role of informal caregivers of loved ones who are sick. However, the community participants who took part in this study showed a very different picture. The research team found that the presence of a single, available and capable informal caregiver in the life of a community participant was rare. In fact, as will be discussed below, community participants relied on one another (peer networks), "formal" caregivers, pets, plants, their cultural identity and nature as sources of resiliency, strength and support.

Lack of Sustained Relationships with Friends, Intimate Partners and Family Members

Relationships were an interesting theme to examine. Societal expectations foster the idea that when illness strikes, family members, close friends and intimate partners should care for one another. However, reality sometimes fails to coincide with societal expectations. This study's participants indicated that the types of relationships that they had with family members and intimate partners were complicated and confusing; many participants had people coming in and out of their lives rather quickly. Isolation was a recurring theme, as was violence. Only 16% of the participants were, at the time of their

⁶² Johnston, D., Stall, R., Smith, K. (1995). Reliance by Gay Men and Intravenous Drug Users on Friends and Family for AIDS-Related Care. *AIDS Care* 7(3): 307-320.

interview, in a familial or intimate relationship with a primary caregiver; the remaining 84% of participants were not.

Some persons we interviewed had moved to get away from dismissive or abusive family members. Others had serious addictions and found themselves surrounded by persons with similar conditions. And yet others were so affected by the discrimination they encountered that they had difficulty developing healthy relationships with others.

A few participants referred to their parents during the open-ended interviews with the project coordinator. These participants indicated that their parents, who were raising their children (i.e., their grandchildren), did not approve of their use of drugs. Other participants indicated that their parents were part of their drug circles. In another case, a female respondent who was HIV/AIDS positive spoke about her overbearing partner who, in the initial interview which they participated in together, interrupted her whenever she began to talk about anything personal.⁶³

81% of the participants had children of their own. Of these, 44% had no contact with their children, who were in the hands of the child welfare system or their estranged parents. 14 participants (56%) had some level of contact with their children, and only 8% spoke of having uninterrupted care of them. Existing literature has suggested that children can be an important source of perceived social support for persons suffering from HIV/AIDS.^{64 65} In one American-based study, for example, children of African American women living with HIV/AIDS showed their mothers love, concern, hope and encouragement as well as instrumental support.⁶⁶ This finding needs to be further explored; however, the fact that so few of the community participants in this study had uninterrupted access to their children may be undermining their potential for a stronger base of social support.

Due to improved health and social services, as well as access to effective anti-retroviral drugs, persons living with HIV/AIDS are living longer lives than they were in previous decades. A general trend in the treatment of the illness has been the shifting of care away from hospitals or clinics into the home, making the role of “informal” caregivers (i.e., family members, close friends and intimate partners) more crucial than ever.⁶⁷

⁶³ During a second project interview with her partner being absent, this participant spoke more openly about her experiences.

⁶⁴ Smith and Rapkin, 1996.

⁶⁵ Johnston, Stall and Smith, 1995.

⁶⁶ Edwards, L. (2006). Perceived Social Support and HIV/AIDS Medication Adherence among African American Women. *Qualitative Health Research* 16(5): 679-91.

⁶⁷ Wrubel J, and Folkman, S. (1997). What informal caregivers actually do: The caregiving skills of partners of men with AIDS, *AIDS CARE* 9(6): 691-706.

However, in line with existing literature, the majority of low income, stigmatized and/or drug using participants in this study tended to have limited sources of informal caregiving support.⁶⁸

Peer-to-Peer Network of Care

Although the majority of this study's participants did not have "informal" caregivers as was expected, we did discover that some of them, particularly those who were homeless, formed part of a loose peer-to-peer network of care. The general picture presented by participants was one of a very transient lifestyle with an unstructured circle of peers who were connected through drugs, poverty and to a lesser extent, extended family ties. In these social circles, no one seemed to overtly feel responsible for anyone else, yet members would work to help one another as a larger group. One community participant revealed the following:

- ***"Ah God man. I was homeless for five months, and they all watch over your, eh. Like we all look over each other like a family."***

Assistance within these peer networks was generally restricted to tangible physical support that included picking up food for friends at a local soup kitchen, giving each other cigarettes, offering advice to each other about safe sex and needle use, and offering space on a couch or floor if it was available. Taking care of each other was simply considered a matter of course within the group, and few if any of the participants whom we spoke with regarded their acts as forms of caregiving. The peer-to-peer circles were not clearly or well defined nor did they appear to be necessarily healthy, but they were examples of persons doing what they could to support others in their lives. Further complicating issues of safety within these social circles would be examples of male members taking sexual liberties with homeless females who needed a place to sleep. One participant, for example, found herself waking up with the hands of the uncle of a friend in her pants.

