

Informal Caregiving Networks and HIV/AIDS: A Community-Based Study



Final Report - Summary

March 2010

This project was a partnership between Family Social Sciences the University of Manitoba and Nine Circles Community Health Centre in Winnipeg and AIDS Programs of South Saskatchewan and All Nations Hope in Regina.

Team members

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HIV Community-Based Research Program

Research Goal

The purpose of this research was to describe and understand the care experiences of both those people living with HIV/AIDS and their informal caregivers, with a focus on low income or stigmatized individuals in Manitoba and Saskatchewan.

Specific Research Questions

- ❖ Upon what types of caregiving networks do people living with HIV/AIDS in Manitoba and Saskatchewan rely? How are these networks developed and maintained? Who belongs to these networks? What are the roles of caregivers in the lives of PHAs?
- ❖ How do caregiving networks affect the quality of life of both the caregiver and care recipient? What are the costs and benefits (both social and economic) associated with caregiving for the caregivers and the care recipient?
- ❖ What are the caregiving and social support needs and issues among different affected groups? How do these needs differ among people living in a resource poor setting, possibly in the context of limited access to formal care systems?

Background parameters

The research was a result of several shifts that had been noted by AIDS Service Organizations in the demographics of the disease as well as its effect on people living with HIV or AIDS (PHAs). Ultimately the goal was to increase the understanding of the needs and wants of those providing care as well as those receiving it.

Shifting Virus

An HIV+ diagnosis was once considered a fatal disease and it meant that a person had relatively little time to get themselves prepared for their death. Systems were put in place to support PHAs with this in mind and both PHAs and their caregivers prepared themselves accordingly for this inevitability.

Canadian PHAs now have access to more effective medications and more information about healthy living with HIV; for the most part, they are living longer and healthier lives. This affects PHAs and their caregivers.

Aside from the shift in the medical implications of the illness, the demographics of PHAs are shifting. Early in the evolution of the virus, the white MSM (Men who have Sex with Men) population was the largest represented population in North America. Currently, the virus is disproportionately affecting people with less power and/or money.

Winnipeg and Regina / Manitoba and Saskatchewan

Currently, in Manitoba, a total of 1477 people have tested HIV antibody positive. In Saskatchewan a total of 707 people have tested HIV antibody positive. (Manitoba Health Statistical Update on HIV/AIDS, 2007) (Saskatchewan Health, 2008)

Accessing Informal Care

If PHAs have support, they may be able to cope with their disease and its effect more readily. Unfortunately, however, the stigma of HIV is strong enough to prevent some PHA's from having solid supports, especially those who are highly stigmatized in other ways. In order for effective caregiving to occur, there must be an element of trust and communication between the caregiver and the person requiring care. With a culture stigmatizing PHAs and holding on to poor information about HIV and AIDS, truth and trust become more difficult. With the influx of individuals from cultures with even stronger myths about HIV/AIDS and stronger stigmas against PHAs, the difficulties compound.



Methodology

Participants

All of the project participants live in either Winnipeg or Regina. Recruitment was made through various social service and medical institutions in the two cities, with a focus on low income or highly stigmatized individuals.

The project was completed with 31 participants, 20 from Winnipeg and 11 from Regina.

Photovoice

Photovoice offers participants an opportunity to take photos of whatever they perceive to be following the guidelines of the project; in this case, their supports. There are no restrictions on the photos they take (except legal ones) and guidelines are presented at an initial meeting and orientation. 804 photos were returned by the 31 participants.

Interviews

The interviews were held individually, using a set of the individual's photos to create the parameters for the interview. Otherwise the interviews were unstructured, with the project goals providing a soft focus for the interviewer. Each interview lasted about an hour. Seven participants had two interviews and two couples did their interviews together (although one of these participants did a second interview by herself). The interviews were digitally recorded and transcribed verbatim.

