



Canadian Palliative Care Association
Association canadienne des soins palliatifs

HIV & AIDS Palliative Care Needs in the Prairie Region

February 2000

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It did strike me as odd, sometimes, that we should pray to be delivered from 'plague, pestilence, and famine' when all the common sewers ran into the Thames, and fevers haunted undrained land, and the districts which cholera would visit could be pointed out. I thought that cholera came that we might remove these causes, not pray that God would remove the cholera.

– *Florence Nightingale*

Presented to:

Canadian Palliative Care Association

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Foreword

This report is dedicated to those who have died and those living with HIV/AIDS and their caregivers.

We started this needs assessment with a number of assumptions about the palliative care needs of people living with HIV in the Prairie provinces. The assumptions came out of the research group members' varied experiences in street outreach, HIV prevention education and HIV clinical care, all in community-based organizations. Many of our assumptions were justified. Some results were unexpected. We found that the term "palliative care" often triggers a fear response and is just about extinct in service providers' usage with clients. We didn't expect the degree of isolation, loneliness and suffering that is experienced by those living with HIV.

As one of our beginning assumptions stated: "Many PHAs currently 'fall through the cracks' of existing palliative care services... People deserve dignity in dying. Approaches to end-of-life care are highly individual and should be based on each person's distinct profile of needs in a client-centered model of care." We hope this report will assist caregivers at home, in hospice or in palliative care units of hospitals to get the resources they need to inform and support them. Most of all we hope it will help to improve the quality of life for people living with HIV.

Acknowledgements

We wish to thank all the persons living with HIV/AIDS who participated in the focus groups and who answered questionnaires. We also thank those busy caregivers who shared their thoughts and time in the interviews. Thank you to the people working at all levels of organizations for taking the time to answer questionnaires, and to the staff in clinical settings and community-based organizations who distributed questionnaires to clients, your assistance is very much appreciated. Finally, our gratitude to the Canadian Palliative Care Association and the members of the HIV/AIDS Committee for the opportunity to carry out this needs assessment on your behalf.

Cover Art

Karen Cook Hutchinson is a 23-year old Aboriginal artist from Grand Rapids in northern Manitoba. She lives in Winnipeg and has studied Fine Arts at the University of Manitoba.

Executive Summary

We approached the “problem” of palliative care and HIV/AIDS as informed and sympathetic listeners with direct experience in the provision of care to people living with HIV/AIDS (PHAs). Our goal was to assess the needs of PHAs for end-of-life care both inside and outside the palliative care system in the prairie provinces. Research was conducted from September 1999 to January 2000. A range of data collection tools were used, including mailed surveys, focus groups and in-depth interviews.

The profile of PHAs who participated in this needs assessment matches the epidemiological profile of new infections in the prairies (injection drug use, ethnicity and gender). For example, 36% of new infections in Manitoba in 1999 were among Aboriginal people, who make up 35% of our sample in client survey participants, and 50% of focus group participants.

Background

The epidemic’s changing profile presents a challenge to traditional approaches to HIV care and palliative care. Traditional palliative care systems are not connecting with HIV clients. Most palliative care organizations who participated in this assessment reported that they had no HIV clients, or only one or two in the last few years. An HIV physician reports in an in-depth interview that her patients die of acute illness, and do not ever get to the stage of needing palliative care.

Needs are complex and fluctuating, as women, injection drug users, Aboriginal people, younger people, people with mental health issues, solvent users, people living in poverty and those infected with Hepatitis C become infected with HIV. This diversity of client profile points to a need for a broad, flexible approach to palliative care, in order to make these services available to a range of people.

The complexity of AIDS care is a major theme of this assessment. PHAs often experience episodes of severe illness followed by long periods of stable health. It is difficult to know when to begin “palliative” services. Again, we see a need for a flexible and dynamic approach to palliative care that is integrated with community HIV care. Increasingly, the term supportive care is being used instead of palliative care, recognizing the need to provide “whole person care of the living” throughout the “roller coaster ride” of HIV illness.

Further complicating matters, treatment regimens are complex and experimental, and side effects are severe and unpredictable. Only 63% of client survey participants in this assessment are taking antiretroviral medications, demonstrating that these treatments are not for everybody and alternative avenues of care need to be explored.

Medical Indications for Palliative Care

Just over one third (35%) had been diagnosed with HIV since 1996, including 53% of women and Aboriginal participants. Eighty percent of client survey respondents reported some experience of pain, with over half reporting medium to high levels of pain.

Access to Services

Information related to services provided to PHAs showed a relatively high level of satisfaction with physicians, nurses, home care workers, nutritionists and others. The highest rating of satisfaction was given by the five Aboriginal clients who had received the services of a traditional healer, perhaps indicating a need for increased access to cultural services. A significant minority (20%) of client participants reported that they had experienced professionals who were unwilling or incapable of providing HIV care.

Organizations surveyed reported a general lack of resources for the palliative care system, however 61% of organizations reported they had a palliative care team, including physicians, nurses, specialists, social workers etc. Nearly half (45%) reported having formal linkages with other organizations in the delivery of palliative care, and 85% reported informal linkages.

Quality of Life

Client survey participants were asked to list their main pleasures – 84% referred to relationships with partners, children, family, friends etc. They were also asked to list the things that gave meaning to their lives. Again, 75% referred to relationships and friendships, with 48% referring to work, hobbies and activities as giving meaning. This demonstrates the importance of connection in quality of life, and may also suggest the need for building and sustaining relationships between care providers and clients as a strategy for quality care.

Preferences for Palliative Care

For those who had already required assistance for an HIV-related illness, 47% reported that their partners/spouses had provided care. Only 35% thought that their partner/spouse should provide care. 38% reported that a friend had provided care, however only 27% thought that a friend should provide care. A high percentage of clients (80%) indicated that medical professionals should provide care, however only 56% of those who had received care received it from a medical professional. Patient autonomy and the physician's role in decision-making was often mentioned as a concern in client focus groups.

Informal Caregivers

In-depth interviews were held with 6 informal caregivers. Their stories are presented in a case study format.

Themes of these interviews include mental health issues of the person being cared for, discrimination because of HIV, need for more support and respite, more consistent homecare, more information and training for informal caregivers, and lack of housing and hospice.

Formal Caregivers

Challenges identified by formal caregivers included:

- Not being able to get out into the community.
- The sense that we are in a honeymoon period right now, and we're heading for a greater demand for palliative care.
- Communication and connecting with clients is difficult.
- Communication with care outside the hospital is difficult.
- Palliative care should start at time of diagnosis.
- More support for caregivers.
- Need for training and education for palliative care system workers.
- Need to get out in the community.
- Mental health concerns in PHAs.
- (See Diagram)

Barriers

The largest barrier experienced by organizations (reported in organization surveys) was the provision of culture-sensitive care to Aboriginal clients and their families, followed by provision of care to people with addictions and coordination of palliative care services with ASOs.

Other barriers identified include:

- Poor communication and boundaries
- Stigma and fear associated with HIV/AIDS
- Complexity of AIDS care
- Lack of confidentiality
- Lack of experience with AIDS
- Lack of funding and staff resources
- Specific profile of PHAs (ie. younger, substance use etc.)

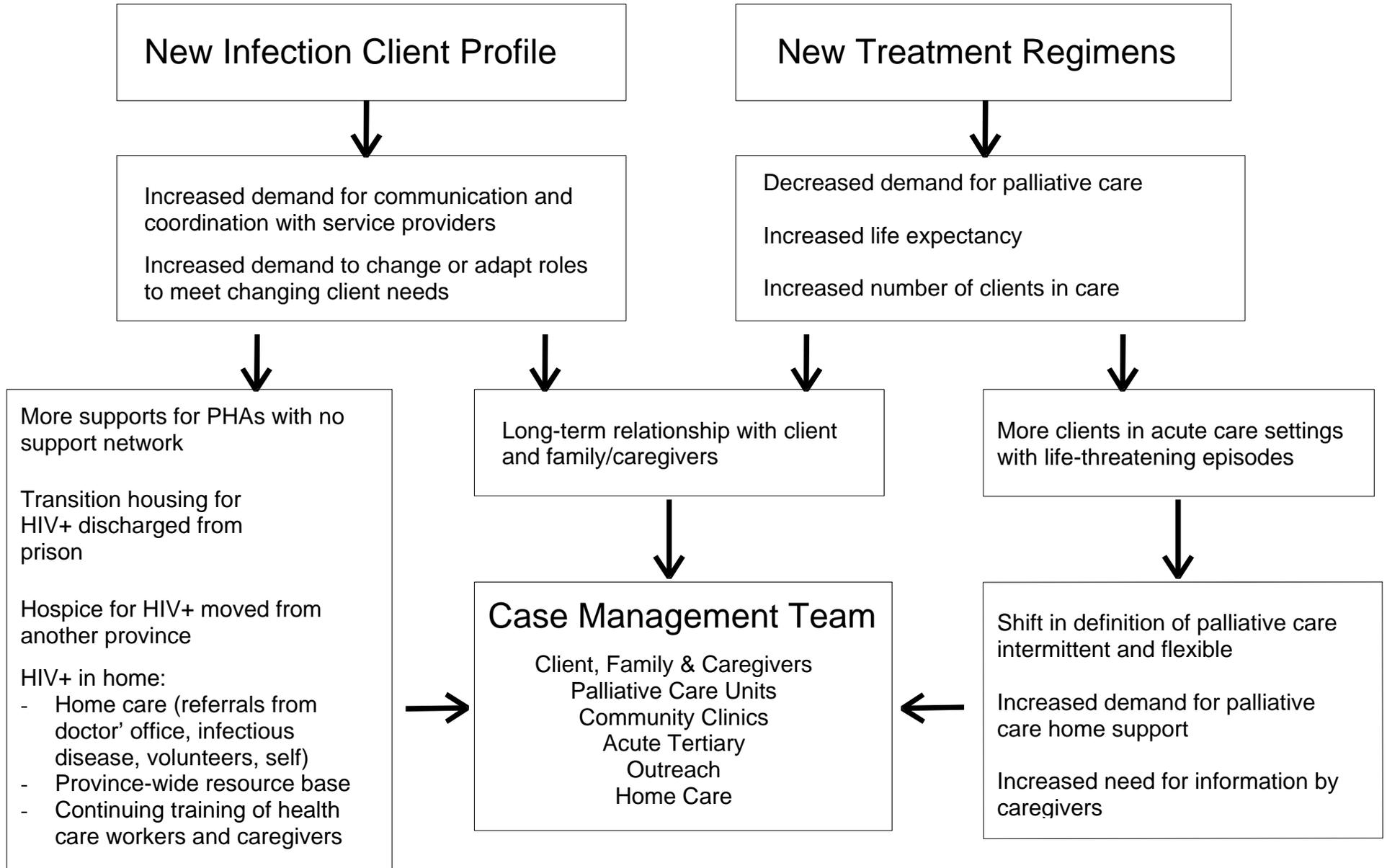
Recommendations

We describe lessons learned and specific recommendations in four key areas:

1. *Broadening Palliative Care* – Earlier Connection, Diverse Access Points, Broader Need Assessment Base, Linkages with HIV Primary Care, Increased Funding and Staff Resources
2. *Approaches to Care* – Outreach, Cultural Mediation, Case Management, Confidentiality
3. *Meeting Service Needs* – Making Services Accessible, Client & Caregiver Supports, Cultural Services, Psychosocial Support, Complementary Therapies
4. *Training & Education* – Information for Clients, Information for Families, Training for Informal Caregivers, Certificate Programs in HIV Palliative Care; Continuing Education

What the formal caregivers describe...

Two major factors have challenged the paradigm of HIV palliative care



Part I

Introduction

There is something in the human mind that demands mystical explanations or non-explanations, something that needs magic, needs to believe that it can control its destiny by wishing its destiny. Our brains are not programmed for logical thought. We have to be taught it and we are always slipping away from it. We resort to supernatural thoughts when we get ourselves into real trouble.

*Sherwin B. Nuland
Globe & Mail, February 19, 2000*

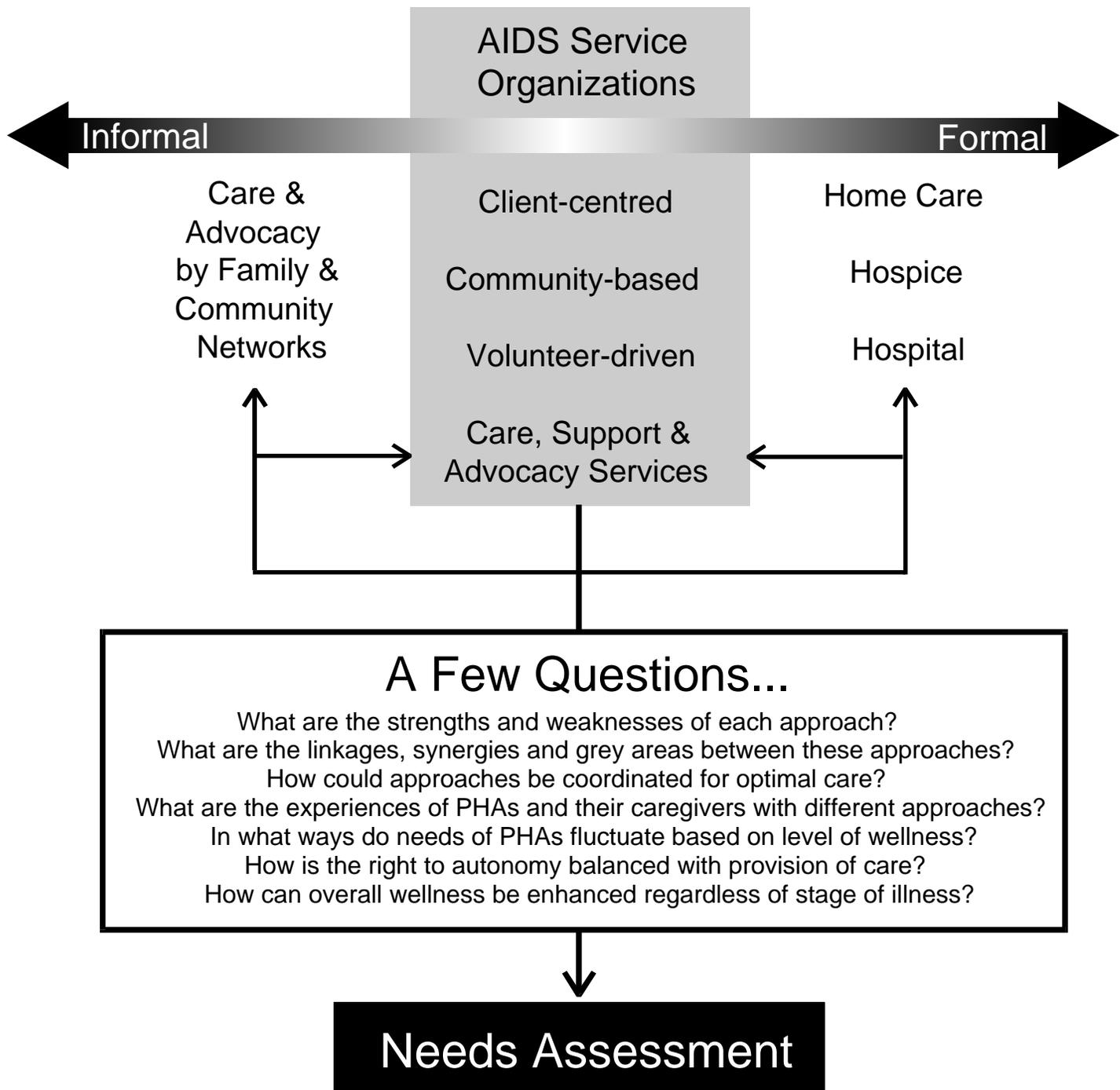
A. Position

We did not approach the “problem” of palliative care and HIV/AIDS objectively. With our front-line, direct service, prevention-focussed background, we approached this needs assessment as informed and sympathetic listeners. The interpretive framework we applied here was based on the changing profile of new infections in the prairie provinces, recognizing that people from different backgrounds and cultures have unique experiences of life and death. This increasing diversity is reflected in the profile of study participants, and in the analysis of the data.

Having been involved in the care of those infected with HIV, we feel a profound sense of incompleteness with every death we have witnessed or been a part of. Overall, the feeling persists that the care wasn't good enough. The relationship between caregiver and client is not valued or gets shuffled to the side. It's not scientific – just stopping by and saying hello, getting to know the person, their needs, their perspectives, following through on care plans and referrals – there's no prestige or glamour in this communicating role. It is the single most important element of care and there is no time for it. Just walking into the waiting room is overwhelming. Relationships with co-workers are brittle and there is no commonality or mutual support there – you must sink or swim. The expectation is that caregivers must be holistic and take a client-centred view when there is no time for anything but scattered pieces, the whole thing held together with tape and spit, and if you can't do it, it's your fault. You're not good enough, you don't have the skills, it's your own personal lack. Meanwhile, community health centres with their primary care ideals are becoming slick efficient outpatient facilities attached to tertiary care centres.

It is in this context that clients are described as “non-compliant” with treatment regimens, as “passive” in relationship to their own care. Are they passive? Or are they exhausted from trying to negotiate a system that is hostile and inflexible and doesn't have time to understand, and therefore does not respect, their position?

Continuum of Palliative Care for People with HIV/AIDS



B. Continuum of Palliative Care

The diagram on the opposite page was included as part of our original project proposal. It demonstrates our original conception of the continuum along which palliative care services are currently delivered, including informal, community-based and formal supports. It was our intention to answer “a few questions” about palliative care. Some of them have been answered, some have led to more questions, and all are still open for discussion. Hopefully, we are contributing a few tools to this much-needed conversation.

C. Goal

To assess the needs of PHAs for end-of-life care both inside and outside the palliative care system in the prairie provinces.