A study carried out by Amy Knowlton revealed that low income African-American drug using persons living with HIV/AIDS were heavily reliant on similarly disadvantaged people with poor health for social support and informal HIV care.⁶⁹ For some PLWHAs, help from similar persons may be preferred due to their greater acceptance, or perceived matching of support need.⁷⁰ In this study, we found that a significant number

⁶⁸ As cited in Knowlton, 2011

⁶⁹ Knowlton, AR. (2003) Informal HIV caregiving in a vulnerable population: toward a network resource framework. *Social Science & Medicine*, 56(6): 1307-1320.

⁷⁰ Johnston, D., Stall, R., Smith, K. (1995). Reliance by Gay Men and Intravenous Drug Users on Friends and Family for AIDS-Related Care. *AIDS Care* 7(3): 307-320.

of participants formed bonds with people who were equally stigmatized and impoverished. Participants connected with others who had shared similar overwhelming experiences, which gave them a sense of comfort and support.

Non Human Sources of Support

In addition to relying on their peers, many participants also sought support from non-human sources. Studies have shown that animal companions can have health enhancing effects on people, and enrich their quality of life.⁷¹ For example, an American based study showed that men who were HIV/AIDS positive and who owned pets reported less AIDS-associated depression than those who did not own pets; this beneficial effect of pet ownership occurred principally among individuals who reported fewer confidants.⁷²

Eleven of the 23 project participants who were HIV/AIDS positive were, at the time of the interview, living with pets. They took multiple photos of their animal companions and spoke about them at length.



⁷¹ Allen, K. (2003) Are Pets a Healthy Pleasure? The Influence of Pets on Blood Pressure. *Current Directions in Psychological Science* 12(6): 236-239.

⁷² Siegel JM, Angulo FJ, Detels R, Wesch J, Mullen A. (1999). AIDS diagnosis and depression in the multicenter AIDS Cohort Study: the ameliorating impact of pet ownership. *AIDS Care* 11(2): 157-70.

The quote below underlines how important pet companions can be to their owners:

- ***“And this is my kittle, and oh what a sweet cat. When I was in the hospital he went, went nuts. He didn’t know where I was. They put me on speaker phone and he was right at the speaker phone. He wanted me; he knows.”***



Plants and nature in general, also came up as a source of support for persons living with HIV/AIDS. Images of beauty, often found in nature, were offered as alternatives to the violence and hardship encountered in their lives:

- ***“Like the prettiness, the flowers, you know you forget when you’re on drugs and drinking, you don’t even look at the pretty flowers anymore, you don’t care. You just walk past them, like who cares, I just got to get to that***



Liquor Mart, or I got to get to the dealers, and you don’t take time to look at the pretty things like the flowers or butterflies, you know, gophers even [laughs].”

Several participants revealed the benefits or positive side effects that they felt when taking care of (or being surrounded) by plants and nature:

- ***“My plant (laughing); I’ve been growing that as therapy for myself.”***



One participant took a photo of her garden. She spoke how important gardening was for her:

Community Participant: *“I helped my dad with a garden when I was a little girl, and he died when I was 22, so I’ve never planted a garden; this is the first one this year. So these are all marigolds. These are tomatoes, and in behind here I have sunflowers and I got all of my bulbs back here.”*

Interviewer: *“You got sunflowers to grow?”*

Community Participant: *“Oh yes, I’ve got a sunflower this tall right now” [she is beaming].*

Another participant photographed a bees’ nest, while others appreciated (and found comfort) in winter beauty:



“Okay, these are pictures of just the scenery during the winter time and I just love it, like it’s just how peaceful it looks and stuff like that, it’s just something I like to look at and see how nature is so beautiful and what you can enjoy when you’re not doing drugs and stuff like that, and when you’re cleaning up, how you notice more things around you, so I just had to take pictures of that. It makes me happy.”

For some participants, Aboriginal art and culture gave them sense of hope and pleasure. One Aboriginal participant shared the following intimate experience with the interviewer:

- ***“I was sent a dream by my grandfather who is a very powerful medicine man and he knew I was struggling.”***



Heavy or Exclusive Reliance on Formal Caregivers, Among PLWHAs

Despite belonging to networks of peers and to relying on non-human forms of social support, many community participants exhibited signs of isolation. Over and over we heard individuals say that they would not or could not ask for help. They were worried about burdening others and felt a need to be strong. A large proportion of the participants were quite isolated from family, friends and intimate partners. Some had moved to get away from dismissive or abusive family members. Others had serious addictions and found themselves surrounded by persons with similar conditions. Some were so affected by the discrimination that they faced as being HIV/AIDS positive and/or gay, and/or Aboriginal, and/or poor that they had difficulty developing supportive relationships with others. The analysis showed that these individuals relied quite heavily on “formal” caregivers (i.e., service providers) for help.