Findings

Formal vs. Informal Caregivers

The first significant discovery was the fuzzy ground between a formal and an informal caregiver. The project team had relatively clearly defined definitions for the two (*formal* being paid or volunteering to complete their caregiving responsibilities and *informal* being a friend or family member), but the participants did not. This led to a subset of data collection that included interviewing 17 *formal* caregivers (14 Winnipeg, 3 Regina) with a more structured format including a set of questions based on boundaries and their own personal and professional supports.



Findings

From the original participant set of interviews and photos, the following themes were developed:

Caregiving

People had different definitions of caregiving for themselves. What it meant to them, how they offered and/or received support and what it meant to them.

Most spoke about care in a very tangible and physical sense (sharing food, offering a place to stay, getting money for travel, etc.). It was often associated to basic needs and usually represented needs from a poverty perspective rather than an HIV or illness perspective.



Childhoods

Sixteen participants spoke of their childhoods without being specifically asked; of those, 15 indicated a history of abuse, violence, adoption, displacement or other difficulties.

Children

Of the 31 participants, 25 have children of their own. Of those, 11 have no contact with their children. They are in the child welfare systems in one way or another. The other 14 have good or relatively good contact with their children. Most of these children are living with ex-partners or other relatives. Only 2 have had uninterrupted care of their children.

Coping Strategies

The project team focused the study on low income or stigmatized individuals. This population is known to struggle with health concerns. The population offered strong examples of violence (current and ongoing since childhood), discrimination, transience, isolation, displacement and death.

Alcohol and Drug Use



Over 2/3 of the participants indicated a current or past struggle with drugs and/or alcohol. Some indicated that their drug use had begun in childhood. Others indicated that they use drugs daily to cope with their lives. One participant indicated a drug connection with every person they took a photo of. Others connected their drug use to the ongoing drug use of their parents.

Culture

Many of the Aboriginal participants had been cut off from their culture as infants or children and struggled with their identities and how to reconnect with their culture.

Death

The reality of death and dying was present throughout the project.

Displacement

Only 4 of the participants were originally from Regina or Winnipeg. Of the 31 participants, only 13 were raised by their biological parents.

Dreams

Thirteen of the participants spoke about their dreams. The dreams expressed varied widely and some examples include: "to grow old and die," "to not have HIV," "to own a house outside the city where I can grow my own vegetables," "to be an addictions counselor."



Education

The education levels ranged from a grade-four education to university graduation.

Employment / volunteering

Two of the participants indicated that they had full-time employment; 17 don't work at all, (3 of those would like to); 11 work casually or illegally and 1 shifted from unemployed to employed between their two interviews.

Isolation

Many of the participants were quite isolated. This is very difficult to quantify and specifically define, but individuals repeatedly stated that they would not or could not ask for help.



Non-human Supports

Eleven of the participants live with pets. They came up repeatedly in the interviews as those who did live with pets took multiple photos of them and spoke a great deal about their relationships with their pets. Plants also came up as a support for participants. Other non-human supports mentioned included: movies, nature, art, city buildings, computers (some were connected to other people through e-mail and other social utilities, but many used the internet to surf sites unrelated to dealing with humans on a social level).



Refugee

Two participants are refugees; each from an African country. While not enough information was gleaned to make any kind of statements about refugees from this study, it was clear that these two belong in a different category for analysis. Their issues were connected to being a newcomer to our country and culture. Language, employment, accommodation, etc were the issues that came up predominantly here. There were also strong emotional connections to the violence of war experience in their homes and other issues related to being in a refugee camp overseas, but again, this was not directly connected to their HIV status.

Relationships

Relationships were an interesting theme to examine. The relationships presented were often convoluted and confusing and many participants had people coming in and out of their lives rather quickly. Isolation was a recurring theme, as was violence (within and outside of the relationships mentioned).