Our approach in this assessment was to:

- Describe the context and environment of palliative care and HIV/AIDS in the Prairie provinces.
- Describe the experiences of PHAs and their caregivers (both formal and informal) related to end-of-life care.
- Understand how “palliative care” is defined by PHAs and their caregivers.
- Describe the needs of *specific and diverse* populations for palliative care in the prairie provinces.

D. Research Assumptions

The assumptions on which this research is based reflect the experience and current knowledge of the research team and its advisors. They should not be considered static or “written in stone”. Rather, they are positions which act as a starting point from which dialogue can begin.

- The majority of HIV/AIDS palliative care is happening in informal networks. Even in tertiary settings, family and chosen family play a crucial but informal role in care, support and advocacy.
- First Nations may have a distinct way of perceiving and approaching end-of life care, with further distinctions based on urban or reserve residence, among other factors.
- Approaches to end-of-life care are highly individual and should be based on each person’s distinct profile of needs in a client-centred, culturally-sensitive model of care.
- Many PHAs currently “fall through the cracks” of existing palliative care services. Identified needs are best addressed by a combination of: 1) increased recognition of and support for informal support, care and advocacy; 2) improved and/or enhanced palliative care services; 3) increased recognition of and support for the client-centred approach of the community-based system and its mediating role between formal and informal systems.

E. Summary of Project Activities

The project began on August 25, and followed the workplan laid out in the original project proposal, with minor changes due to unanticipated circumstances.

September	October	November	December	January	February
	Developed Methodology. Conducted literature review and environmental scan. Attended Palliative Care Conference. Developed Organization Survey.				
		Mailed out Organization Survey. Development of Client Survey. Recruitment and delivery of Initial Focus Group. Refinement of Client Survey			
				Delivery of Client Survey. Delivery of Focus Groups	
	Caregiver Interviews conducted. Data Entry & Analysis begun. Preparation and presentation to CPCA.				
		Ongoing data analysis. Writing of Final Report			

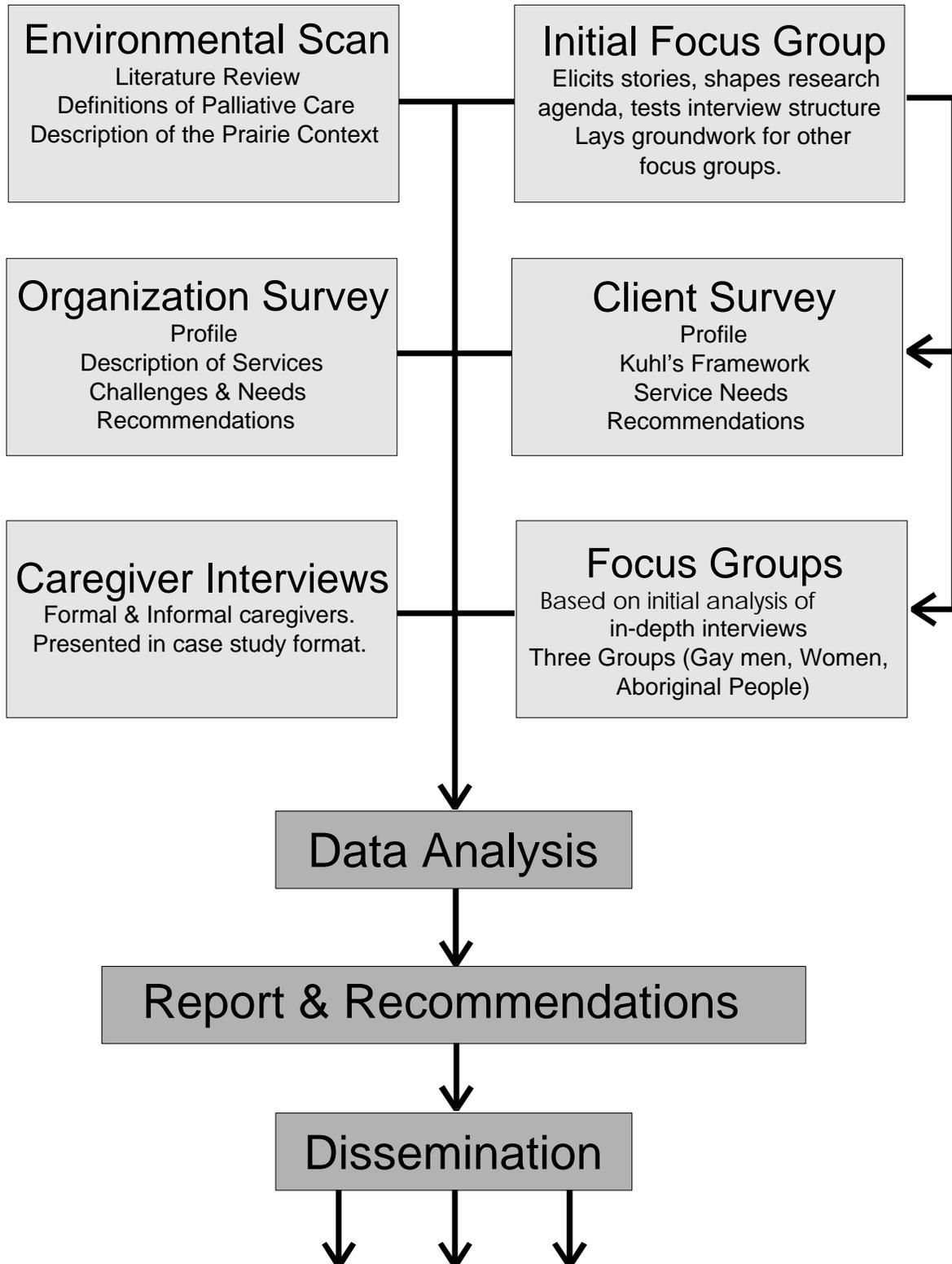
F. Study Limitations

1. Our distribution to Saskatchewan for all data collection tools was smaller than for the other provinces, however the percentage of responses was also lower than in the other provinces, possibly leading to an under-representation of interests and perspectives from Saskatchewan.
2. The organizational survey was not tested prior to going into the field. In retrospect, the tool could have been more refined.
3. Quantitative information related to the Environmental Scan outlined in the original proposal was not available, even at the governmental level. The approach we have taken in response to this has been to provide a series of “snapshots” of the prairie context.
4. The information collected and discussed in this report may be limited by the amount of time available for its distillation and refinement. The analysis might benefit from a longer period of time for reflection and consideration.

Part II

Methodology

Needs Assessment Methodology



A. Research Framework

The framework we used was based on a presentation made by Dr. David Kuhl of St. Paul's Hospital in Vancouver in a presentation entitled "Making Choices Together" at the 9th Annual Provincial Hospice and Palliative Care Conference held in Winnipeg on September 23 and 24, 1999. He proposes a 'Model for Ethical Clinical Decision-Making', in which an understanding of the following is critical to the planning and delivery of palliative care for people living with HIV/AIDS.

- Medical Indications for Palliative Care
- Quality of Life
- Context & Access to Services
- Preferences for Palliative Care

These elements were the starting point for data collection strategy and tools. In particular, the client survey and focus groups were explicitly structured on this framework. This report is also organized according to these central themes.

B. Data Collection

1. Strategy

- Descriptive and exploratory, using a range of approaches to facilitate the inclusion of participant perspectives.
- Recruitment of participants in order to be representative of patterns of emerging infections in the prairies (ie. Aboriginal people, women, injection drug users).

2. Initial Focus Test (6 participants)

The initial focus test helped set the overall direction of the project, eliciting stories and getting feedback on the client survey instrument.

3. Client Surveys (N=49)

These were distributed through service providers in clinics, ASOs and tertiary care centres. Of the 159 distributed, 49 were returned for a return rate of 31%. (See Appendix)

Table 1: Return Rate by Province (N=49)

	Sent Out	Returned	Rate
Manitoba	86	32	33%
Saskatchewan	30	3	10%
Alberta	43	14	37%

4. Organizational Surveys (N=33)

These surveys were mailed out to ASOs, hospices, home care agencies, regional health authorities and palliative care units in hospitals. in the prairie region based on lists provided by the CPCA, Canadian AIDS Society, and word of mouth. Out of 100 surveys mailed out, 33 (33%) were returned. (See Appendix)

5. Caregiver Interviews (15 participants)

In-depth interviews were held with 15 care providers. Nine of these were with formal care providers in hospitals, home care, community clinics, and hospices. Six were with informal caregivers of people with HIV (partners, friends, buddies, etc.). These were selected through existing contacts of researchers, and by word of mouth. (See Appendix)

6. Focus Groups (20 participants)

Participants in the focus groups were recruited through HIV service agencies in Winnipeg. In total, three focus groups were held with PHAs (See Appendix)

- Gay Men (7 participants)
- Women (10 participants)
- Aboriginal (3 participants).

7. Data Entry & Analysis

All survey data was entered into Microsoft Excel. Quantitative data was analyzed using Epi Info 6.0. Qualitative data was sorted and coded or compiled into lists.

Part III

Background

A. Definitions of Palliative Care

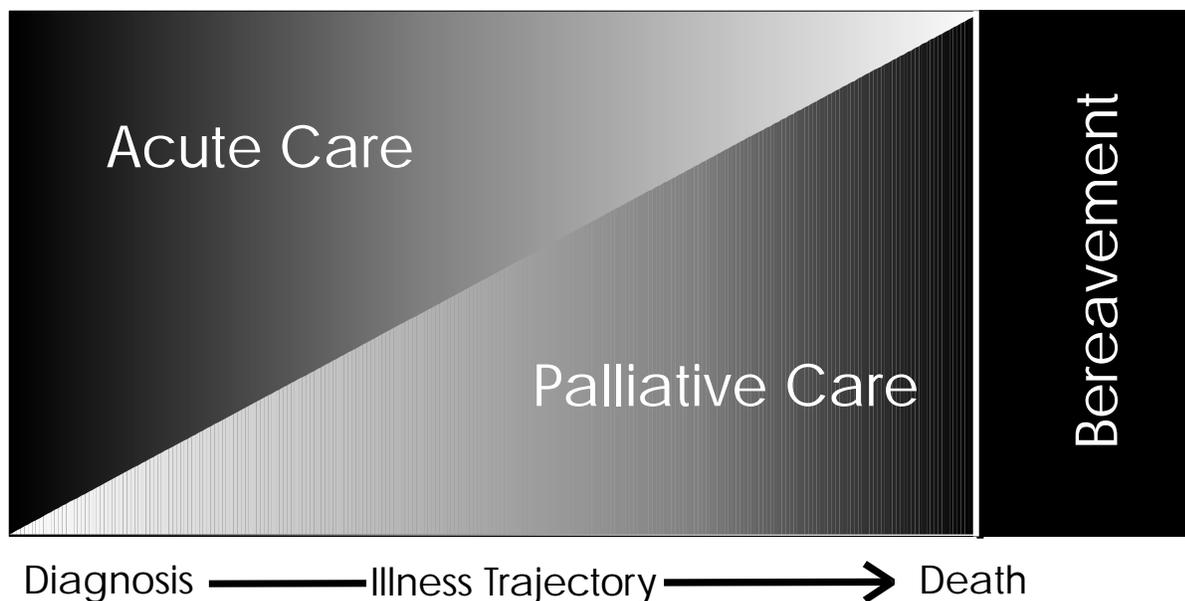
The definition of palliative care used in our research was:

“Active compassionate care of the terminally ill at a time when goals of cure or prolongation of life are no longer paramount. Compassionate care to soothe or ease symptoms, without curing.”

The Canadian Palliative Care Association defines palliative care as:

“A philosophy of care... the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illness. During periods of illness and bereavement, palliative care strives to meet physical, psychological, social and spiritual expectations and needs, while remaining sensitive to personal, cultural and religious values, beliefs and practices. Palliative care may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care. Palliative care is planned and delivered through the collaborative efforts of an interdisciplinary team including the individual, family, caregivers and service providers. It should be available to the individual and his/her family at any time during the illness trajectory and bereavement.” (CPCA, 1995)

1. Definitions from the Literature



This model of palliative care was adapted from diagrams in Ferris et al. (1995), Foley et al (1995), Kuhl (1995), and Glare & Cooney (1996).

The definition of palliative care used by the World Health Organization is, in part, “the active total care of patients whose disease is not responsive to curative treatment” (quoted in Bloomer, 1998, p.45).

Palliative care is appropriately administered throughout the disease continuum and is compatible with restorative or curative treatment (Bloomer 1998, Newshan & Sherman 1999). “Imagine a

seesaw bench with curative therapy and symptom management at opposite ends. The fulcrum is the patient's quality of life" (Bloomer, 1998, p.46).

Control of pain and psychologic support preserve a person's quality of life by protecting their self-integrity, reducing helplessness, and conserving coping resources. Key aspects of palliative care are comprehensive caring, respect for patient goals and wishes, use of interdisciplinary resources, and building systems and mechanisms for support (Newsham & Sherman, 1999).

According to Singer et al. (1999), patient definitions of quality end-of-life care are "simpler and more straightforward" (p.166) than expert-derived models. Elements of quality end-of-life care are described from the perspective of patients, including PHAs, in Toronto. These include: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships.

"The philosophy of contemporary palliative care is to shift the focus of care away from the disease and prolonging survival towards meeting the patient's needs and improving quality of life." (Glare & Cooney, 1996, p.612)

Bloomer (1998) quotes Eberle (1997): " 'We must be skilled in transforming metaphors of limitations into metaphors of possibility' ... This is the essence of palliative care" (p.46).

2. Definitions from Participant Organizations

In the organization surveys delivered as part of this study, participants were asked to provide their definition of palliative care.

Many participants mentioned that they followed the CPCA definition or the World Health Organization definition. In fact, many had participated in the creation of the CPCA definition. Elements most often mentioned were an active, compassionate approach to comfort (10 mentions), and a holistic approach to physical, spiritual, emotional, and social care (8 mentions). Many defined palliative care as taking place when cure is no longer a factor (7 mentions), while others defined it as concurrent with curative care. Some mentioned control of pain and symptoms, improving quality of life, and care for family and significant others as key elements of palliative care. Other elements mentioned include using a team approach, patient autonomy, and providing non-medical services such as basic needs. The services are best provided in the client's home or in hospice, may be continuous or interrupted, and should be sensitive to cultural and personal values and beliefs.

Selections from the qualitative data:

- Palliative care is active, total care of patients whose disease is not responsive to curative treatments. Control of pain, symptoms, and psychosocial, spiritual and social problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and families.
- A philosophy of care that combines active and compassionate therapies intended to comfort and support individuals and families who are living with a progressive terminal illness. Palliative care may be combined with therapies aimed at reducing or curing the illness or it may be a total focus of care.
- Whole person care of a person diagnosed with an incurable disease, providing emotional, spiritual and physical care.

- Palliative care is supportive care of a person who chooses to live the rest of their lives without invasive treatment. A person can choose palliative care whether they have months or days left to live. They receive comfort measures (pain medication included) from supportive caregivers.
- Providing active and compassionate therapy to support and comfort the client and their significant others. Should be delivered through a collaborative team to meet the physical, psychological, social and spiritual needs. Should be sensitive to cultural and personal values as well as their beliefs (religion).
- Care for those that can no longer provide for their basic daily needs alone. This may be on a continuous or an interrupted basis.
- As much comfort as possible and as home like as possible in the final weeks of life.

3. Client Perspectives

Client survey respondents were asked to complete the following sentence: “Palliative care should start for me when...” Responses are summarized in the table below, followed by qualitative data for each category.

Table 2: Palliative care should start for me when... (N=49)

	#	%
No longer functioning	23	46%
AIDS/life threatening illness	7	14%
At diagnosis/Long before dying	5	10%
When ready	4	8%
Already started	3	6%
Hopefully never	1	2%
Don't know/No answer	7	14%

No longer functioning

- I get really sick and can't do anything.
- I cannot function on my own; personal care like bathing, eating, toilet.
- When I lose the rest of what's left of my memory.
- I will not be able to move, go to the washroom, eat by myself.
- When I can't function on my own.
- When difficult to manage everyday activities ie cooking, cleaning, laundry, travel.
- I am unable to receive care at home.
- I can no longer do things for myself.
- When I can't clean myself after soiling.
- I or my partner is unable to care for my daily needs.
- I'm unable to take care of myself.
- I can't take care of myself.
- Bedridden.
- When I can no longer care for myself and have no independent source of assistance.
- I can no longer function or take care of myself very good.
- I am unable to function in daily activities or to fend for myself.
- I am no longer able to walk.
- I can't walk, talk or eat on my own or go to the washroom by myself.
- I start to get too sick or tired (fatigued) to look after myself.
- I'm unable to take care of myself and depend on anyone other than my son.
- I need help as follows: bathing, eating, walking, dressing.
- I can no longer work or look after my children ages 8, 3 and 2 years.
- I can no longer perform routine tasks of cleanliness and food preparation.

AIDS/Life threatening illness

- I start getting AIDS.
- I have progressed to AIDS and have a terminal opportunistic infection.
- I have an irreversible condition that will cause my death.
- I feel sick to death.
- When problems arise. I tend to procrastinate so waiting too long is no good for me.
- Develop AIDS
- Suffering irreversible damage and want to die.
- On my last legs on death bed in hospital.

At diagnosis/Long before dying

- As soon as you find out when you are HIV+ for support and symptom management.
- As soon as diagnosed with disease.
- I should have started palliative care at the point of diagnosis.
- I have no idea. My Oxford dictionary defines palliate as alleviate (disease) without curing. Therefore, it would appear that my palliative care began when I started taking prescribed medicines to counteract the HIV. It would appear, also, that palliative care could be as simple as taking an aspirin to alleviate a headache.
- Way before dying to prepare them.