As seen on the following page, a few participants photographed and named medical and social support professionals as friends and even as family members, without citing a single “informal” support person anywhere in their lives. Health clinics and AIDS serving organizations were presented as places of relative calm and safety that they were able to access during their daily lives.

**Health Facilities, as photographed by
Community Participants**



One PLWHA revealed how she was recognized and valued at the local care centre that she attended, indicating that the social support she received there promoted her sense of personal and emotional well being; this indicates that programs available at formal service organizations can, in addition to promoting healthier physical activities, support clients' emotional health and sense of resiliency.

Interview excerpts and photographs taken by project participants brought to light how the extent to which they relied on professional service providers for support and help. In one instance, a PLWHA spoke about needing help at night time, but said that there was no one that she could call for help at that time of the day, since his main supports did

not start work until the following morning. In her own words, he explained to the interviewer how she considered professional service providers as his friends:

“Sometimes I get really sick, and when it’s 2 a.m. in the morning, I can’t really call my son, and my friends from the health district [emphasis ours] won’t be at work yet, so I just wait - - a few times, sometimes, I...I [thought] ‘this is it. I’m going to die now!’ but what can I do? I do what I can to just wait until 8 a.m. when people will be at work and then I can call them.”

Another study respondent spoke about the agency where she received support as a place of safety and comfort. She said: “I love it here. I like everybody’s company, everybody, um, makes me feel comfortable.” The brief exchange below further illustrates this pattern:

Interviewer: “So who helps take care of you?”

Respondent: “Me”

Interviewer: “Just you?”

Respondent: “You guys”

Interviewer: “Us, at the organization?”

Respondent: “Everyone, well of course.”

The person above is not alone in her depiction of formal caregivers being among her primary supports. The feelings of support and an almost family-like connection with service providers was a recurring theme gleaned from our analysis.

Service Providers’ Views on their Caregiving Roles

Most of the 14 Winnipeg-based service providers whom we interviewed indicated that they (and their agencies) supported their clients quite well:

- ***“I think we have a good system to deal with our clients. Yeah, I think it works. I think...like I feel I can do what I need to do, to care for my clients.”***
- ***“I think we are supporting our clients the best way we can. I know that our clients get the best care here that I have ever seen.”***

Although the research team only interviewed three service providers from Regina, these respondents, unlike their Winnipeg counterparts, felt that their agencies were not supporting clients to the best of their ability.⁷³ Nonetheless, what was consistent in both

⁷³ To explore and adequately discuss this issue further, the research team would need to have interviewed more service providers from Regina.

Winnipeg and Regina was that many project participants who were living with HIV/AIDS regarded service providers (i.e., their “formal” caregivers) as their primary supports, friends and even family members. The following interview excerpts draw attention to this significant finding:

- ***“Some think I’m like their auntie, some like a big sister...some like their mom from hell when they get the mom look. Some see me as a friend. A part of the family, or very, very intimate and special to them.”***
- ***“They look up to me for support; both [as] a caregiver and a friend. First and foremost as a friend, a colleague... a healthcare provider, someone to trust, someone who is approachable and reliable.”***
- ***“You’re someone that I can come and talk to and you never turn us away.”***

To determine whether feelings were reciprocal, we asked the “formal” caregivers whom we interviewed if they considered any of their clients as friends. Here, we received a variety of responses:

- ***“I know there are some of my clients [who] have identified me as their friend. I think I would too probably identify them as a friend in a sense. I don’t know how to explain it.”***
- ***“When you are caregiving sometimes people think of that as friend where all of a sudden they’re saying: ‘you’re my friend’ and it’s like: ‘I’m actually not your friend, I work here.’ Sometimes that’s actually a disappointment for clients to hear.”***
- ***“...I don’t know, like, how do I even decide [whether I consider them my friends]? I know I have friends that are working in the field that also have a history of sex work; I have friends working in the field who are dealing with addiction. Is that different? That’s just the reality of people’s lives.”***
- ***“I think they all are friends.”***

Formal Caregivers: Occupying an Essential Role in their Clients' Lives

At the outset of the study, the project team had a fairly defined separation between the meaning of “formal” and “informal” caregivers. The bulk of existing literature conceptualizes a “formal” caregiver as one whose caregiving duties are the responsibilities of a paid or volunteer job. An informal caregiver, on the other hand, is generally a friend, partner or family member who is not paid or compensated for performing caregiving tasks. The results from this study challenged the conceptual dichotomy between “formal” and “informal” caregivers. Community participants who were HIV/AIDS positive named “formal” caregivers as occupying a primary role in their daily lives; they considered their “formal” caregivers as friends and, even at times, as family members. As Ungerson argued in 1990, the conceptual splitting of “formal” and “informal” care poses a false dichotomy by assuming that the nature of the relationships that prevail in each one of these domains is totally different.⁷⁴

Finding
Community Participants who were HIV/AIDS positive named “formal” caregivers as occupying a primary role in their lives; they considered their “formal” caregivers as friends and, even at times, as family members.