Networks of care

Five of our participants did indicate a partner who was providing much of their care and/or support. The others were not relying heavily on anyone. While most of the participants did not have caregivers as expected, it was noted that there were interesting networks of care. Circles of support, that may or may not include their families, connected a number of the participants together as peer supports. The general picture presented was of a very transient lifestyle with a loose circle of friends that was connected through drugs, extended family ties and poverty. "Clumps" of

support also existed, often through an organization; they did not seem to interweave with each other.

Resilience and resourcefulness

Members of the project team were often struck by the resilience shown by the participants. After offering tales of violence, abuse or such difficulties as most people would never face, participants would indicate the desire to keep on going or to face their difficulties head-on. As a group, they presented tremendous ability to cope with their lives. It was by no means all joy and prettiness, but there was a surprising amount of hope and joy offered through the interviews and tremendous examples of resiliency and resourcefulness.

Stigma

Stigma is a presence in virtually all of the participants' lives. It's a layered and complex theme that presented itself repeatedly in many guises. Participants felt it as discrimination against their HIV, their culture or race, their sexual orientation, their poverty, their abilities (and inabilities or disabilities), their gender and/or sex, their drug use, and their levels of education. Most of the participants felt this stigma throughout their lives and in layers, compounding against them.

Transience

Because of their low positions in society or because of their lifestyles or both, many of the participants are susceptible to being pushed out of apartments as much as they simply move from house to house, sleeping where they can.



Violence

The violence represented in the participants' lives was layered and complex. In the initial analysis, we divided the violence into sections:

Childhood Violence

As noted elsewhere, their childhoods were often violent. Memories of substance abuse, physical, sexual and emotional abuse, racism and displacement spoke of a population who began their lives in under tremendously difficult circumstances.

Street Violence

This was defined as violence occurring in public, usually outside. Beatings, attacks, etc. were discussed in the interviews as part of the daily life for many of the participants.

Drug Violence

Many of the participants used drugs or alcohol as a coping mechanism. The violence associated with their use was prevalent enough to be given a category of its own.



Current Violence

This was used to differentiate between the violence talked about in the participants' histories and the violence experienced in their current lives. A number of the participants lived lives of extreme violence in their current lives, and less in their childhoods, or vice versa, or violence in both or neither. A pattern of long-term violence appeared for many when the two are separated as such.

Formal Caregivers

With the realization that so many of the participants were naming formal caregivers as their friends and family members - and that there was a gap in their informal caregiving networks, the project team chose to supplement the research with an additional piece on this topic alone. Seventeen formal caregivers (14 from Winnipeg and 3 from Regina) were interviewed for this secondary phase.

As noted through the initial set of interviews, boundaries were a big concern. The participants had indicated that many of the formal caregivers were not only their primary supports, but that they were named as friends and even family members. Many of the formal caregivers had had to navigate the fuzzy ground between job responsibilities and connections with their clients without the benefit of support from their organizations, not necessarily because the organizations didn't want to support, but because the nature of the relationships themselves are so nebulous as to make clear policies virtually impossible to create. The major areas were with setting boundaries, ensuring consistency and clarity with clients, how to define "friendship", the place of friends as clients, and organizational policies.

Support was also an issue that was raised. With regards to client support, most Winnipeg service providers felt that the organizations they were working for supported their clients very well. Regina interviewees, on the other hand, suggested that their organizations were not really supporting their clients to the best of their ability. Issues that came up included accountability and community representation.

With regards to staff support, there was a feeling across the board that more could be done in this area. The work is draining and can be traumatic for the staff; most of the service providers interviewed felt that their organizations could do more to support them better. When asked to offer suggestions for improvement, well over half those interviewed indicated that some kind of staff retreat or regular bonding activity would be helpful. Other suggestions offered by staff included debriefing sessions, better communication, more recognition that staff is knowledgeable and working hard, more team work between areas, more understanding of the effects of violence, death and other vicarious trauma on the staff.

Photo Analysis

There was no restriction on the number of photos any participant could take so the project gathered a much higher number of photos than the Photo Voice methodology recommends. Eight hundred and four photos were developed from 31 participants. Analysis is in progress.