Focus Group data also illustrate the many ways that palliative care is perceived by client participants:

- To ease the burden of those passing away. (Aboriginal Focus Group)
- Palliative care should start at diagnosis of HIV. (Initial Focus Group)
- I would have wanted palliative care at time of diagnosis; as time progressed, this changed and I had less need of this, not more. (Initial Focus Group)
- It should start when I need help. (Initial Focus Group)
- You can't really trust the doctor's prognosis, they are often wrong. (Initial Focus Group)
- A flexible definition should be acknowledged (Gay Men's Focus Group)
- When assistance is needed with basic activities. (Gay Men's Focus Group)
- For people who are really sick and don't have anyone with them. (Aboriginal Focus Group)
- For comfort and pain control. (Gay Men's Focus Group)
- A place to get away. (Aboriginal Focus Group)

B. Palliative Care in the Context of AIDS

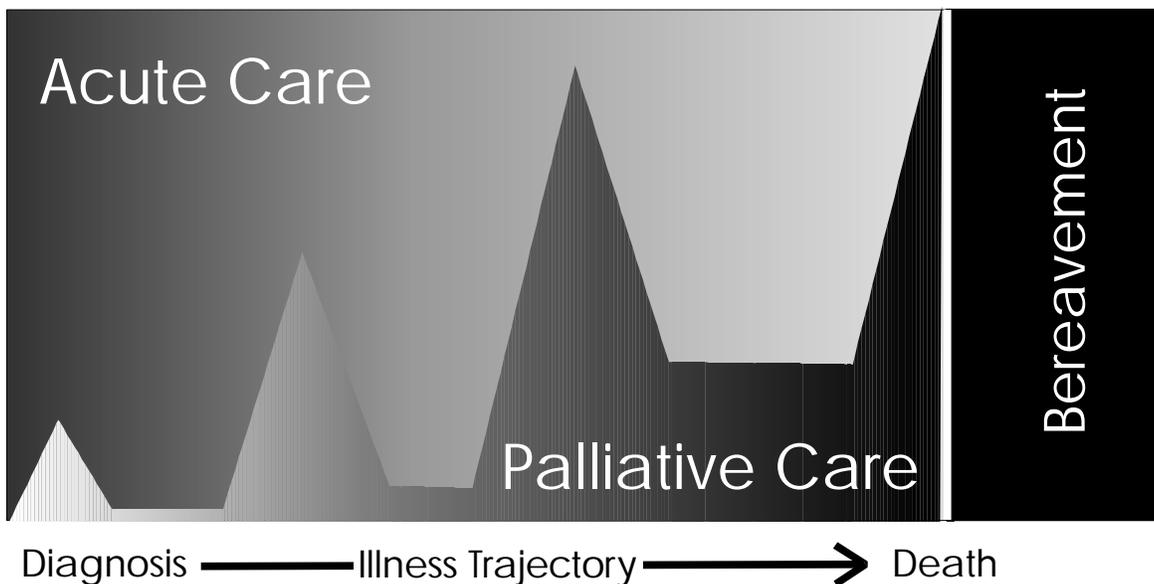
HIV/AIDS has challenged Palliative Care in Canada to grow and fulfill the broadest aspects of its mandate. *Ferris et al. 1995, p.3*

Unlike any other pestilence previously known to humankind, HIV does not limit its array of deadly options... when a heart fails, or a kidney, very specific events take place... Not so with HIV – it offers seemingly endless choices as one organ system and then another is set upon by a wide assortment of microbes and cancers. *Nuland, 1993, p. 192*

The context of HIV/AIDS care is extremely dynamic. This section outlines the specific concerns faced by PHAs, caregivers and health care systems as they approach palliative care, recognizing that the palliative care needs of persons with HIV/AIDS have been “largely neglected“ (Newshan & Sherman, 1999, p.131).

1. Complexity of AIDS Care

Many researchers point to the severity, complexity and unpredictable progression of AIDS (Foley et al. 1995, Kuhl 1995, Johnson 1995, Newshan & Sherman, 1995, Armes & Higginson, 1999, Singer et al. 1999).



The diagram demonstrates the specific profile of palliative care in the context of AIDS, where treatment is complex and lines between active treatment, primary care and palliation are blurred (Selwyn & Arnold 1998, Glare & Cooney 1996).

Many people may come very close to dying from an opportunistic infection and then recover and return to relatively good health. This has been termed the “Lazarus Syndrome” (Foley et al. 1995, Selwyn & Arnold 1998). Variability in emotional and spiritual well-being is also experienced due to the unpredictability of disease progression, leading to a “chronic uncertainty about the meaning and potential outcome of each event (infection) and its intervention” (Kuhl 1995, p.27).

Differences between AIDS palliative care and traditional palliative care listed by Glare and Cooney (1996) include: 1) predominantly younger age group; 2) multisystem disorders are commoner; 3) wide variation of disease patterns and goals of treatment; 4) a more unpredictable terminal phase; 5) polypharmacy; 6) higher incidence of dementia and psychiatric problems; 7) higher prevalence of substance abuse; 8) more psychosocial problems.

There is a need identified to develop different models of care that are relevant to the PHA’s community and specific profiles (Foley et al. 1995), and a recognition that the community, specifically the home environment, will increasingly be the setting for the delivery of HIV care (Baker, 1999). Inflexible palliative models that do not acknowledge the specific needs of PHAs are seen as a barrier to quality care (Armes & Higginson, 1999).

Six key components of high-quality HIV palliative care are proposed: *effectiveness* (competent skilled practitioners), *acceptability* (confidential, non-discriminatory and culturally sensitive care), *efficiency* (collaborative, coordinated and continuous care), *equity* (fair access to all groups) *access* and *relevance to need* (flexible and responsive care). (Armes & Higginson, 1999)

2. “The Modern Era of AIDS Treatment”

Before any therapies for HIV existed, patients and care providers were “united in a kind of immediate, naked solidarity” (Selwyn & Arnold, 1998, p.902). Goldstone (1995) reports that “the summer of 1987 was terrible” (p.54). Life expectancy at AIDS diagnosis was nine months. AIDS deaths peaked prior to the availability of AZT, and then in fall 1987 dropped dramatically. “The lull supported the denial of the meaning of HIV/AIDS, perhaps to AIDS care providers, but most certainly to the health care system and to society at large” (p.54).

This look at history highlights the current situation in AIDS treatment. Since 1996, there has been a marked reduction in AIDS deaths in Canada and the developing world, based on the success of “drug cocktail” regimens, HAART and protease inhibitors specifically. Meanwhile, unstable epidemics continue to emerge in new populations with specific needs, undermining advances in HIV therapeutics.

HIV care has typically been seen as paradigmatic primary care, demonstrating the importance of addressing illness within its broader human and social context (Selwyn & Arnold, 1998). The advent of new treatments may undermine sensitive end-of life care (Curtis et al. 1999)

Selwyn & Arnold (1998) recognize that powerful new treatments often stop working, cannot be tolerated, or are not available to patients for a variety of social, economic, or behavioural reasons. When treatment regimens fail, doctors may be likely to feel guilty or inadequate, and “respond defensively either by emotional withdrawal or inappropriate overtreatment... When death occurs, it can seem more aberrant, more unusual, more isolating... serv[ing] as an unpleasant reminder that the new treatments are not as potent as we would like them.” (p.900-1)

[Title of this section from Curtis et al. 1999, p.1130]

3. Organization & Client Perspectives

Participants in the client surveys and organization surveys were asked: “What is unique about providing palliative care to HIV+ people?”

Organization responses focussed on the complexity of AIDS care due to illness progression, symptoms, and the profile of PHAs (10 mentions). Fear and stigma attached to AIDS was also frequently mentioned as a unique factor (8 mentions). Other factors mentioned include confidentiality issues in AIDS care, specific access issues for injection drug users, and the generally younger age of people with HIV/AIDS.

- In some cases the family and lifestyle issues are more complex than those seen in the general palliative care population. These present special needs that must be addressed in the plan of care.
- Difficult to determine palliative care status. Patient may be terminal in disease trajectory several times.
- Many injection drug users choose not to quit, but have difficulty obtaining HIV medications.
- Among the gay population families sometimes feel ashamed. I anticipate there may be problems in the stigma many people still have towards this virus/illness. Special training and education will be required to overcome this stigma.
- I think in the area of HIV/AIDS, a health care worker working in the palliative setting must be in touch and truly honest with their own spirituality, sexuality.
- I would think having well-educated and confident staff on care management related to HIV/AIDS. Sensitivity and acceptance of individual's values and beliefs. HIV/AIDS is unique for its stigma in society. This means that clients, families and friends have to contend with guilt and shame in addition to fear and anger normally associated with life-threatening illnesses.
- The uncertainty of the virus. Our care teams have to be versatile in providing a palliative care situation but with new drug treatments, individuals may experience a degree of recovery (become asymptomatic again) but need other needs met.

Client responses to this question demonstrated a lack of knowledge of palliative care. Some recognized the complexity of AIDS care, the fear and stigma attached to the disease, and societal homophobia as factors in AIDS care. Others expressed the desire for more information, autonomy in decision-making, and an individualized approach to care.

- I don't know, but I think if I had a different illness, I would be treated better.
- Each client is unique and different and requires individual assessment and will also require varied needs depending on family supports and financial state.
- A unique understanding of growing up in a homophobic society and how that impacts one's life.
- What bothers me the most about providing palliative care is the exchange of information from client to professional is often misconstrued due to terminology (ie. condition, disruptions, symptoms). Nobody has time to explain much of anything.
- Family relationships. Lack of medical insurance/coverages. Age
- It's unique for people to actually really care.
- Treat me as if we are adults and not children.

C. Issues in HIV Care

1. The Role of Informal Care in HIV/AIDS Palliation

An article in the latest issue of the Canadian Nurse discusses a University of Alberta study by Fast & Keating, which discusses informal caregivers and their role in the care of the elderly. According to this study, it would take 276,509 full-time employees to do the work of the 2.1 million informal caregivers now providing service. They also point to the harsh price these caregivers pay for their labour, running the risk of becoming isolated, frail and poor themselves. According to the researchers, “what we really have is an informal system poorly supported by formal care services” (Canadian Nurse, February 2000, p.13).

While this study focussed on Canada’s elderly population, striking similarities can be seen with HIV/AIDS care and the role of informal caregivers. According to Goldstone (1995), “we have an epidemic that, for the most part, leaves the HIV-infected person heavily dependent on family, friends, and the health and social service systems for the last two to five years of life.” (p.55)

Clipp (1995) discusses the ‘secondary epidemic’ of psychosocial distress among caregivers of PHAs. “Caregivers experience significant discontinuity in their lives” (10) as care demands increase, threatening to “deplete caregivers’ physical and emotional reserves” (10).

The AIDS caregiver role is increasingly demanding, pushes against the limits of energy, is emotionally depleting and ultimately defeating. (Clipp, 1995) Three patient concerns about burdening family members proposed by Singer et al. (1999) were: the burden of providing physical care, witnessing their death and substitute decision making for life-sustaining treatment.

Among AIDS caregivers in Clipp’s study (1995), “appraisal of benefit was more intense in magnitude than appraisals of threat or stress... the reported difficulty associated with interpersonal care is clearly greater than difficulties associated with instrumental or direct care tasks” (p.14). “Caregivers’ task of providing emotional support to their loved ones with AIDS was the most difficult and demanding aspect of their work.” (p.16)

“Often it was the sick caring for the sick. The patient’s partner might also be HIV positive, and whoever felt better that day cared for the sicker one.” (Slone & Stephany, 1995, p.35)

2. Exhaustion

“Battle fatigue has set in.” *Goldstone, 1995, p.55*

“Professional caregiver exhaustion is a reality”
Kuhl, 1995, p.29

The complexity and variability of HIV may lead to anticipatory grief and energy depletion in formal and informal caregivers and a profound sense of loss of control for the PHA. Attendant care needs such as counselling, nursing, medical and spiritual are best delivered by a multidisciplinary team (Singer et al. 1999). “Peer, administrative, and social supports for caregivers are essential to enable palliative care providers to continue their efforts in the face of this challenging work.” (p.20). “Staff involved in AIDS palliation find that their role constantly changes with the evolution of intensive medical and nursing care.” (p.21)

According to Perreault (1995), caregivers in AIDS agencies are more likely to belong to the same age cohort as their clients, share the same experiences and struggles in identity, marginalization, and seropositive status than caregivers in other palliative care networks. AIDS caregiver grief “is usually suppressed or appears in other contexts, such as continued organizational crisis/worker dissatisfaction. It has often snowballed into grief saturation, with problematic effects on the well-being of caregivers, staff continuity, and agency health” (p.35).

Cost of unaddressed agency-wide grief listed by Perreault (1995), include absenteeism, illness, high job turnover, decrease in productivity, poor morale, flatness, lack of creativity, higher employer costs (relief staff, hiring, training) and disruption to clients and communities.

Although Perreault focusses on grief (perhaps because she is with the AIDS Bereavement Project of Ontario), it seems fair to assume that other factors leading to staff burnout could include lack of resources with no relief in sight, political indifference, hostility between boards, management, care providers and clients, not to mention plain old stress. According to Slone & Stephany (1995), “...providing hospice care for AIDS patients requires additional support and resources for nurses who provide the care. To do otherwise is to invite staff burnout.” (p.36)

“We challenge boards and executive directors to view grief not simply as a ‘personal problem’ but rather as an ‘occupational hazard’. We ask: What are the unique manifestations of grief in your workplace?... What systemic responses, policies, procedures, and concrete supports are in place to offer paid and unpaid workers timely, appropriate interventions prior to burnout and diminished effectiveness?” (p.35) (Perreault, 1995)

3. Decision-Making, Ethics & Medical Futility

With the optimism born of therapeutic successes came a determined cockiness that sometimes goes beyond reason... The boundaries of medical futility, however, have never been clear, and it may be too much to expect that they ever will be... The very success of his esoteric therapeutics too often leads the physician to believe he can do what is beyond his doing and save those who, left to their own unhindered judgment, would choose not to be subjected to his saving. *Nuland, 1993, p.221*

The ethics of end-of life decision-making must be addressed in palliative care, and caregivers must look at their own values in relation to the global view of the patient. Some caregivers may have difficulties with the limitations of therapy and see death as a failure or a barrier (Ferris et al. 1995). “Confronting personal limits overwhelms some caregivers with paralyzing helplessness, preventing them from finding other uses for their skills” (p.15).

Guidelines proposed by the *Comité de bioéthique, Centre Hospitalier, l’Université de Laval* (quoted in Ferris et al. 1995) for arriving at clinical decisions about resuscitation, unjustified or excessive treatment, refusal of treatment or cessation of treatment include:

- Evaluation of clinical condition;
- Evaluation of decision-making competence;

- Detailed explanation of necessary facts, if competent, and with family if not;
- Evaluation of the individual's perception of quality of life, and the impact of decisions being made;
- Evaluate the ultimate objective of treatment (maintain life, maintain quality of life, or both);
- Obtain the opinion of the care team;
- Keep a clear record of all conversations and decisions concerning treatment;
- Respect any changes in the wishes of the individual;
- Periodically revisit all decisions;
- Discuss unreasonable demands of patient or family;
- Provide palliative care to improve physical and psychological comfort, and support the family.

The American Medical Association recommends a “process-based approach” (p.937) to decision-making about the futility of medical care (Council on Ethical and Judicial Affairs, 1999), partly due to concerns that “judgements about futility mask a covert motive to conserve resources” (p.938). “The choice of the patient and the decision of his or her next of kin or designated health care proxy take precedence over the physician's recommendation.” (p.938).

4. Advance Care Planning

There is an “explicit link” (p.91) between the psychosocial benefits of advance care planning and the goals of palliative care. “Our society has developed a ‘pornography’ of death – talking about death is unseemly, indecent, and taboo”(Martin, 1999, p.91).

“Advance treatment preferences have been shown to be difficult to form, communicate, and implement.” (Martin et al., 1999, p.86).A barrier is the burden borne by family in substitute decision making. Up front discussion about planning for death may be inappropriate in some cultures and should be approached with great sensitivity. (Ferris et al. 1995)

Patients should address the issues of advance directives and power of attorney for financial and care and treatment matters (Ferris et al. 1995). People with HIV may benefit from doing this earlier rather than later because of the ‘roller coaster’ nature of the disease.

A checklist for advance planning includes:

- Fully understanding all the benefits available from government agencies, private insurance, AIDS service organizations etc.
- Know where all relevant information and documentation (legal documents, policies etc.) are located, and make sure they are accessible to the people who need them.
- Ensure financial matters are in order.
- Plan for care and treatment (power of attorney, advanced directives, court application for incompetence, setting of care, access and visitation privileges)
- Plan for what is needed after death (rituals, will, post-mortem, burial/cremation, death benefits, beneficiaries, guardianship).

5. Complementary & Alternative Medicine

A recent article which evaluates alternative treatments for HIV draws parallels between the tradition of nursing care and the tenets of complementary and alternative medicine (CAM). This involves “placing patients in the right relationship to their environments... [including] adequate air exchange, light, nutrition, rest and quiet.” (Freeman & MacIntyre, 1999, p.147) The focus on patterns of balance may be obscured by microbe isolation and targeted treatment, ignoring emotional state, nutritional balance, physical activity, community, family, self-care etc.