Blurred Professional Boundaries

The differentiation between “formal” and “informal” caregivers became further complicated with the outreach workers whom we interviewed, who often came from the peer groups that they were working with and who therefore had both formal and informal connections to clients. An essential feature of outreach work is its highly unstructured and unpredictable nature.⁷⁵ Unlike office based practices, where both the amount of time spent with clients and type of role are limited, outreach workers maintain extended contacts in informal settings and use an informal provider style. These blurred responsibilities appeared to confuse both clients and staff members, who were interviewed in this study. If a staff member was or is a good friend of a client, determining where the official professional duties end and the friendship begins can be difficult; this can cause concern with regards to confidentiality, conflict of interest, and equity of care for clients.

⁷⁴ Ungerson, C. (1990). The language of care: Crossing the boundaries. In C. Ungerson (Ed.), *Gender and caring: Work and welfare in Britain and Scandinavia* (pp. 8–33). New York: Harvester.

⁷⁵ Strike, C., O’Grady, C., Myers, T., and Millson, M. (2004) Pushing the Boundaries of Outreach Work: The Case of Needle Exchange Outreach Programs in Canada *Social Science and Medicine* 59(1): 209-219.

Professional boundaries concern interpersonal relationships between staff members and clients. Boundaries provide workers with guidance to avoid situations in which vulnerable clients may be subject to harm. Boundaries also provide clients and workers with a sense of predictability and safety, and they define the parameters of relationships in order to avoid situations that encourage dependency of clients on workers.⁷⁶

A major theme presented during interviews with “formal” caregivers was one of professional boundaries. A couple of service providers, for example, claimed:

- ***“You do cross a boundary somewhere when they [clients] rely on you more than they would their own family members.”***
- ***“A lot of clients want to know personal information about their caregivers. We want to dig and prod and get everything out of our clients and yet we don’t share anything [with them].”***

Winnipeg and Regina are small Canadian cities, relative to Toronto, Montréal and Vancouver. In this context, issues of client confidentiality become particularly relevant:

- ***“Sometimes things do happen with clients in the evening . . . You just see them somewhere. Say you go to a restaurant and your client is there and they want to talk to you about something that has happened, it kinda puts me in an awkward situation. Seeing a client in public can be, and usually is an innocuous event, but if they want to talk about work, there may be confidentiality issues that come up that they might not be aware of. It’s a public place ... and ... if my company ... says ‘Well who is that?’ I can’t really discuss it with them.”***

Due to the extended duration of an HIV/AIDS infection, service providers are developing long-term connections with clients. Where staff, in the 1980’s and 1990’s did not have 15-25 year relationships with clients, they do now; this has created a big shift in the types of connections that they are developing, sustaining and managing with clients.

The results of a study looking into the experiences of outreach workers in Ontario drew attention to this issue. In this study, the outreach workers who participated in needle exchange programs felt a strong commitment to their long-term clients and provided extra assistance to ensure that the clients’ needs were met. Outreach workers knew that providing extras for clients cemented their relationships with them, and that for many clients, their program was the only stable source of support.⁷⁷

⁷⁶ As quoted in Strike et al., 2004.

⁷⁷ Strike et al., 2004.

Developing Professional Boundaries

Formal caregivers who were interviewed as part of this study were asked how they set professional boundaries with clients. Replies revealed that service providers were quite alone in this process. Many of them learned how to create and enforce professional boundaries on their own, by trial and error:

- ***“I think that, ah, I’ve learned some very hard lessons along the way.”***
- ***“In this job you have to know your boundaries and you’re always crossing and making mistakes and going back and going, ‘okay, how do I change this for next time?’”***
- ***“Well some things are grey and some things have been up for discussion and such, right.”***
- ***“Well I’ve been doing it for a really long time so a lot of it is just really intuitive.”***
- ***“I make up my own rules that protect me; that’s it.”***

One service provider spoke about relying on organizational policies to help deal with client-staff member relations:

- ***“I fall back on the old, um, you know, due to the nature...ummm...the policies of the organization, you know, we have to, we just can’t go there.”***

In addition to asking how staff members established professional boundaries, the research team also enquired about how clear and consistent they were when applying boundaries. Some staff members demonstrated a determined level of clarity and consistency, while others did not:

- ***“I have very firm boundaries that I have to have professionally, you know, so I can’t share; and it’s about them and their time; it’s their space to heal and move forward. It’s not my space; I have other spaces.”***
- ***“Sometimes you do wanna cross boundaries or get more or you know there’s people I meet that I enjoy tremendously, would love to be friends with them; can’t do that. I could never bring that into another realm and sustain that. It’s just inappropriate.”***

- ***“A client says ‘Oh, can we go out for coffee some evening just to talk?’ I can’t do that...I can’t give out my home phone number to a client.”***
- ***“Yeah, no, they’re not entirely consistent from client to client . . .There’s things I will do for some clients that I wouldn’t do for others.”***
- ***“..Not clear, I’ve maintained boundaries, but they are not clear.”***

Caring for the Caregivers: The Provision of Organizational Support

Formal caregivers indicated that they had little guidance and support from their organization when it came to developing guidelines around client-staff relationships. Others, who spoke about the existence of organizational policies around professional boundaries, did so in a critical fashion:

- ***“We have these boundaries that we have to abide by, which some days I think is a crock of crap.”***
- ***“I often find that some of those [organizational] policies are contradictory, like in our theories and practice of work that we are trained to do, you’re first, you’re told to help others, that you’re there to help them, but they [management] put policies in place, and rules in place where they inhibit you...from helping.”***
- ***“I think that management tries to understand or support certain things, but management is disconnected from people to a degree. The support that’s offered is really, um, telling you what you need to do. You need to go for a massage. You need to take a flex day; you need to go out and have a day just for you...whatever, I get that and it’s probably true, but, you know, the management life isn’t my life. Sometimes life doesn’t allow for that.”***

The type of work that staff members in AIDS service organizations are involved in, can be emotionally draining. In this light, many of the service providers interviewed felt that their organizations could do more to enhance their wellbeing:

Interviewer: So is this organization doing what it can to support the staff?

Service Provider: [shakes her head fervently and laughs] “You can say that out loud.”

Without enhanced supports, high staff turnover levels will continue:

- ***“I think it’s the staff turnover . . . it’s like some crazy South American country where people would be gone in the middle of the night and there’s nothing ever said.”***

When asked to offer suggestions for improvement, one interviewee noted the need for management personnel to interact and be more responsive to the needs of clients:

- ***“I think some people in management need to interact with the clients more . . . [As someone in management] you hear about it but you’re not in it so you can detach from it.”***

Furthermore, over half of the service providers who were interviewed indicated that some kind of staff retreat or regular bonding activity would be helpful. Others noted the need for more debriefing sessions, enhanced communication within the agency, and increased recognition that staff members are knowledgeable and hard working.

PART 7

Conclusions and Recommendations

In Canada, as elsewhere, HIV/AIDS disproportionately affects poor and stigmatized communities. The role and extent to which social support and informal care networks influence the lives of people affected by the illness have been largely unexplored, particularly in medium and small sized Canadian cities. Through photographs and personal interviews, this study explored the social and caregiving networks of persons affected by HIV/AIDS in Winnipeg and Regina. The study's focus was on learning the experiences of people from disadvantaged and/or stigmatized communities, such as drug users, homeless persons, newcomer refugees and Aboriginal People. With cameras in their own hands, persons affected by HIV/AIDS were able to photograph and discuss their own realities from their point of view. Service providers were also interviewed to shed light on their experiences when working with clients affected by HIV/AIDS.

The results of this study indicated that the presence of a single, available and capable "informal" caregiver in the life of a PLWHA was rare. The findings challenged the view that - with HIV/AIDS becoming a chronic disease - the responsibility assigned to "informal" caregivers such as family members, intimate partners and close friends has greatly increased.⁷⁸ In fact, this study suggests that PLWHAs who come from low income and/or stigmatized communities rely on similarly disadvantaged peers and on "formal" caregivers for support and assistance. Hence, it cannot be assumed that family members, intimate partners or close friends provide the necessary instrumental or emotional care for all persons living with HIV/AIDS.

Non-human sources of support were important to this study's community project participants. In fact, pets, plants, nature and (for Aboriginal respondents, cultural identity) were repeatedly cited as sources of resiliency, strength and support. Formal caregivers were integral in the lives of PLWHAs, and were often regarded by their clients as friends or family members. Where staff may now have 15-25 year relationships with clients, creating a lengthy and possibly different client-staff relationship.

Although the lives of this study's project participants were riddled with violence and risk, there are clear features to which they turned for support and strength. Honing in and

⁷⁸ Wrubel J, and Folkman, S. (1997). What informal caregivers actually do: The caregiving skills of partners of men with AIDS, *AIDS CARE* 9(6): 691-706.

enhancing these features through programs and services can only improve the situation of stigmatized yet hopeful and resilient persons affected by HIV/AIDS.