Presentations - dissemination

Conference Oral presentations

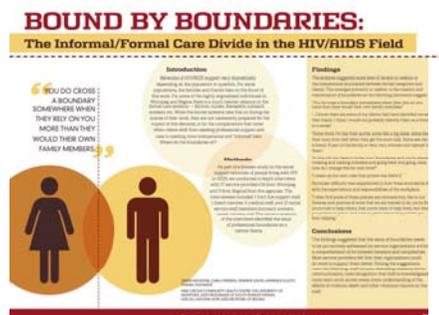
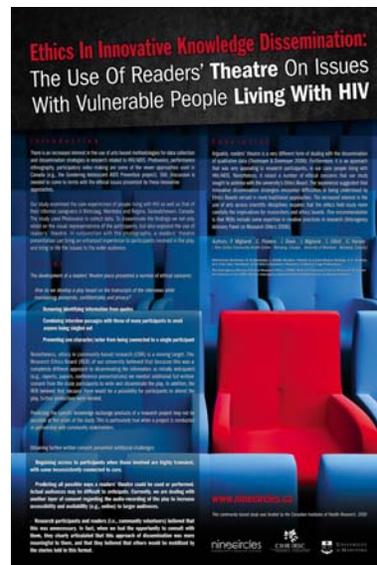
- Social Supports and Caregiving among Aboriginal Women Living with HIV, Wise Practices III: Creativity + Research = Positive Action, Conference of the Canadian Aboriginal AIDS Network, Halifax, March 2011.
- Bound by Boundaries: Informal/Formal Care Divide in the HIV/AIDS Field. Annual Manitoba HIV conference - Winnipeg - October 2009
- Caregiving in the Context of HIV: A Manitoba Saskatchewan Research Project, 17th Annual Canadian Association of Nurses in AIDS, Saskatoon, April 2009.
- Windows and Walls: Care Experiences of People Living with HIV/AIDS, 14th Qualitative Health Research, Banff, October 2008
- Research with photography: Methodologies, Assumptions, Emerging Themes, Beyond the Epidemics Conference, Regina, September 2008.

Colloquium presentations

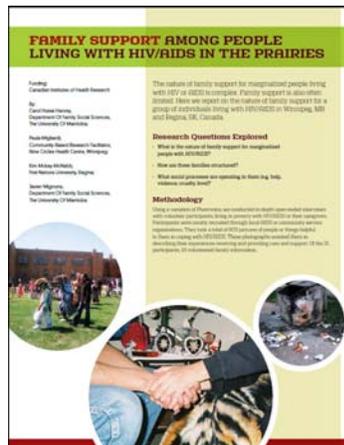
- Caregiving Networks and HIV: A Photographic Look at Networks of Care in Winnipeg and Regina. Community Health Sciences, UM Colloquium, January 2010
- Use of photovoice in informal caregiving in HIV, Qualitative Research Colloquium, May 2009, Winnipeg

Poster presentations:

- Ethics in innovative knowledge dissemination: the use of reader's theatre on issues with vulnerable people living with HIV AIDS 2010, Vienna, July 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 2010.



- Family Support among People Living with HIV/AIDS in the Prairies, Annual conference of the Canadian Association of HIV Research (CAHR), Saskatoon, May 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 2010.



Informal Caregiving Networks and HIV/AIDS: A Reader's Theatre Performance

- Unitarian Church congregation, Winnipeg, December 2010
- Connecting Communities Coalition World AIDS Day Community Event, December 2010
- CATIE Western Regional Conference, Saskatoon, May 2010
- Park Theatre – Winnipeg, April 2010
- Nine Circles Lunch and Learn, Winnipeg, March 2010
- Reader’s Theatre presentation to the participants – Winnipeg, February 2010

Photographic Installation

- Urban Shaman Gallery, Winnipeg, February 4 – March 19 2010
- Centennial Concert Hall in Conjunction with the Winnipeg Symphony Orchestra’s 20th New Music Festival, January 2010