“Given the widespread and popular use of CAM among HIV-infected individuals, we consider that it is necessary for advanced-practice nurses to integrate knowledge and recommendations concerning CAN in their collaborative efforts with allopathic providers and other practitioners of conventional western medicine.” (p.160)

D. Psychosocial Concerns in HIV/AIDS Palliative Care

Among the manifestations of grief associated with AIDS are a greater than usual amount of rage, fear, shame, and unresolved grief, feelings of guilt, helplessness, loss of intimacy, increased physical symptoms, self-destructive behaviours, insecurity, numbness, and pessimism... these symptoms might signal 'pathology'. But this type of reaction can also be seen as a normal response to catastrophic events rather than a maladaptive reaction to a normal stressor. *Perreault, 1995, p.34*

1. Multiple Loss

As well as facing loss of life, PHAs also must face the possibility of loss of "body functions, body image, sexual function and attractiveness, ability to work and mental capacity" (p.29), and may already have experienced the multiple loss of friends and lovers. Existing fears of dying are aggravated by these multiple losses, and may be compounded by "stigmatization, isolation and marginalization... It is no surprise that psychological support has been identified as the greatest need in this population" (p.29). (Kuhl, 1995)

Perreault (1995) states that "time alone does not heal all wounds" (p.34). Issues in multiple loss include guilt, survivor guilt, individual burnout, workplace burnout, and symptoms of post-traumatic stress disorder.

2. Pain & Suffering

38% of ambulatory HIV-positive patients in one study reported persistent pain (Selwyn & Arnold, 1998). Glare & Cooney (1996) also report that pain is common in HIV/AIDS, occurring in 25% of asymptomatic patients, 40 to 50% of ambulatory AIDS patients and over 80% of hospitalized patients. A strong relationship between pain and psychological distress and negative thoughts about body image and social support.

Cognitive and emotional elements of the experience of pain are reinforced by issues related to the family, social milieu, and health care system. Factors in AIDS pain include a high incidence of substance abuse, psychiatric disorders, financial problems and lack of social support (Breitbart, 1996). Undertreatment of pain in primary care facilities is predicted by gender, education, and a history of injection drug use. "Women with HIV and pain were twice as likely to be undertreated than their male counterparts." (p.24)

Symptoms of HIV, including pain, can occur simultaneously, affect one or more body functions or systems at a time, produce excitation or depression, and lead to other symptoms (Ferris et al. 1995).

3. Marginalization & Poverty

“When we speak of the poor who have AIDS, we are not talking only about those who have little money, but about that deeper level of poverty of never really having a place in our society.” (Roy 1995, p.3)

A 1999 Montreal study found that patients with HIV/AIDS living in extreme poverty were “more likely to complain of uncontrolled pain... and were more likely to die in hospital than were their more financially secure counterparts” (Daneault & Labadie, 1999, p.6), despite having a similar clinical profile at diagnosis and being provided with similar services. Living alone and previously receiving the services of a community resource were significantly linked to poverty, and poor patients were significantly more likely to access psychosocial services.

Curtis and Patrick (1997) found that discrimination by the medical system against individuals with AIDS, women, nonwhite individuals constitutes a barrier to patient-physician communication about end-of-life care. Those with AIDS may be at increased risk for having care withheld or inappropriately aggressive care. This is particularly likely among non-white patients, injection drug users and those with lower income (Curtis et al. 1999).

“Hospice care can be viewed by low-income clients as a push towards less expensive care. When cultural issues are added, palliative care can be viewed as giving up on a person...” (Robb, 1995, p.50).

4. Substance Use

A recent Swiss study found that HIV-infected injection drug users start antiretroviral treatment later than other patient groups. This delay, however does not appear to result in increased risk of clinical disease progression. (Junghans et al. 1999)

The complexity of care for the substance using client is exacerbated by several factors:

- The client may like to get high.
- Drug use is prohibited by law.
- Caregivers may have legitimate fears about how best to provide care.
- Caregivers may have legitimate concerns about where care is provided.
- The specific mechanisms of action of individual drugs may make pain and anxiety control difficult to achieve.

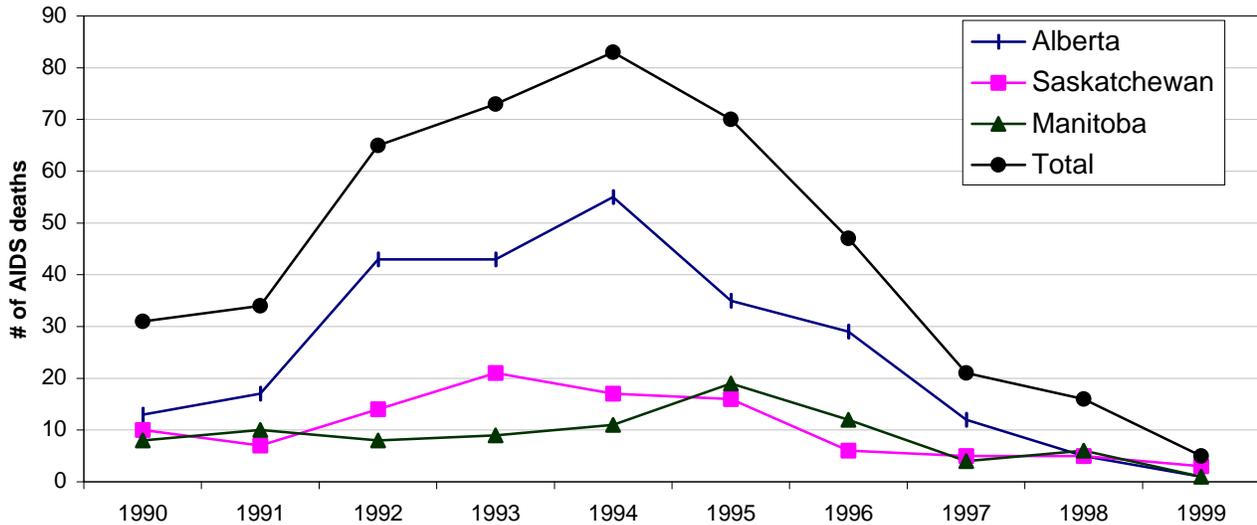
Part IV

Context

A. AIDS in the Prairies

Total AIDS Deaths in the Prairie Provinces, 1990-99

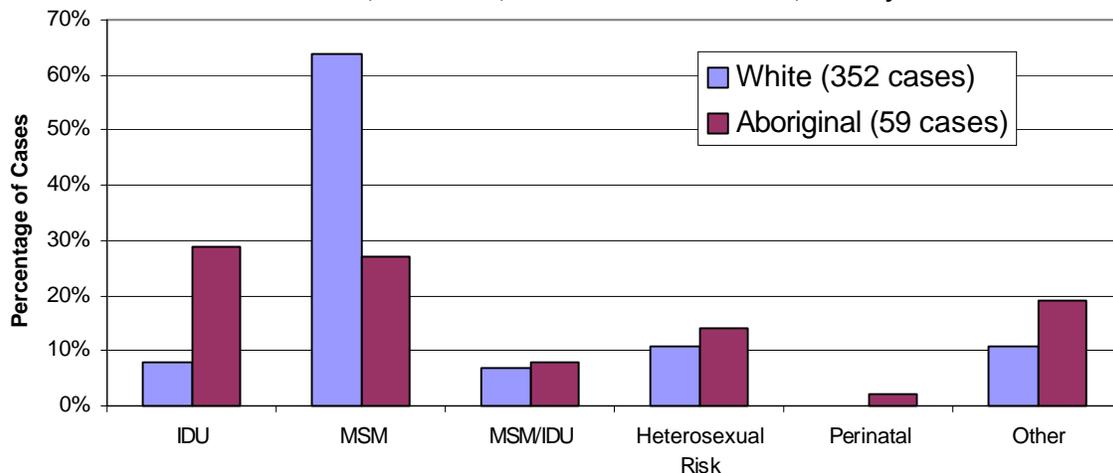
Bureau of HIV/AIDS, STDs & TB, Health Protection Branch, February 2000



Like most places in the developed world, AIDS deaths in the prairie provinces have declined remarkably since the introduction of protease inhibitors and cocktail approaches to antiretroviral therapy (ART). However, this rate of decline is slowing, evidence of viral resistance to new therapies is increasing, and emerging populations of infected people may be less likely to have or want access to treatment regimens. The trend information on the above diagram may be misleading due to under-reporting and late reporting of AIDS deaths. Breakdowns of AIDS deaths along gender, age and ethnicity lines were also not available from Health Canada due to federal/provincial agreements on confidentiality (Yan, 2000).

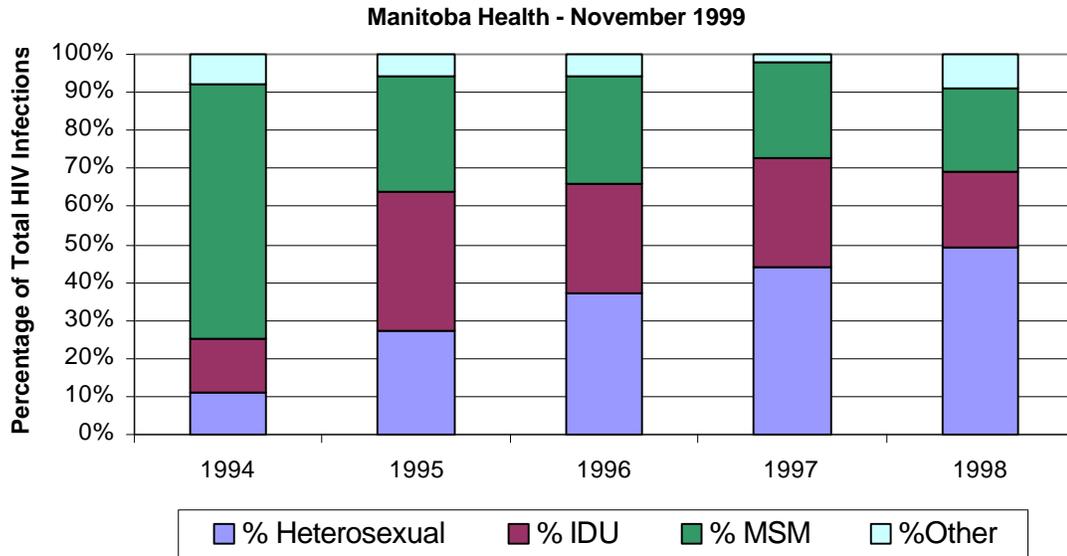
Total AIDS Cases in Prairie Provinces by Ethnicity & Risk Factor

Bureau of HIV/AIDS, STDs & TB, Health Protection Branch, January 2000



A general shift in profile for new HIV infections in Manitoba has been observed, with proportion of those infected through heterosexual risk factors increasing from 10% of total new infections in 1994 to 50% in 1998. This shift in risk profile has future implications for HIV service provision including palliative care, and will be discussed further in this section.

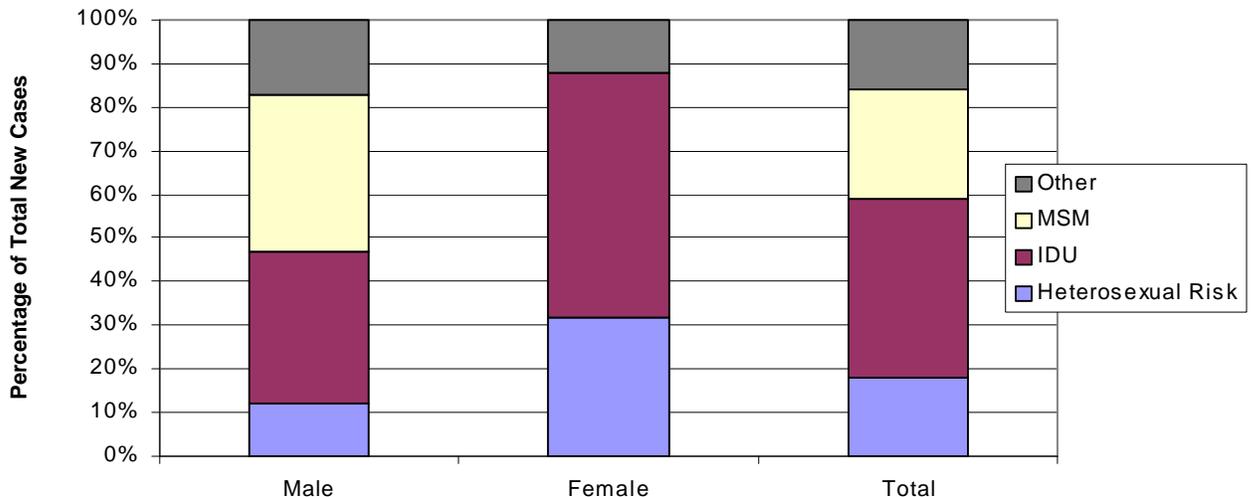
Shift in HIV Positive Risk Profile in Manitoba



Alberta's new HIV cases (January to September 1999) show a significant difference in risk profile for the two provinces. 40% of new cases are attributed to injection drug use (including 58% of females), compared to 20% of new cases in Manitoba in 1998. Heterosexual risk factors accounted for less than 20% of total new cases in Alberta (including 31% of female cases), compared to 50% of new cases in Manitoba in 1998.

New HIV Cases in Alberta by Exposure Category

January to September 1999 – Alberta Disease Control – November 1999



B. Trends in Palliative Care

As mentioned in the introduction, environmental scan data regarding resources for palliative care and AIDS was not available in a coherent form. Instead, we present here a series of snapshots and observations related to palliative care in the prairie provinces.

1. Recent Developments

In Manitoba, more funding was allocated to palliative care by the government in Spring, 1999. Out of the 3 million allocation, 1.8 million was being designated for renovations in a hospital which provides palliative care. It remains to be seen how that funding will be disbursed by the new government. The move within Manitoba's Regional Health Authorities, now three years old, to create palliative care coordinator positions who would network with one another, should improve the infrastructure for linking rural, urban and northern client care and resources and the communication of up-to-date information.

In Saskatchewan, regionalization of health services has brought about an improved coordination of palliative care services, both between urban and rural locations and between the disciplines. New palliative care staff receive an extensive two-week orientation, including one day on HIV/AIDS. Employees are kept up to date and attend at least one conference per year.

In Southern Alberta, the total cost of HIV care has decreased between 1991 and 1998, due to combination drug therapies increasing life expectancy and reduced hospitalization. In the Capital Region of Edmonton, a Palliative Care Coordinator oversees developments which include very few AIDS clients in hospital palliative care, possibly 3 per year, out of 30 AIDS-related deaths per year.

2. Hospice & Palliative Care Conference, Winnipeg, September 1999

Observations and connections made during this two-day conference helped in overall project delivery:

- Present services in Winnipeg were described as uncoordinated, inconsistent, providing limited access, with gaps in service, and with an increasing number of "orphan" patients unlinked to a family doctor.
- 66% of patients with a distressing chronic or terminal illness had seen between 20 and 49 doctors and 16% had seen more than 50 doctors. It was suggested that information should travel with the patient as "hand-held charts".
- A "fear" reaction in clients and their families has been observed when the term "palliative" was used. The interplay between curative and palliative care was stressed. A dynamic model of palliative care is an "active, comfort, urgent, emergent" continuum. The term "supportive care" is increasingly being used in place of "palliative care".
- There is a push for more systematization in palliative care, removing institutional barriers and developing interdisciplinary care teams.
- Seamless palliative care was described as: 1) Adapting to home-based needs; 2) Offering day programs with access for client and family, including peer support and complementary therapies (ie. massage); 3) Providing out-patient and emergency hospital departments on a 24-hour basis for pain and symptom control; 4) Providing hospice care; 5) Providing long-term palliative care in hospital.

3. Trends in AIDS Palliative Care: Formal Caregivers

It is important to gear down palliative care programs [for AIDS] and retain the expertise rather than shut down those programs and lose the expertise which will probably be needed again within 5 years. *Physician, Calgary*

Saskatchewan palliative care service providers interviewed as part of this study reported having seen only a very few HIV cases in the past few years. An Albertan medical expert interviewed for this study stated his concern that while less people are needing formal palliative care services, this is likely only a honeymoon period, and demand will edge up again based on increasing failure of current regimens and the recurrency of “old” HIV diseases such as CMV and dementia. A Manitoban HIV nurse interviewed for this study stated that if all the patients currently on combination therapies were to decline at once, there would be a crisis in palliative care in Winnipeg.

The following trends were identified through interviews with 9 formal caregivers (physicians and nurses in palliative care and HIV) conducted as part of this needs assessment.

Comments on the changing profile of HIV/AIDS clients:

- New client profile of co-infection with HIV and Hepatitis C.
- Mental illness and solvent use are also more common.
- Many new clients are not at all interested in new treatments or ANY treatments
- Poverty is the main issue limiting quality of any care.
- Clients require more planning around immediate day to day needs – pharmacare, social assistance, etc. In the past this time would have been spent planning end-of-life care. Now, it never gets to that point.
- Previous clients were educated and involved in care. They may not have opted for aggressive medical treatment but they took very good care of themselves. With new patients, HIV is not their main priority – day-to-day existence is.
- Clients now only access care when acutely ill and as walk-ins. This makes it difficult to establish a relationship and impossible to raise issues of palliative care.
- Some clients are very clear about how they want their care to be managed. Others find even the dialogue about care of any description strange or intimidating.
- People with need for basic shelter, food and community – not necessarily palliative care.

Comments on the role of clinical practitioners in palliative care:

- A Team approach to palliative care is new for doctors – they don’t adapt well.
- Difficult to reconcile personal aspects of caregivers in order for them to do the work of palliative care. They must confront their own “darkness” in order to do “whole person palliative care”.
- Clinical medicine approach is sharply opposed to whole person/system dynamic approach.
- In view of the highly experimental care of HIV patients utilizing combination drug therapies, one physician takes a “We’ll wait and watch with you” approach to clients.
- The system takes a long time to change; discipline lies in recognizing useless expenditures of energy.
- A nurse recognizes the limitation of her job within hospital. There is a need to maintain contact outside of the institution, but very little opportunity to do this.
- Palliative care is being done in acute care settings, on active medical wards where clients are acutely ill-- staff is not well prepared for this. Palliative Care doesn’t really happen.