The following recommendations stem from the findings of this study:

- **Assess both human and non-human sources of support for clients affected by HIV/AIDS.** Social programs which incorporate pets, plants and cultural identity, may be particularly valuable and effective to this clientele.
- **Pay increased attention to the informal care dynamics of clients, and be alert to the areas where social or family networks cannot meet the basic needs of a client living with HIV/AIDS.**
- **Further develop and evaluate programs whereby client peers connect with one another. These programs should value clients' connections to their street communities (e.g., what is good about their connections) and the strengths they exhibit in those communities.** In this study, a significant number of participants formed bonds with people who were equally stigmatized and impoverished. Participants connected with others who had shared similar overwhelming experiences, which gave them a sense of comfort and support. As such, programs should not focus solely on clients' vulnerabilities or poor health related behaviours; they also should endeavour to foster healthy connections among peers.
- **Ensure health and social programs recognize and help ameliorate (via guaranteed referrals) clients' pressing issues that are not related to HIV/AIDS (e.g., poverty, housing, and violence).**
- **Organize workshops within service organizations whereby front line staff members and management develop clear yet flexible professional boundaries.** Since boundaries can be subject to change, they need to be continuously discussed and debated among staff members. Ongoing meetings between supervisors and staff members are crucial. Ideally these meetings should be characterized by full and honest communication between the parties involved.⁷⁹ Discerning supervisors create an environment that encourages disclosure and discussion of concerns and professional boundary issues.

⁷⁹ Knapp, S., and Slattery, J.M. (2004) Professional Boundaries in Nontraditional Settings. *Professional Psychology: Research and Practice* 35(5): 553-558.

- **Organize staff retreats or regular bonding activities, so that staff members among different areas can debrief with one another and communicate stressors, concerns and promising practices.** During these retreats and meetings, recognize that staff members are knowledgeable and hard working, and that they need to take care of themselves as well as their clients.
- **Create opportunities for management to interact with clients and learn about how violence, death, colonization and other factors affect clients' every day realities.**
- **Develop contextually responsive organizational policies.** Each organization has a different set of clients and organizational needs. Within the context of HIV/AIDS, it is also important to remember that, as the course of the illness and the medical interventions shift, so do the needs of the clients, the staff and the organizations. PLHWAs are living longer lives and developing long term relationships with service providers. Formal caregiving systems should develop strategies to support long-term chronic care patients.
- **Fund and undertake research studies examining the experiences of Aboriginal People affected by HIV/AIDS.** The notable over-representation of Aboriginal People in HIV/AIDS statistics strongly suggests a need to place them on the research, policy and program agendas.

PART 8

To Disseminate is to Act

The research team shared the results of this study in various ways. We gave talks at local, national and international conferences.^{80 81 82 83 84} We submitted manuscripts to peer-reviewed journals, we drafted reports, and we delivered information sessions to share findings with AIDS service organizations. The intention of all of our dissemination activities was to better serve people currently living with HIV/AIDS.

While academic papers and conference presentations certainly have value, they are often inaccessible to community members. Furthermore, professionals who offer services to stigmatized populations rarely read such literature or attend scholarly conferences. In an attempt to create a dissemination tool that could engage community participants, their caregivers and other key stakeholders, we wrote a play (i.e., a script) based on the data that was attained and analyzed throughout the project. Called Reader's Theatre, this was the least traditional but possibly most fulfilling dissemination activity that we engaged in. With different themes being divided into different scenes, there are opportunities to pick and chose which aspects of the data to present to a given audience.

Reader's theatre scripts are written so that people read from the script in front of the audience; this cuts production costs as there is no rehearsal process or set development, and it serves to make the work more portable: readers can be selected from the audience, so actors do not have to be transported along with the play. A single

⁸⁰ Migliardi, P, Pindera C, Davis J, Harvey C, Mignone J (2010) Ethics in Innovative knowledge dissemination: the use of reader's theatre on issues with vulnerable people living with HIV. *XVIII International AIDS Conference*. Vienna, Austria, July.

⁸¹ Migliardi P, Harvey C, Mckay-McNabb K, Mignone K (2010) Family support among people living with HIV/AIDS in the Prairies. *New Challenges, New Commitments: 19th Annual Canadian Conference on HIV/AIDS Research*. Saskatoon, May.

⁸² Migliardi P, Pindera C, Mignone J, Harvey C, Davis, J (2010) Use of arts-based approaches to engage marginalized populations in HIV research on social support: from individual snapshots to collective performances. *Canadian AIDS Society, Skills-Building Symposium*. Montreal, March.

⁸³ Mignone J, Pindera C, Davis J, Elliott L, Oghiakhe T. (2010) Bound by boundaries: The informal/formal care divide in the HIV/AIDS field. *New Challenges, New Commitments: 19th Annual Canadian Conference on HIV/AIDS Research*. Saskatoon, May.

⁸⁴ Mignone J, Harvey C, Elliott L, Pindera C, Davis J, Migliardi P. (2010) When photos tell the story: Using cameras to examine social support and HIV with marginalized populations. *AIDS Conference*. Winnipeg.

facilitator can lead the activity with a group of participants. The script is accessible to many people, and it can be presented anywhere quickly and easily.

By using the voices of the study participants in writing the theatre script, we made their ideas appeal directly to the audience. The theatre productions also offered an opportunity for a visual representation of some of the photos from the data set as a backdrop for the play.

The play was written with very careful consideration to confidentiality. All identifying information was removed; the dialogue was carefully created with chosen quotes from participants intertwined with each other; the play was set so that no persons would be reading from any one demographic group (gender, cultural background, HIV status, etc.) as these were all intertwined with each other as well. We read the initial script with the participants and obtained unrestricted consent from them to produce the play publically. Community participants provided feedback before the final script was completed. In this way, participants may have felt strengthened by the experience as they heard their voices come to life. Through the script, we presented the research results to various audiences in Regina and Winnipeg. In most of these representations, study participants themselves were hired to be readers.

In reaching a wider audience, Reader's Theatre along with more conventional dissemination activities allowed for the study to become a catalyst for programmatic change, and signified one more step towards enhancing the support networks of people affected by HIV/AIDS.

References

- Allen, K. (2003) Are Pets a Healthy Pleasure? The Influence of Pets on Blood Pressure. *Current Directions in Psychological Science* 12(6): 236-239.
- Amaratunga, C., and Gahagan, J. (2002) Striking to the Heart of the Matter - Selected Readings on Gender and HIV. Atlantic Centre of Excellence for Women's Health. Retrieved from http://www.acewh.dal.ca/pdf/Striking_to_the_Heart_of_the_Matter.pdf
- Catz SL., Kelley J., Bogart L., Benotsch E., and McAuliffe, T. (2000). Patterns, Correlates, and Barriers to Medication Adherence Among Persons Prescribed New Treatments for HIV Disease. *Health Psychology* 19(2): 124-33.
- Ciambrone, D. (2002) Informal networks among women with HIV/AIDS: present support and future prospects. *Qualitative Health Research* 12(7): 876-896.
- Dickson-Swift, V., James E.L., Kippen, S., and Liamputtong, P. (2009). Researching sensitive topics: qualitative research as emotion work. *Qualitative Research* (9)1: 61-79.
- Edwards, L. (2006). Perceived Social Support and HIV/AIDS Medication Adherence Among African American Women. *Qualitative Health Research* 16(5): 679-91.
- Friedland, J., Renwick, R. and McColl, M. (1996). Coping and social supports as determinants of quality of life in HIV/AIDS *AIDS Care* 8(1): 15-31.
- Gonzales JS, et al. (2004). Social support, positive states of mind, and HIV treatment adherence in men and women living with HIV/AIDS. *Health Psychology* 23(4):413-418.
- Interagency coalition in AIDS and development (2006). HIV/AIDS in African Diaspora Communities Living in Canada. Retrieved from http://www.icad-cisd.com/pdf/HIV-AIDS_AfricanDiaspora_EN.pdf
- Johnston, D., Stall, R., and Smith, K. (1995). Reliance by Gay Men and Intravenous Drug Users on Friends and Family for AIDS-Related Care. *AIDS Care* 7(3): 307-320.
- Knapp, S., and Slattery, J.M. (2004) Professional Boundaries in Nontraditional Settings. *Professional Psychology: Research and Practice* 35(5): 553-558.
- Knowlton, AR. (2003) Informal HIV caregiving in a vulnerable population: toward a network resource framework. *Social Science & Medicine* 56(6): 1307-1320.
- Knowlton AR, et al. (2011). Informal care and reciprocity of support are associated with HAART adherence among men in Baltimore, MD, USA. *AIDS Behaviour* 15(7):1429-36.

Land, H., and Hudson, S. (2002). HIV serostatus and factors related to mental and physical well-being in Latina family AIDS caregivers. *Social Science and Medicine* 54 (1): 147–159.

Leserman, K., Perkins DO, and Evans DL. (1992). Coping with the threat of AIDS: the role of social support. *American Journal of Psychiatry* 149(11): 1514-1520.

Manitoba Health (n.d.) Statistical Update: HIV and AIDS – Report to December 31, 2009. Retrieved from <http://www.gov.mb.ca/health/publichealth/surveillance/hivaids/dec2009.pdf>

McCausland, J. and K. I. Pakenham (2003). Investigation of the benefits of HIV/AIDS caregiving and relations among caregiving adjustment, benefit finding, and stress and coping variables. *AIDS Care* 15(6): 853-69

Migliardi P., Harvey C., Mckay-McNabb K., and Mignone J (2010). Family support among people living with HIV/AIDS in the Prairies. New Challenges, New Commitments: 19th Annual Canadian Conference on HIV/AIDS Research. Saskatoon, May.