Comments on services and required systemic changes:

- 3 years ago, quality of care depended on where you were, now there's more standardization.
- On financial burden: Pain medication is covered for hospital patients, but not covered at home.
- Careful attention must be paid so that palliative care does not become only medical and nursing care, excluding psychosocial and spiritual needs.
- It is difficult to establish a communication system with others on team to describe the needs and wants of the client (from a Home Care Attendant's (or Aide's) perspective).
- Classical institution-based palliative care likely replaced by need for hospice type care.
- People are dying at home with very limited support, in an environment where the expectation is that whoever is in the home will provide all the care.
- Challenges of multiple diagnoses push the system. There are few advocates for comprehensive care within tertiary setting.

4. The Manitoba AIDS Hospice

In May 1999, the Manitoba AIDS Hospice Inc. submitted a project proposal to the provincial government modelled on existing AIDS hospices in Montreal and Toronto, and Jocelyn House, a hospice for terminally ill patients in Winnipeg. They are responding to a need for hospice care specific to HIV, recognizing the fact that many PHAs are falling through the cracks of the Manitoba health care system, by being too well to be in hospital but too sick to stay at home. They are offering a model in which 24-hour care in a home-like setting would cost less than \$300 per day, considerably less than comparable hospital costs.

Focus groups held in mid-1998 demonstrated a need for an AIDS-specific hospice, and that it should complement the existing palliative care program in Manitoba. Focus group participants said the hospice should have a home-like atmosphere, be sensitive to individual needs, be accessible to anyone with AIDS including women, children, drug users etc., provide advocacy services, provide respite services for caregivers, and involve PHAs in all aspects of the organization.

Their mission is "to provide comprehensive and compassionate palliative care to persons living with AIDS. Provision of this care is based on respect for the individual's dignity and autonomy, and employs a holistic interdisciplinary approach. Our care emphasizes: Quality of life and a dignified death; Uniqueness and autonomy of the individual; The right of the individual to remain active in treatment decisions; Bereavement support; Respite support for caregivers" (Manitoba AIDS Hospice, 1999, p.25).

C. First Nations & AIDS

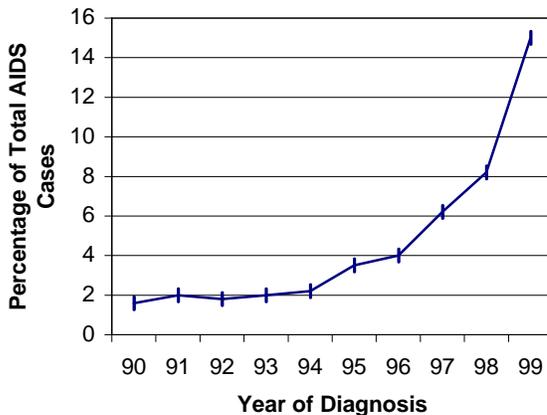
1. First Nations in an Emerging Epidemic

The Royal Commission on Aboriginal Peoples states: "Risk factors identified among Aboriginal people suggest a serious AIDS problem may be in the making" (RCAP, 1996, v.3, p.141).

Given the high proportion of Aboriginal people in the prairie provinces, with concentrations in urban inner-cities and northern communities, consideration must be given to the specific profile of the HIV epidemic in Aboriginal communities.

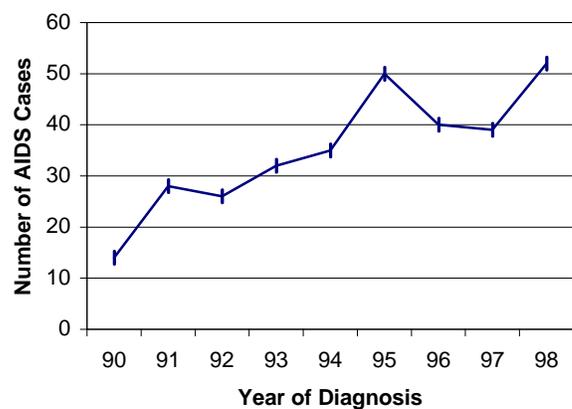
Aboriginal AIDS Cases (Percent of Total) in Canada, by Year

LCDC - November 1999



Aboriginal AIDS Cases (Number) in Canada, by Year

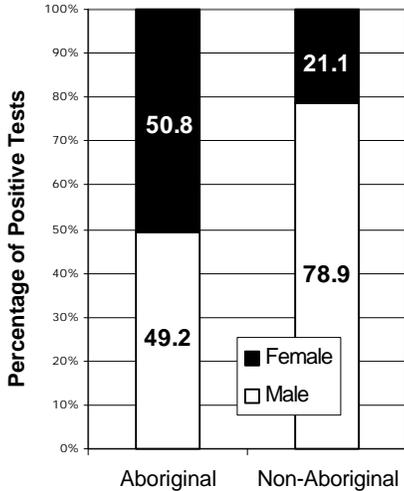
LCDC - November 1999



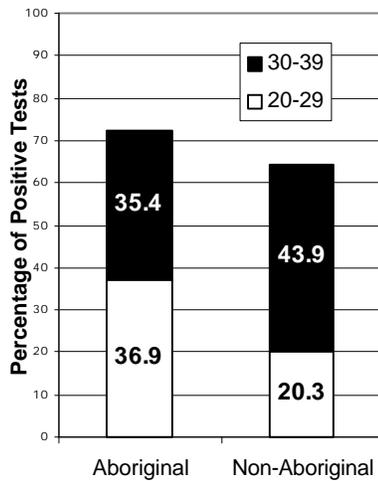
The overall decline in AIDS cases is not seen in Aboriginal people. The actual number of AIDS cases (above right) saw a decline in 1996 and a substantial increase in 1998. As a percentage of overall AIDS cases (above left), the proportion of Aboriginal AIDS cases has increased dramatically, nearly doubling in 1999.

Canadian epidemiological data on new HIV infections among Aboriginal people help us to see the possible future of HIV services including palliative care in the prairie provinces. New infections (January to June 1999) affect Aboriginal men and women equally, affect a younger age group among Aboriginals, and are more likely to be associated with injection drug use among Aboriginals. While limitations in ethnicity data are acknowledged, this is most likely to result in under-representation of Aboriginal people among new infections and AIDS cases. (LCDC, 1999).

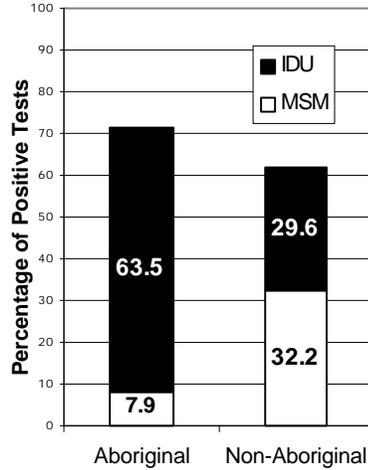
HIV+ Test Results in Canada by Gender and Ethnicity
January to June 1999
LCDC - November 1999



HIV+ Test Results in Canada by Age and Ethnicity
January to June 1999
LCDC - November 1999

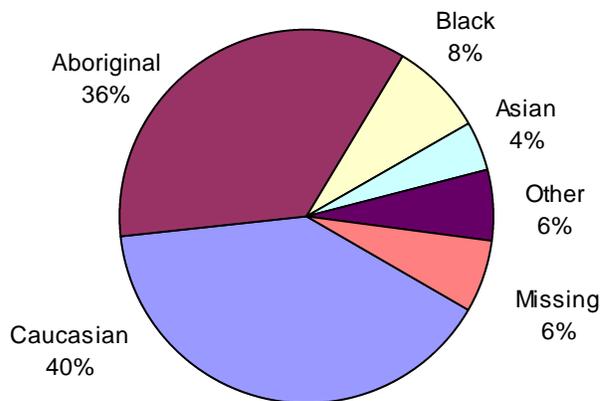


HIV+ Test Results in Canada by Risk and Ethnicity
January to June 1999
LCDC - November 1999



HIV testing data from Alberta and Saskatchewan indicate that a significant proportion of persons testing newly HIV-positive are Aboriginal, and that this proportion is greater when one considers only female HIV-positive cases. For example, in Saskatchewan (1993 to 1997), 26.4% of all new HIV cases were among Aboriginal people, and 51.4% of all female cases were Aboriginal women. In northern Alberta (1993-1996), almost identical rates were observed. In Manitoba, HIV only became reportable to Public Health in January 1999. 48 new HIV diagnoses have been reported since that time.

New HIV Cases by Ethnicity
January to October 1999 - Manitoba Health - 1999



2. Cultural Factors in Palliative Care – A Case Study

Among Aboriginal Canadians in a recent Winnipeg study (Kaufert et al. 1999), conflicts between clinicians and patients and their families were observed regarding approaches to end-of-life care. “In some cases, the provider’s emphasis on maintaining autonomy through explicit truth telling conflicted with family members’ emphasis on maintaining hope” (p.31). This study focussed on “the dynamics of culture and power in situations involving value conflicts” (p.31), and explored the role of interpreters in cultural mediation between patient, family and health care system. Cree and Ojibway elders were found to profess beliefs that “truth-telling may be disrespectful, could be dangerous, and could shorten the life of the terminally ill patient” (p.33). Interpreters involved in mediation have stressed the need for a balance between ‘reality’ and messages of hope and support.

The study included a case study of a 25-year old Aboriginal AIDS patient in a Winnipeg hospital, originally from a Northern community. He was referred to the Aboriginal Services Program of the hospital and interpreter advocates from the program provided psychosocial support, communicated with the patient’s family members in Ojibway and helped to establish connections with counsellors and traditional healers. The interpreter also negotiated with the hospital to allow the burning of sweetgrass in the patient’s room, necessitating the shutdown of fire alarm systems in that wing of the hospital. After the patient’s death, Aboriginal service workers held a family conference or sharing circle “in which each member spoke about their memories of the patient... emphasizing the continuity of the man’s life with the lives of his ancestors” (p.37).

“The ethnocentric perspectives and personal values held by patients, families, and caregivers influence day-to-day clinical communication. However, they may have their most profound impact on end-of-life decision making. Without the intervention of cultural mediators they are all too often invisible and pass without commentary” (p.38).

3. A View from the North...

A response to a survey by the Northern AIDS Initiative outlining home care needs for Aboriginal people with HIV/AIDS in northern communities was prepared by a health care worker in Thompson, Manitoba, 800 kilometres north of Winnipeg.

The most urgent needs of Aboriginal people living with HIV/AIDS in northern communities were identified as:

- Regular and consistent counselling, starting from diagnosis, for both client and family.
- Care which maintains the dignity of the client and does not shame or disgrace them.
- Information on medical profile of the disease, and access to the latest medical treatments. These should be adequate, affordable and not be held up in “political and commercial red tape”.

Issues faced most frequently by clients with HIV/AIDS were identified as:

- Lack of properly trained care providers, including hospital workers and counsellors.
- Lack of understanding and resources in home communities when clients try to reintegrate.

Challenges faced by home care nurses in this area were identified as:

- Those created by the caregiver, including mindset, prejudice, lack of understanding and information.
- Financial restrictions placed by various levels of government on the departments they work for.
- Lack of resources to help care for clients
- Minimal information passed on from major centres to smaller communities.

Differences in approaches to care for Aboriginal clients were identified as:

- Need to address the cultural, spiritual and personal needs of the client. In a major centre, services to address these needs would have to be brought to the client, whereas in the client's home community, these may be at hand.

4. ...& One From Inside

A recent broadcast on CBC told of the efforts of inmates at Stoney Mountain Federal Penitentiary in Manitoba to record a cassette in order to raise funds to support those among them who were infected with HIV or Hepatitis C. There are 9 known cases of HIV and 84 known cases of Hepatitis C among the 320 inmates. Aboriginal people are over-represented in provincial and federal jails across the country, especially in the prairies.

A recent report on Aboriginal people in prisons (Warhaft, 1997) recommends that inmates with progressive life-threatening illness be released early in the course of their disease, before they are terminally ill, when they do not constitute a threat to public safety. It also recommends that external, community-based AIDS, health or prisoner organizations that provide services and education to people with HIV infection or AIDS should be encouraged to provide such services in correctional institutions so that inmates will have established links with these organizations prior to release.

D. Women & AIDS

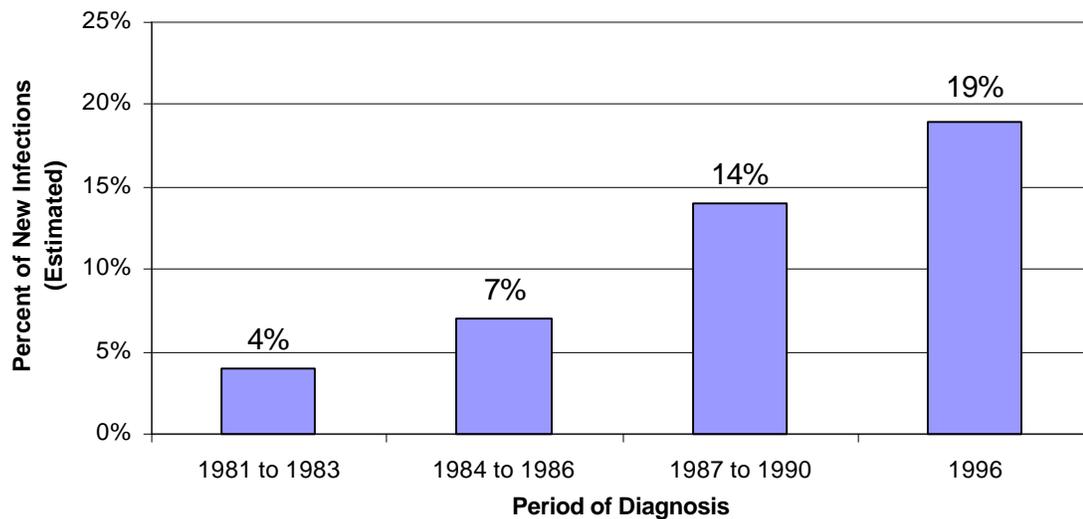
Epidemiological data published in May 1999 identifies the HIV epidemic among women in Canada as of particular concern because of the transmission to their infants. It tends to create a picture of women of childbearing years as valuable because of their capacity to reproduce, and dangerous in their capacity to reproduce HIV-infected children.

In women, the age of first positive HIV test is more likely to be between 20 to 29. It is acknowledged that women have physiologically increased vulnerability to HIV, are more likely to be at risk for injection drug use as a co-factor, are more likely to live in poverty with dependent children. The vulnerabilities for contracting HIV are likely the same problems to be considered in providing palliative care.

In providing for the palliative care needs among women, because of the matrix of relationships that characterizes a woman's experience, it is not realistic to consider her outside of those relationships. To do so may damage any frail connection she may have to care and service providers who may be truly motivated to help.

Estimated Proportion of Women among New HIV Infections

LCDC - May 1999



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Part V

Results

A. Profile of Participants

The following section describes those who participated in the client questionnaires, the client focus groups, the organization surveys and the caregiver interviews.

1. CLIENT QUESTIONNAIRES

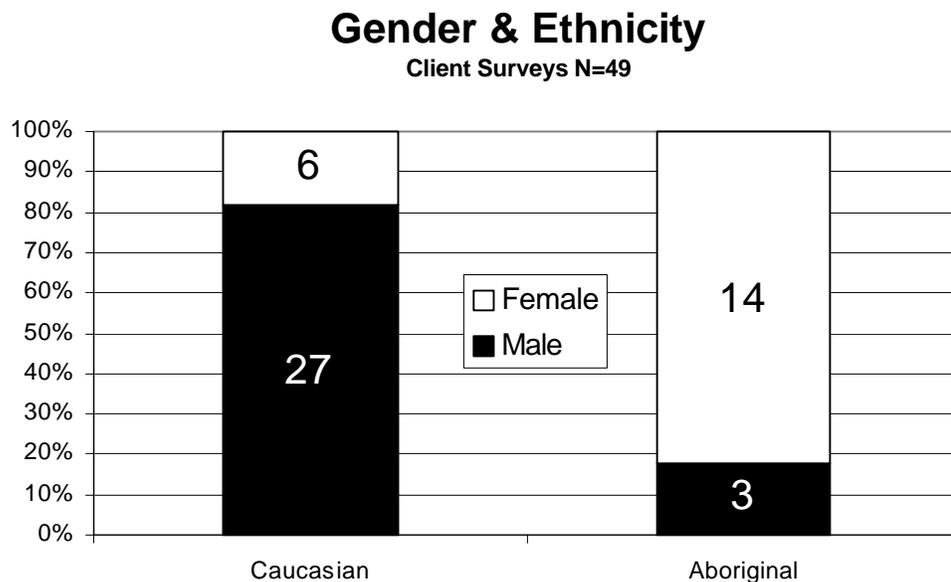
A total of 49 surveys were returned from clients.

a) Gender (N=49)

Sample was 61% male (30 participants) and 39% female (19 participants)

b) Ethnicity (N=49)

Sample was 65% Caucasian (33 participants) and 35% Aboriginal (17 participants). Caucasian participants were largely male (27 out of 33) and Aboriginal participants were largely female (14 out of 17). No Aboriginal participants identified as gay. One Aboriginal female and one Aboriginal male identified as bisexual.



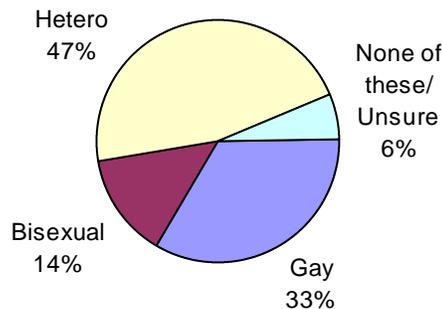
c) Sexual Orientation (N=49)

16 out of 30 males identified as gay, 5 as bisexual, 7 as straight, and 2 as none of these or unsure. 16 out of 19 females identified as straight, with 2 females identifying as bisexual and 1 indicating none of these.