Migliardi, P, Pindera C, Davis J, Harvey C, Mignone J (2010) Ethics in Innovative knowledge dissemination: the use of reader's theatre on issues with vulnerable people living with HIV. XVIII International AIDS Conference. Vienna, Austria, July.

Migliardi P, Pindera C, Mignone J, Harvey C, Davis, J (2010) Use of arts-based approaches to engage marginalized populations in HIV research on social support: from individual snapshots to collective performances. Canadian AIDS Society, Skills-Building Symposium. Montreal, March

Mignone J., Harvey C., Elliott L., Pindera C., Davis J., and Migliardi P. (2010) When photos tell the story: Using cameras to examine social support and HIV with marginalized populations. AIDS Conference. Winnipeg.

Mignone J., Pindera C., Davis J., Elliott L., and Oghiakhe T. (2010) Bound by boundaries: The informal/formal care divide in the HIV/AIDS field. New Challenges, New Commitments: 19th Annual Canadian Conference on HIV/AIDS Research. Saskatoon, May.

Public Health Agency of Canada (2010). HIV and AIDS in Canada. Surveillance Report to December 31, 2009. Ottawa 2010. Retrieved from <http://www.phac-aspc.gc.ca/aids-sida/publication/survreport/2009/dec/index-eng.php>

Public Health Agency of Canada (n.d.) Population Specific HIV/AIDS Status Report – Fact Sheet. Retrieved from <http://www.phac-aspc.gc.ca/aids-sida/publication/ps-pd/pdf/factsheet-info-eng.pdf>

Saskatchewan Ministry of Health (2009). HIV and AIDS in Saskatchewan 2009. Retrieved from <http://www.health.gov.sk.ca/hiv-aids-annual-report-2009>

Saskatchewan Ministry of health (2010) Saskatchewan's HIV strategy 2010-2014. Retrieved from <http://www.health.gov.sk.ca/hiv-strategy-2010-2014>

Ship, J. and Norton, L. (2001). HIV/AIDS and Aboriginal women in Canada. *Canadian Women Studies* 21(2): 25-31.

Siegel JM., Angulo FJ., Detels R., Wesch J., and Mullen A. (1999). AIDS diagnosis and depression in the multicenter AIDS Cohort Study: the ameliorating impact of pet ownership. *AIDS Care* 11(2): 157-70.

Simoni, J. M and N. A. Cooperman (2000) Stressors and strengths among women living with HIV/AIDS in New York City. *AIDS Care* 12(3): 291-97.

Smith, M and B Rapkin (1996). Social Support and Barriers to family involvement in caregiving for persons with AIDS: implications for patient education. *Patient Education and Counselling* 27(1): 85-94.

Stein, J. A. and A Nyamathi (2000) Gender differences in behavioural and psychosocial predictors of HIV testing and return for test results in a high-risk population. *AIDS Care* 12(3): 343-56.

Strike, C., O'Grady, C., Myers, T., and Millson, M. (2004) Pushing the Boundaries of Outreach Work: The Case of Needle Exchange Outreach Programs in Canada. *Social Science and Medicine* 59(1): 209-219.

Tharao, E. and Massaquoi, N. (2001). Black Women and HIV/AIDS Contextualizing Their Realities. *Canadian Woman Studies* 21(2): 72 -80.

Ungerson, C. (1990). The language of care: Crossing the boundaries. In C. Ungerson (Ed.), *Gender and caring: Work and welfare in Britain and Scandinavia* (pp. 8–33). New York: Harvester.

Wang, Caroline (2006). Youth Participation in Photovoice as a Strategy for Community Change. *Journal of Community Practice* 14(1): 147-161.

Ward D, and Brown, MA (1994) Labour and cost in AIDS family caregiving. *Western Journal of Nursing Research* 16 (1): 10-25.

Wight, R. G. (2000). Precursive depression among HIV infected AIDS caregivers over time. *Social Science and Medicine* 51(5): 759–770.

Winnipeg Regional Health Authority. (2009). Working with Immigrant Communities: A Guide for Service Providers: The Improving Access Project.

Worth, H., Denholm, N. and Bannister, J (2003). HIV/AIDS and the African Refugee Education Program In New Zealand. *AIDS Education and Prevention* 15(4):346-56.

Wrubel J, and Folkman, S. (1997). What informal caregivers actually do: The caregiving skills of partners of men with AIDS, *AIDS CARE* 9(6): 691-706