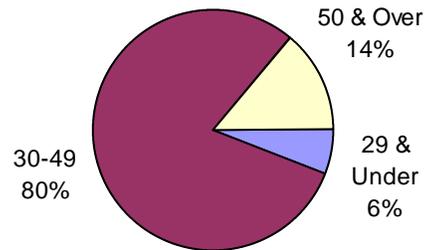
d) Age (N=49)

Those who completed the client questionnaires were largely aged 30 to 49 (nearly 80% or 39), with 14% (7) over 50 and 6% (3) aged 29 and under. All three of the under 29 participants were female (2 Aboriginal, 1 Caucasian). The mean, median and mode for the data set was 41 years.

Sexual Orientation
Client Surveys (N=49)



Age
Client Surveys (N=49)



e) Languages Spoken (N=49)

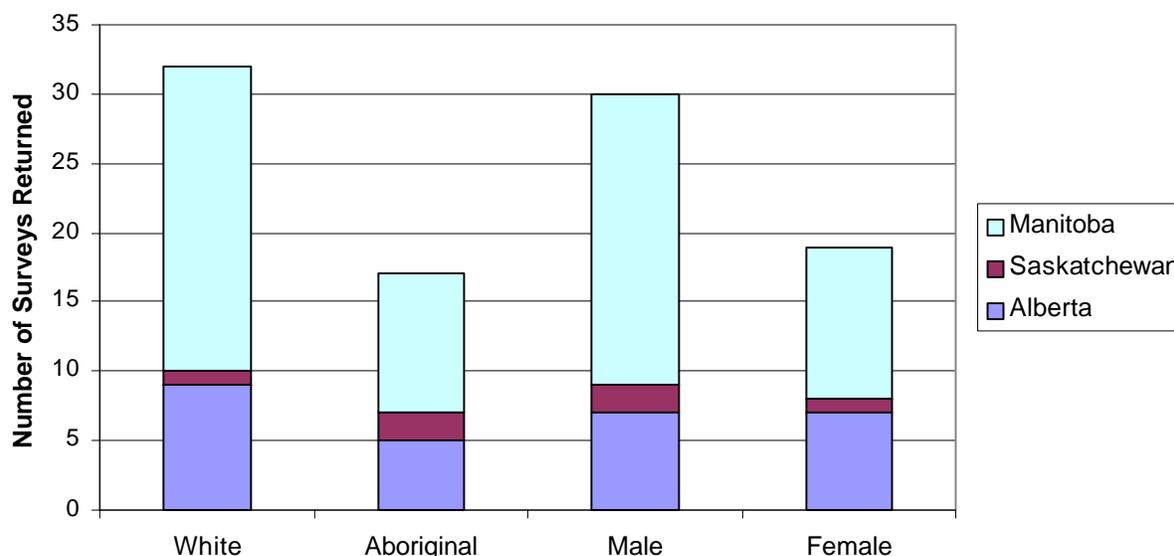
8 out of 17 (47%) Aboriginal participants speak an Aboriginal language, while 11 (36%) of 30 Caucasian participants and 3 Aboriginal participants speak French, Spanish or another language besides English.

f) Location (N=49)

65% (32 participants) live in Manitoba, with 14 or 29% from Alberta, and only 3 or 6% from Saskatchewan, demonstrating problems in data collection for that province. Despite this, the distribution of gender and ethnicity is fairly even across all provinces, reflecting emerging trends in HIV infection and AIDS diagnosis.

90% of participants said they lived in a city, including 100% of Aboriginal respondents, and all but one of the female respondents.

Distribution of Ethnicity & Gender by Province Client Surveys (N=49)



g) Living Situation (N=49)

The majority of participants (42% or 20) live in an apartment. 19% (9) of participants live in a house which they own, with a further 23% living in a house which they rent. 3 participants said they lived in a rooming or boarding house, and another 2 said they lived in hospice. 8 out of 9 homeowners are Caucasian males, as are all of those living in rooming/boarding houses and hospice.

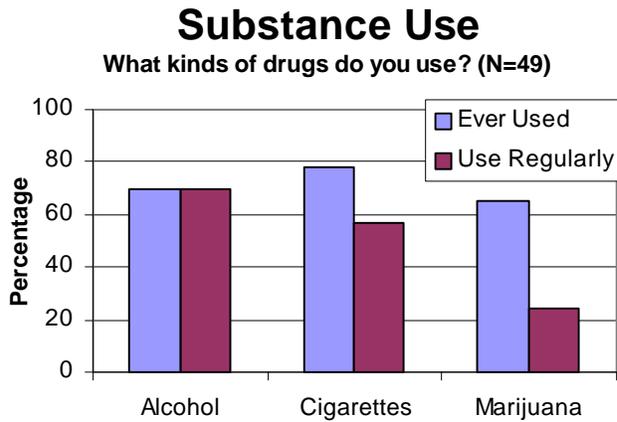
Table 3: Who do you live with?

Client Surveys (N=49)	#	%
Alone	24	49%
Spouse/Lover	11	22%
Roommate	6	12%
Children	5	10%
Parents	2	4%
Other	7	14%

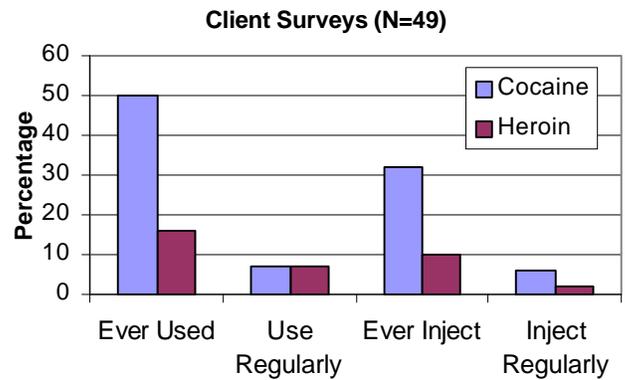
Note: Participants were asked to check all that apply. Other category includes: other inmates, friends, hospice tenants, halfway house tenants, homecare worker, and renter (tenant).

49% (24) of participants live alone, including 60% of males and 32% of females. All women living alone are Aboriginal, although this is likely due to the fact that most women in the sample are Aboriginal.

h) Substance Use



Cocaine & Heroin Use



16 participants (33%) of sample have injected drugs. 100% of this sub-sample have injected cocaine. It is felt that these findings may be under-representative of actual injection drug use among participants.

Table 4: Profile of Past & Present Injection Drug Users (N=16)

	Male	Female
Aboriginal	1	8
Caucasian	4	3

11 (58%) out of 19 female client survey participants report past or present injection drug use, including 8 (57%) out of 14 Aboriginal females. 53% (9 out of 17) of Aboriginal participants report past or present injection drug use.

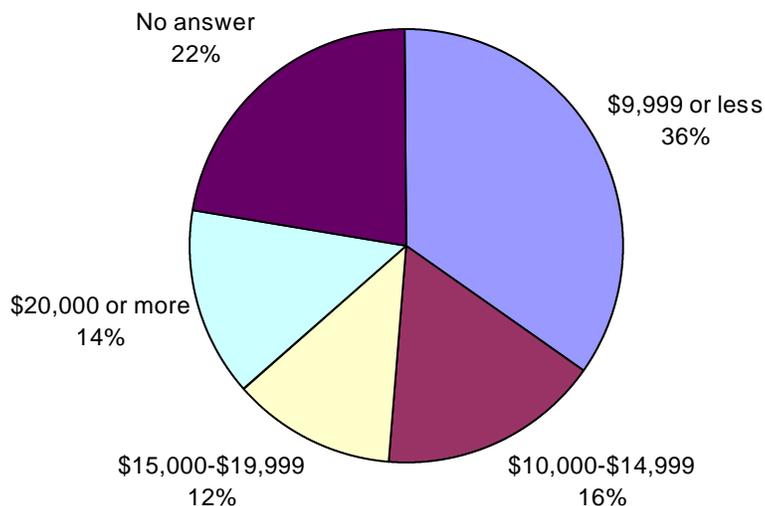
i) Employment & Income

Nearly 40% said they were “disabled” when asked their present employment situation, and a further 18% (9) said they were unemployed, either looking for work (2) or not looking (7). 14% (7) of respondents were working full-time or part-time. 10% (5) were students (4 out of 5 students were Aboriginal females), 12% (6) were volunteers, and 6% (3) were retired. Others said they were homemakers (2), self-employed (2), on social assistance (2), on maternity leave, or working a prison job.

In retrospect, the results of this question would have been more useful had “source of income” been asked rather than “employment situation”. As well, no data was received to qualify the response of “disabled”.

Income

What is your current household income? Client Survey (N=49)



Out of the 26 men who answered the income question, 14 (54%) earned less than \$15,000, including 9 (35%) who earned less than \$10,000. Of the 12 women who answered the question, 11 (92%) earned less than \$15,000, including 9 (75%) who earned less than \$10,000.

2. CLIENT FOCUS GROUPS

Four focus groups were held with a total of 26 participants, all in Winnipeg. Their profile is summarized in the table below.

Table 5: Profile of Focus Group Participants (N=26)

	Male	Female	Aboriginal	Caucasian
Initial Group (N=6)	4	2	3	3
Gay Men's Group (N=7)	7	-	-	7
Women's Group (N=10)	-	10	7	3
Aboriginal Group (N=3)	3	-	3	-
<i>Total:</i>	14	12	13	13

3. ORGANIZATIONAL QUESTIONNAIRES

A total of 33 questionnaires were returned from organizations.

a) Type

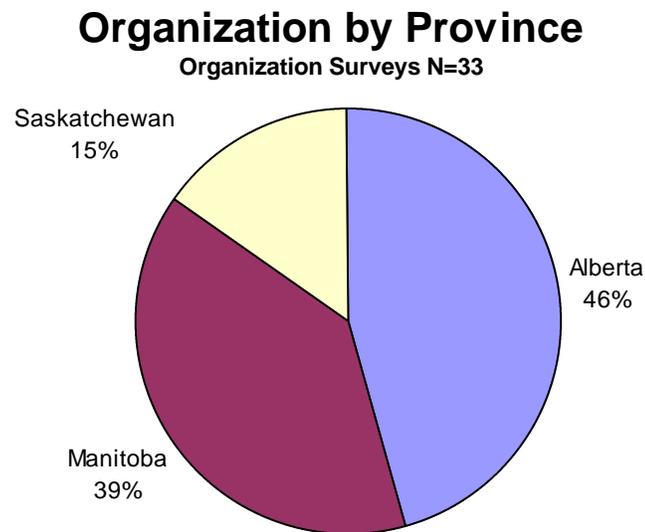
Table 6: Type of Organization (N=33)

	#	%
AIDS service organization	9	27%
Home Care	6	18%
Hospital	4	12%
Urban RHA	3	9%
Rural RHA	3	9%
Hospice	2	6%
Personal Care Home (Long-term care facility)	2	6%
Hospice	2	6%
Needle Exchange	1	3%
Ambulatory Care Clinic	1	3%

A total of 15 (45%) of these organizations indicated that they were community-based.

b) Location

15 (45%) of surveys were returned from Alberta, 13 (39%) from Manitoba and 5 (15%) from Saskatchewan, again demonstrating the under-representation of Saskatchewan throughout this report.



20 (60%) of organizations were located in a city, with 13 (40%) from towns, villages and rural areas, including northern, remote and reserve communities.

c) Language

As well as providing service in English, 9 (27%) of organizations provide services in French, and 6 (18%) provide services in an Aboriginal language.

d) Number of HIV clients

The structure of questions regarding number of HIV clients did not result in very clear data, however the mode (most frequent response) for all organizations was zero HIV clients. A range of 0 to 1 HIV clients was identified in personal care homes, with ranges from 0 to 2 in hospices and hospitals.

4. CAREGIVER INTERVIEWS

A total of 15 in-depth interviews were conducted, 6 with informal caregivers and 9 with formal caregivers. The profile of informal caregivers is as follows.

- Caucasian male caring for Caucasian male
- Aboriginal male caring for Aboriginal male
- Caucasian female caring for Caucasian male
- Caucasian male caring for Caucasian male
- Caucasian male caring for Aboriginal female
- Caucasian couple caring for Aboriginal female (foster child).

Profile of formal caregivers is as follows:

Table 7: Profile of Formal Caregivers (N=9)

Position	Province	Years of HIV Experience
HIV Nurse	MB	6 years
Infectious Disease Doctor	AB	11 years
Home Care Orderly	MB	1 year
Palliative Care Doctor	MB	5 years
HIV Nurse	MB	10 years
Hospice Coordinator	MB	2 years
Palliative Care Doctor	AB	8 years
Palliative Care Nurse	SK	8 years
Community Physician	MB	8 years
<i>Total Years Experience:</i>		59 years
<i>Average:</i>		6.5 years

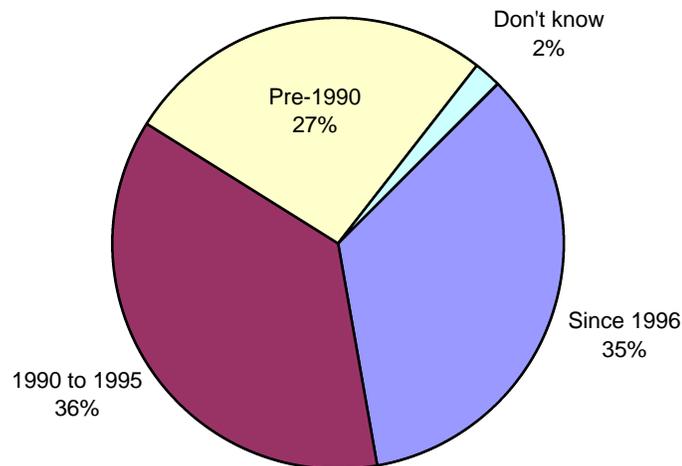
B. Medical Indications for Palliative Care

The following section discusses various aspects of the HIV/AIDS experience from the perspective of client survey participants, exploring indicators of HIV progression (year of diagnosis, hospitalization, CD4 count, viral load, medications), subjective experiences of ability to function and level of suffering, as well as participant beliefs about the benefits of aggressive antiretroviral treatment and reasons for stopping treatment.

1. DIAGNOSIS

Year of Diagnosis

When were you diagnosed positive for HIV? Client Surveys (N=49)



10 (53%) out of 19 women and 9 (53%) out of 17 Aboriginal participants were diagnosed since 1996. In contrast, only 23% of male participants and 25% of Caucasian participants were diagnosed since 1996.

Only 2 females (11%) and only one Aboriginal participant tested positive before 1990, in contrast to 11 males (38%) and 12 Caucasian participants (38%).

2. HOSPITALIZATION

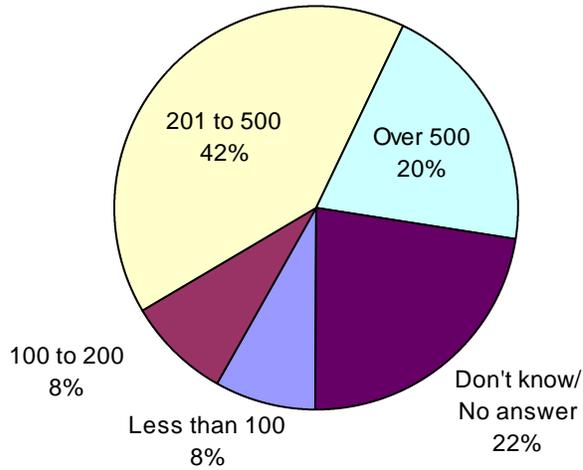
15 or 31% of client survey participants indicated that they had been hospitalized for HIV-related illness. 26 or 53% had been hospitalized for a non-HIV related illness. Fewer Aboriginal participants had been hospitalized for an HIV-related illness (24% of Aboriginal participants, 34% of Caucasian participants), perhaps reflecting year of HIV diagnosis (above).

90% of total participants who had been in hospital (N=32) described the care they received in hospital as adequate (50%) or totally adequate (40%). This question did not differentiate between care received for HIV or non-HIV related illnesses. Further, 65% of participants have ever required assistance due to an HIV-related illness.

3. CD4 COUNT & VIRAL LOAD

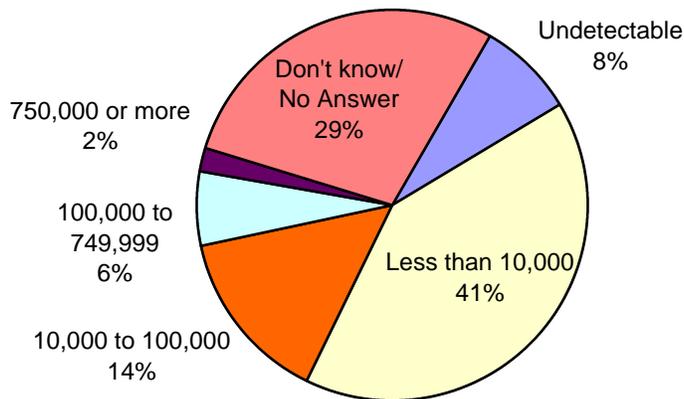
CD4 Count

What is your current CD4 count? Client Surveys (N=49)



Viral Load

What is your viral load? Client Survey (N=49)



Reported CD4 counts were generally high, and reported viral loads generally low among participants who answered the question. No Aboriginal participants or female participants had CD4 levels below 200, or viral load levels above 10,000, however both questions had a high rate of participants who didn't know their levels or didn't answer the question.

4. MEDICATIONS

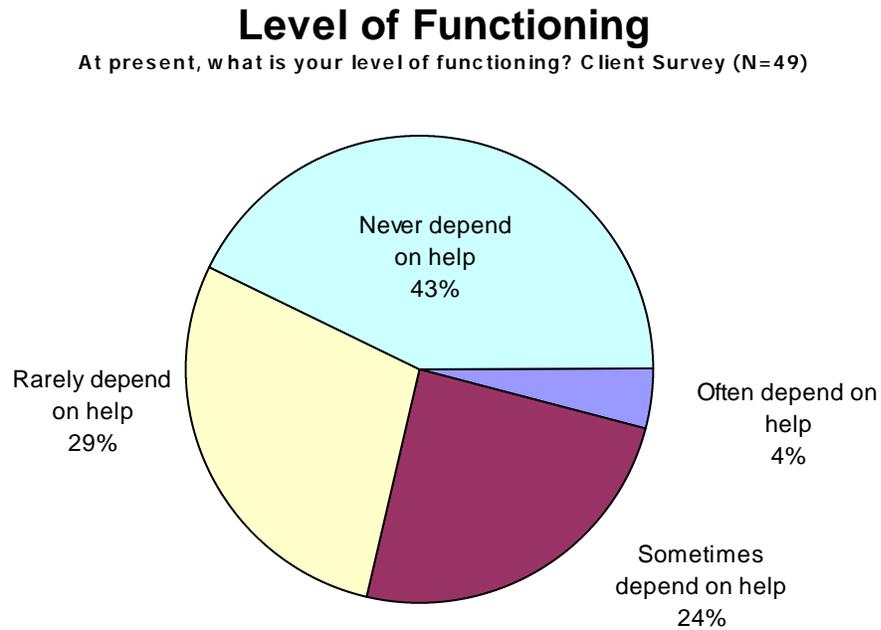
Table 8: Types of Medications & Treatments

Type of Medication	#	%
Antiretroviral Therapy	31	63%
Opportunistic Infection Prophylaxis	11	22%
Anti-depressants	10	20%
Vitamins	10	20%
Analgesic	9	18%
Antinauseants	9	18%
Anti-anxiety	8	16%
Antibiotics	6	12%
Sleeping pills	5	10%
Herbal/Chinese	3	6%
Other	13	27%
Don't know/No answer	5	10%

Other includes: anti-fungals, diuretics, blood thinners, estrogen, inhalers, insulin, skin moisturizers, medications for ulcers, diabetes, high cholesterol, hemeophilia and hypo-thyroid.

70% (21 out of 30) of men and 72% (23 out of 32) of Caucasian participants are taking anti-retroviral therapy, in contrast to 10 out of 19 (53%) women and 8 out of 17 (47%) Aboriginal participants.

5. LEVEL OF FUNCTIONING & SUFFERING



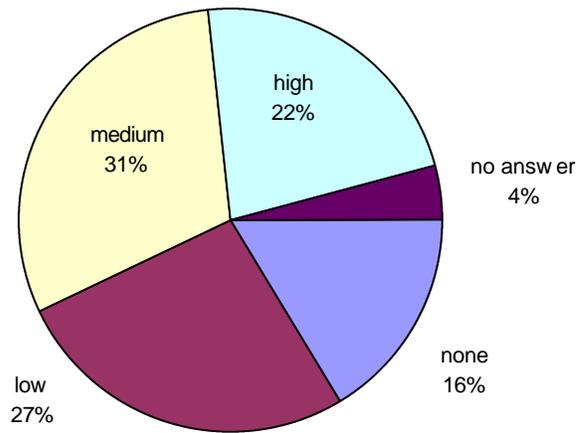
Level of functioning was assessed by asking participants whether they ever depended on ‘help’. Help was not further defined, leaving the concept open to interpretation. By far the majority of

participants said they never (43%) or only rarely need help (29%). While 50% of males said they never need help, only 32% of women said they never need help.

Another question related to functioning (Have you ever required assistance due to an HIV-related illness?) was asked later in the survey. 65% (32) of participants said yes and 17 or 35% said no. Broken down by ethnicity, 13 (76%) out of 17 Aboriginals said they required assistance due to an HIV-related illness, compared to 19 (60%) out of 32 Caucasian participants.

Level of Suffering

If you have pain, what would you say is your level of suffering (as you experience it)? Client Surveys (N=49)



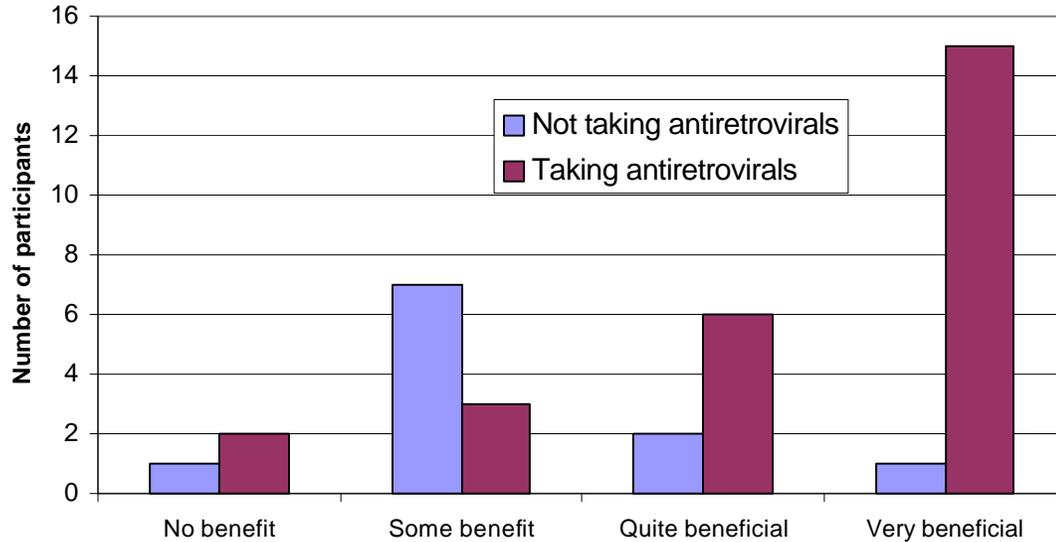
80% of participants report some experience of pain, with over half reporting medium to high levels of pain. There seems to be no correlation between level of suffering and functioning and taking ART, CD4 count, or viral load. In fact, the one person with a viral load of over 750,000 reported never needing help and no pain.

Participants were also asked how much they experienced “physical pain or other HIV discomforts”. 37% of total sample reported this experience either quite a bit or a lot, 39% reported this experience a little, and only 24% reported never having this experience.

6. BELIEFS ABOUT TREATMENT

Perceived Benefit of Treatment

Do you believe aggressive treatment to be beneficial? Client Survey (N=49)



A total of 33% (16) of participants in the client survey believe that aggressive HIV treatment is very beneficial, with a further 16% (8) calling it quite beneficial and 22% (11) saying it has some benefit. Only 14% (7) said aggressive treatment was of no benefit. A majority (55%) of client participants believed there was no cure for their illness.

63% (31) of participants said yes when asked “Are there any circumstances under which you would consider stopping all treatment?” Reasons given for stopping treatment were summarized as follows, with a full listing of qualitative data provided beneath the table.

Table 9: Reasons for stopping treatment (N=31)

	#	%
Side Effects – Reduced quality of life	13	41.9%
No hope of recovery	11	35.5%
Other	3	9.7%
No answer	4	12.9%

Side Effects – Reduced quality of life

- If intervention depleted or resulted in depleting quality of life.
- After being on treatment for 9 years, I do feel better off the medications and vomit considerably less.
- Too many side effects and poor outcome.
- If my quality of life was unsatisfactory.
- [Treatments] making me sick.
- When side effects outweigh the benefit of antiretrovirals (a quality of life issue).
- If the pills stopped working or if they had bad side effects. I don't want pills that make me sick.
- If treatment takes away from my quality of life or makes me feel sicker than I am.
- Some of the side effects of medications scare me.

- I've got peripheral neuropathy in feet due to Zerit medication (side effects).
- When treatment is too much of my life, I would rather die.
- If and when the drug regimens and the disease so reduce the quality of life that communication is no longer possible.
- If I get too sick with HIV or with treatment.

No hope of recovery

- When it becomes useless.
- When level of functioning stops completely.
- Too ill with too much pain and too hard on family; just too tired of fighting.
- Prolonging just to keep the body alive.
- If the end result of treatment would not return me to independent living.
- If drug therapies stopped working.
- When any hope of recovery is gone, brain damage.
- When I'm in the end stages of AIDS and treatment is no longer beneficial.
- If no medicine was beneficial to me.
- Running out of present cocktails.
- Likely when I loose everything in my health, I will say enough. Why put myself and especially others through it when there is no hope?

C. Access to Services

The following section summarizes data from the client and organization surveys related to accessibility of and satisfaction with various services. Clients were asked about their care providers, alternative/complementary therapies available in their area, other supports, and knowledge of palliative care teams. Organizations were asked about the services they provide, other supports available, palliative care teams, and level of resources available for palliative care.

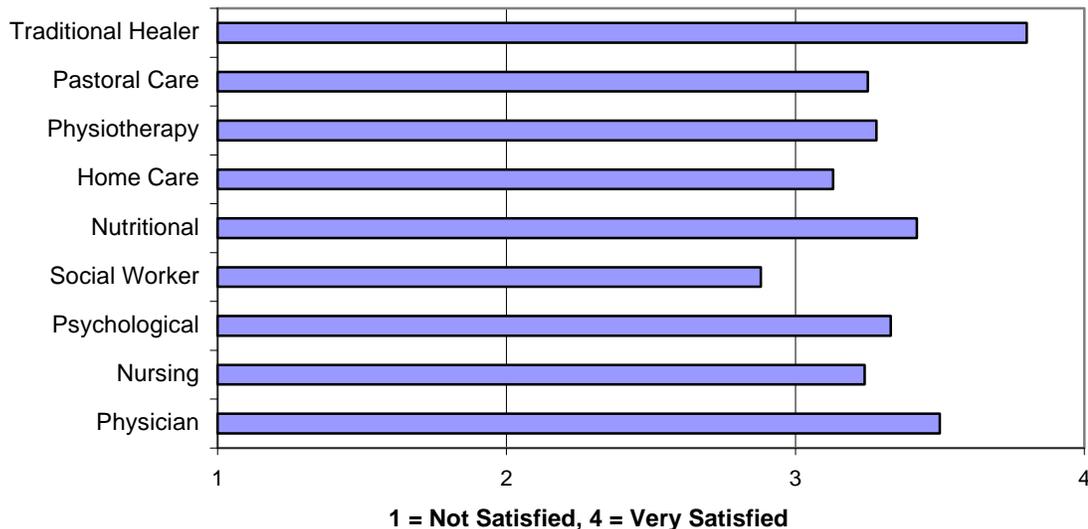
1. CARE PROVIDERS

Table 10: Which care providers have you accessed for your HIV treatment? (N=49)

Service	#	%
Physician	43	88%
Nursing	29	59%
Psychological	24	49%
Social Worker	24	49%
Nutritional	21	43%
Home Care	9	18%
Physiotherapy	7	14%
Pastoral Care Worker	5	10%
Traditional (Native) Healer	5	10%
Other	7	14%

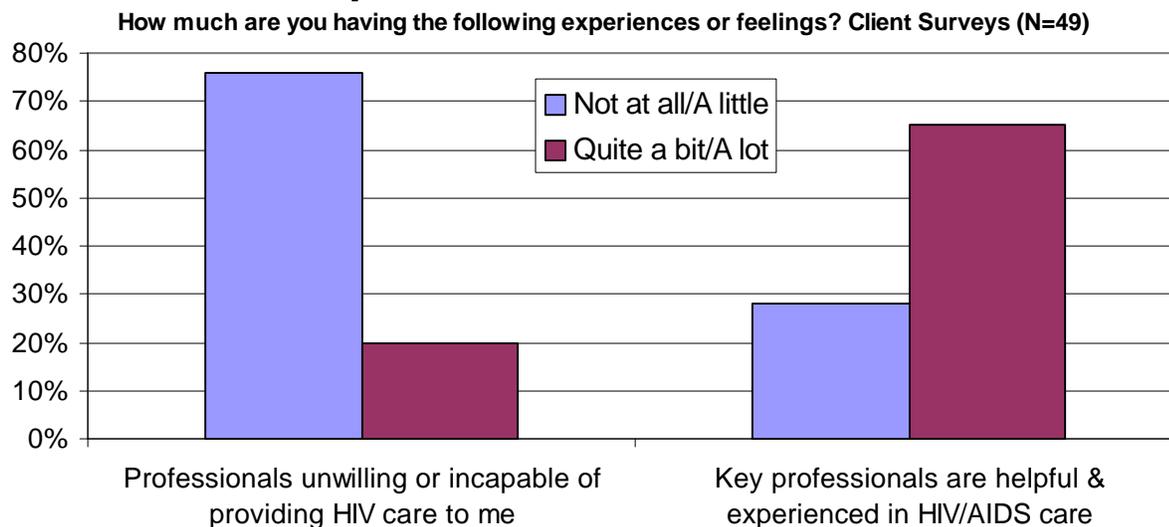
Satisfaction with Care Providers

How satisfied are you with the care you received? Client Surveys (N=49)



In general, client survey participants were satisfied with service they received from care providers. The lowest rating was given to service provided by social workers (N=24), and the highest to services provided by traditional healers (N=5). The following table, however, illustrates that a significant minority of participants are not receiving what they see as optimal care from professionals.

Experience with Professionals



A further breakdown of the first category (Professionals unwilling or incapable of providing HIV care to me) reveals a distinct distribution of responses between Aboriginal and white participants, with 30% (5 out of 17) saying they had this experience ‘a lot’, compared to only 3% of white participants saying they had this experience.

Respondents from the organizations reported that they either provided or referred the following services.

Table 11: Organizations – Client Services to PHAs (N=33)

Services	Provided		Referred	
	#	%	#	%
Nursing	22	67%	10	30%
Home Care	17	52%	13	39%
Social Worker	16	48%	10	30%
General Practice Physician	15	45%	14	42%
Nutritional	14	42%	12	36%
Physiotherapy	12	36%	11	33%
Pastoral Care	11	33%	13	39%
Psychological	10	30%	13	39%
Specialist Physicians	6	18%	15	45%
Psychiatrist	5	15%	13	39%
Other	11	33%	6	18%
No answer	2	6%	2	6%

Other Services Provided include: Support group, resource materials, pharmacy (2), volunteers, care teams, care coordination, peer counselling, home oxygen.

Other Services Referred include: AIDS Service Organizations (2), treatment centres (2), volunteer support.

2. COMPLEMENTARY THERAPIES

Table 12: What services are available in your area? Have you accessed any of the following complementary therapies? (N=49)

Services	Available		Received	
	#	%	#	%
Massage	26	53%	20	41%
Aboriginal Ceremonies	21	43%	20	41%
Reiki	20	41%	13	27%
Acupuncture	19	39%	11	22%
Art/Music Therapy	18	37%	12	24%
Therapeutic Touch	17	35%	11	22%
Medicinal Marijuana	13	27%	15	31%
Other	12	24%	11	22%
No Answer	7	14%	6	12%

In general, services were more available in Alberta than in Manitoba or Saskatchewan, with the exception of acupuncture (roughly equal in Alberta and Manitoba), and Aboriginal ceremonies (roughly equal in all three provinces). White participants were more likely to report that services were available in their area and were more likely to receive those services than Aboriginal participants, with the exception of Aboriginal ceremonies. As well, those currently taking HIV medications were more likely to report receiving complementary services.

Aboriginal participants were less likely to report benefit from any of the complementary therapies listed above, although only 3 to 4 Aboriginals in the sample had received most services, again with the exception of Aboriginal ceremonies.

Availability & Benefits of Aboriginal Ceremonies by Ethnicity

Client Surveys N=49

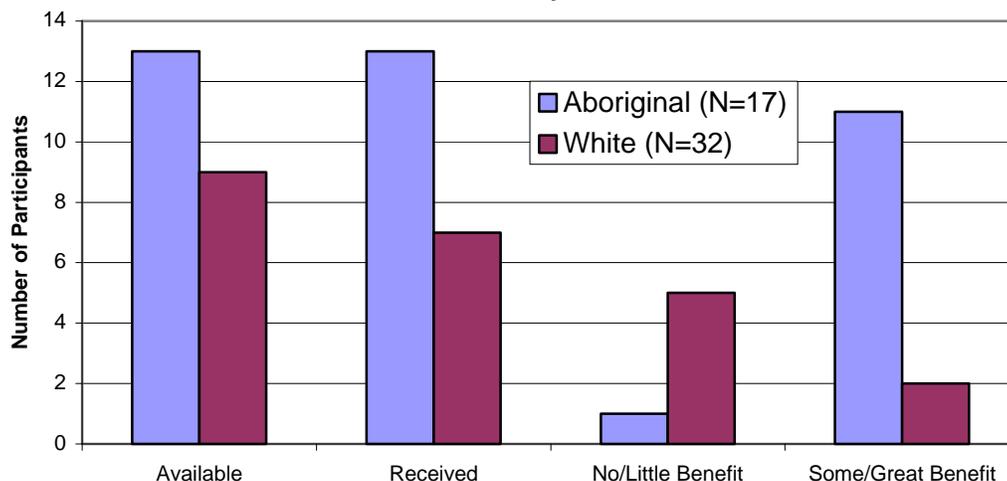


Table 13: Organizations – Complementary Therapies for PHAs (N=33)

Services	Provided		Referred	
	#	%	#	%
Massage	7	21%	12	36%
Therapeutic Touch	5	15%	6	18%
Aboriginal Ceremonies	5	15%	11	33%
Reiki	4	12%	7	21%
Art/Music Therapy	4	12%	8	24%
Acupuncture	2	6%	6	18%
Medicinal Marijuana	1	3%	4	12%
Other	11	33%	4	12%
No answer	2	6%	1	3%

Other Services Provided include: Relaxation, visual imaging, aromatherapy, exercise program, support group, needle exchange, volunteer services, companions, free haircuts, vitamins, community kitchen.

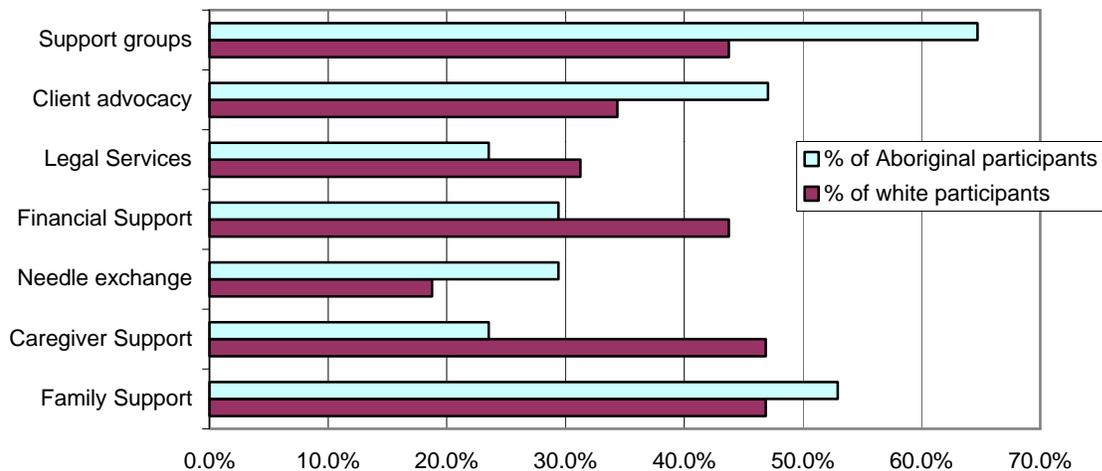
Other Services Referred include: Support group, ASO programs and services, volunteer training.

3. OTHER SUPPORTS

49% (24) of participants indicated that family supports were available. It is unclear from the questionnaire whether this means family supports for the client or outside supports for family members. 19 or 39% indicated that caregiver supports were available (this category is also unclear). 25 or 51% said support groups were available, 19 or 39% said client advocacy services were available, and 19 or 39% said financial support was available. Only 14 (29%) said legal services were available, and 11 (22%) said needle exchange was available. There was significant variation in responses among Aboriginal and white participants:

Other Supports Available by Ethnicity

Are there any other support services/resources available? Client Surveys (N=49)



Aboriginal participants were more likely to indicate that support groups, client advocacy, needle exchange and family supports were available, and less likely to indicate that legal services, financial support and caregiver supports were available.

Table 14: Organizations – Other Supports Available (N=33)

Services	Provided	
	#	%
Caregiver Support	19	58%
Family Support	17	52%
Client Advocacy	15	45%
Volunteer Support/Training	5	15%
Legal Services	3	9%
HIV/HepC Support Group	3	9%
Counsellor	2	6%
Emergency Financial Assistance	2	6%
Other	5	15%

Other includes: Respite, peer training, pastoral/spiritual care, bereavement care.

4. PALLIATIVE CARE TEAMS

7 or 14% of client survey participants reported having taken part in a palliative care team meeting. Palliative care team members mentioned include nurses (4), family/caregivers (4), physicians (3), nutritionist (2), physiotherapist, psychologist/counsellor, pastor/priest and volunteer.

20 out of 33 organizations (61%) who returned a questionnaire said they had a palliative care team. A wide range of disciplines were reported to take part in these team, including physicians, nurses, specialists, social workers, pastoral care workers, nutritionists, home care support workers, nutritionists, occupational therapists, physiotherapists and psychologists/psychiatrists. Other participants included the client (12 out of 20), family and caregivers (13 out of 20), peer supports (7 out of 20), traditional healers (4 out of 20) and volunteers (6 out of 20).

Another aspect of palliative care teams explored in the organizational survey was community partnerships, both formal and informal. 15 or 45% of organizations reported having formal linkages with other organizations in the delivery of palliative care, and 28 or 85% reported informal linkages. These linkages include health authorities, ASOs, palliative care units, funding bodies, private donors and hospices.

5. RESOURCES FOR PALLIATIVE CARE

Only 27% (9 out of 33) of organizations described funding for palliative care human resources as adequate. An upward trends in funding for palliative care human resources was identified by 21% (7) of organizations, a downward trend by 6 or 18% of organizations, and a stable trend by 12 or 36% of organizations.

Comments by organizations on adequacy of funding for palliative care:

- Any programs run are on donated dollars. There is provincial funding for one palliative care nurse per region.
- Awaiting funding for program expansion.
- Not funded.
- With no designated palliative care beds, no additional funding provided to provide the service.
- Provincial government is not funding the agency.
- No designated funds by the provincial government, however regional authorities are seeing the need and budgeting funds. We need funding but are happy with the initial support.
- Will need to keep pace with expected increase in workload.
- Difficult to get personal care due to inadequate funding.
- We are a non-profit registered society. We do not have a guarantee on funding. We depend on grants, donations and fundraising activities.
- I believe increased funding needed for home care nursing support, financing medications, and 24 hour crisis support. Local funding coordinators.
- We still require education of doctors, nurses, physiotherapists, occupational therapists, clergy, social service to the palliative care needs.
- We cannot provide direct palliative services due to lack of resources and training.
- Interest just beginning to increase. Physician complains of lack of money for service. Refers out, does not provide direct service.
- Needs presented by clients are moving away from palliative care to more crisis response.
- District is planning to post a position for a palliative care coordinator.

D. Quality of Life

This section summarizes client survey and focus group data related to experiences and feelings, including pleasure, meaning, isolation, connectedness, suicide, dying with dignity, money, discrimination and other elements of their experience with maintaining quality of life.

1. PLEASURE & MEANING

Client survey participants were asked to list their main pleasures. 43 out of 49 responded to the question, and a list of 180 responses was generated and coded.

Table 15: Can you list your main pleasures? (N=43, R=180)

	#	% of individuals	% of responses
Relationships (partner, spouse, children, family, friends, loving, being loved, talking with people)	36	83.7%	20.0%
Reading	17	39.5%	9.4%
TV/movies	16	37.2%	8.9%
Nature/being outdoors	13	30.2%	7.2%
Music/art	13	30.2%	7.2%
Food/cooking	12	27.9%	6.7%
Creative activity	11	25.6%	6.1%
Exercise/sports	10	23.3%	5.6%
Pets	5	11.6%	2.8%
Health/happiness	4	9.3%	2.2%
Travel	4	9.3%	2.2%
Bed/sleeping	4	9.3%	2.2%
Spirituality/meditation/aboriginal culture	4	9.3%	2.2%

Client participants were also asked to list the things that give meaning to their lives. 42 out of 39 answered the question, and a list of 148 responses was generated and coded.

Table 16: Can you list the things that give meaning to your life? (N=42, R=148)

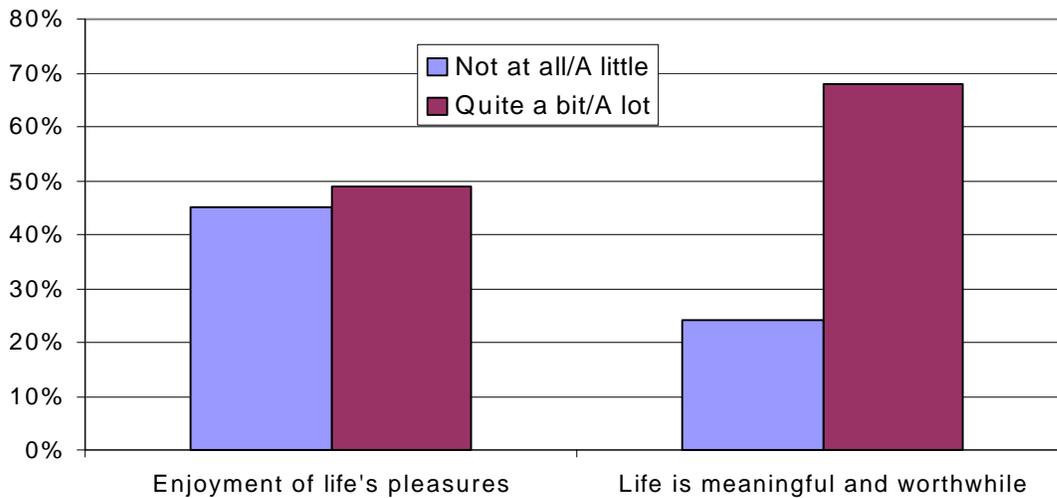
	#	% of individuals	% of responses
Relationships (partner/spouse/ friendships/loving/being loved)	63	74.6%	42.6%
Activities/hobbies/work	20	47.6%	13.5%
Family	18	42.9%	12.2%
Children/being with children	10	23.8%	6.8%
Religion/spirituality/meditation	10	23.8%	6.8%
Pets	9	21.4%	6.1%
Helping others/volunteering	8	19.0%	5.4%
Life itself/health	8	19.0%	5.4%
Other supports	5	11.9%	3.4%
School/learning new things	5	11.9%	3.4%
Possessions	4	9.5%	2.7%
Peer supports	3	7.1%	2.0%

The emphasis placed by participants on the role of relationships in pleasure and meaning of life is clear. Whether with a partner, spouse, lover, parent, child or just talking with people in general, relating with others is identified as a central aspect of quality of life.

The range of responses to these questions also demonstrates highly individual preferences for meaningful activity. Work, including hobbies and activities, was also identified as an important aspect of quality of life.

Pleasure & Meaning

How much do you have the following experiences and feelings?
Client Surveys (N=49)

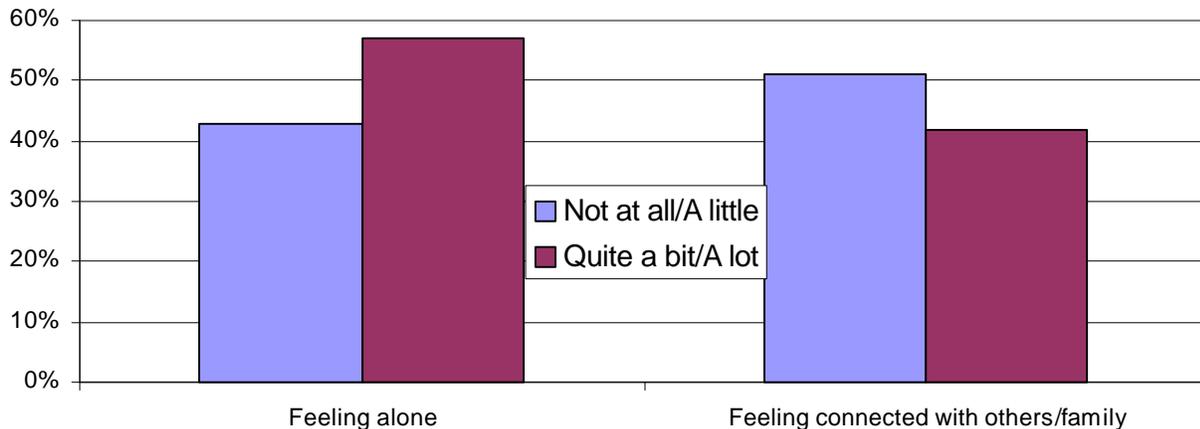


2. ISOLATION & CONNECTION

A majority (58%) of client survey participants reported feeling alone quite a bit or a lot, and 51% reported feeling not at all or only a little connected to others, highlighting the isolation experienced by many PHAs.

Isolation & Connection

How much are you having the following experiences or feelings? Client Survey (N=49)



Focus group data illustrate the experience of isolation and connectedness:

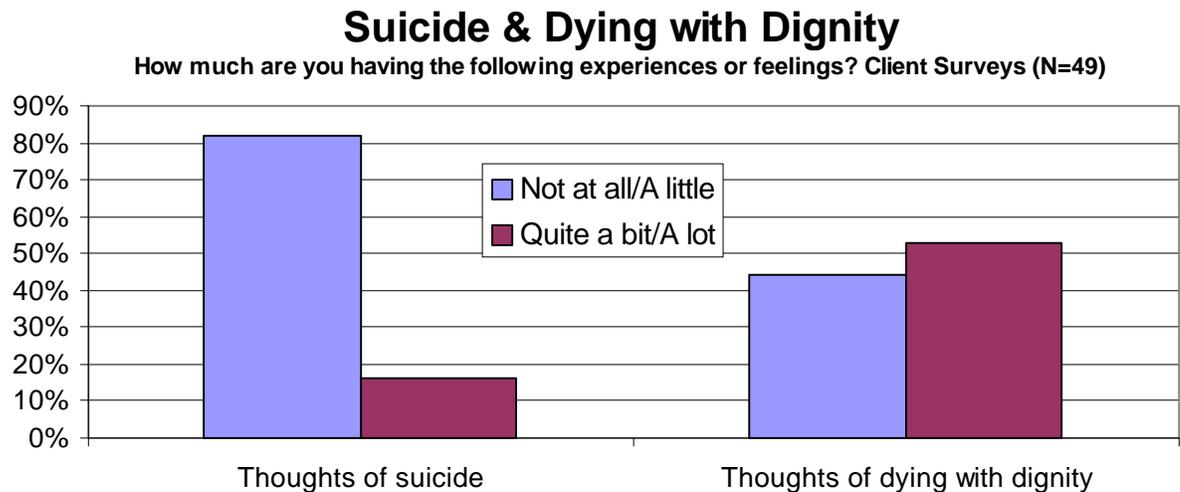
- I want to spend time with my kids. (Women’s Focus Group)
- Being around people you like. (Gay Men’s Focus Group)
- I’ve become more of an unconditional friend. (Aboriginal Focus Group)
- My own family shunned me. I have to rely on ASO’s to act as family. (Initial Focus Group)
- HIV makes you go back to your family, to find out what you lost. (Aboriginal Focus Group)
- My family should have helped me, but they weren’t there. I don’t think they do anything for me. No one loves me enough to help me, they’re not possibly strong enough to do it. (Aboriginal Focus Group)

Another aspect of connection discussed in the focus groups was sex. This discussion was particularly animated during the women’s focus group. Several focus group participants said they had “given up on sex”, however many also said that they wanted more intimate sex, with an increased focus on giving, sharing and enjoyment.

- Sex is no longer a factor. (Aboriginal Focus Group)
- I don’t want anyone to touch me, I start shaking. (Women’s Focus Group)
- I don’t get sex, but I do get orgasms. (Gay Men’s Focus Group)

3. SUICIDE & DYING WITH DIGNITY

22% of white participants said they had thoughts of suicide either quite a bit or a lot, while only 6% of Aboriginal participants said this.



- I want to be able to die with dignity. (Women’s Focus Group)
- The Aboriginal approach to death is that it’s a good thing. (Aboriginal Focus Group)
- Aboriginal approach to dying is that death is a good or at least neutral thing. White people always see it as bad. (Women’s Focus Group)
- I have a strong wish to help others to have a good life and a good death. (Initial Group)
- Life is to be celebrated. You are leaving a legacy behind, a symbol of joy. (Women’s Focus Group)
- I don’t want to see death as my ‘failure of choices’. (Women’s Focus Group)

4. MONEY

65% of client survey participants said they experienced not having enough money to meet their basic needs either quite a bit or a lot. Only 14% said they never had this experience. Nearly 77% of Aboriginal participants reported this experience either quite a bit or a lot, compared to 59% of white participants.

- Basic needs are not adequately covered by Social Assistance. (Gay Men's Focus Group)
- Access to anything other than drugs is limited by money. (Gay Men's Focus Group)

5. DISCRIMINATION

In general, few participants indicated that they experienced discrimination. Only 12% of total participants said they experienced discrimination because of their sexual orientation either quite a bit or a lot (10% of Caucasian participants and 17% of Aboriginal participants). 25% of Aboriginal participants experienced discrimination because of race or ethnic identity either quite a bit or a lot. Only 12% of total sample felt they were discriminated against because of their non-medical drug use either quite a bit or a lot.

Discrimination because of HIV status was more commonly reported. Only 37% of participants said they never experienced discrimination due to their HIV status. 26% said they experienced this quite a bit or a lot, including 35% of Aboriginals and 22% of white participants.

- I think if I had a different illness, I would be treated better. (Client Survey)
- If we weren't PHA's, we would be thought of as hypochondriacs. (Gay Men's Focus Group)

7. OTHER FOCUS GROUP DATA

a) Catalyst for Change

- My life changes all the time in response to changing circumstances. I'm leaving the old life behind and finding a different focus (Initial Focus Group)
- My major pleasures have changed.
- I'm finding other priorities, and changing my focus.
- I am able to change my old, inadequate patterns of coping, so I can move on and grow. (Gay Men's Focus Group)
- There is a sense of impermanence, that I have to seize the time.
- I have more confidence in my ability to change things.
- I'm more focused on trying to build a good life for myself. (Women's Focus Group)
- The fear of dying pushes you to achieve your goal of staying sober. (Aboriginal Focus Group)
- Basic things like food, friends, and creative activity became more important. (Aboriginal Focus Group)

b) Coping

- You have to take a serious approach to anxiety. (Initial Focus Group)
- Don't panic with small things. (Gay Men's Focus Group)
- It's important to have an awareness that the body is going through its own normal processes, not only HIV. (Gay Men's Focus Group)

- Healing involved being able to grieve. (Women's Focus Group)
- Try to push negative things into positive. (Aboriginal Focus Group)
- Getting high, dancing, laughing. (Gay Men's Focus Group)

c) Helping others

- Helping someone else helps (Initial Focus Group)
- I'm determined to get things accomplished for my son. (Women's Focus Group)
- Nurturing, being kind, caring, these things about me were hidden under drugs/alcohol. (Women's Focus Group)
- The opportunity to tell my story to someone else, to share my story to help someone else avoid this. (Women's Focus Group)
- Work pulls me out of myself, "helper's high". (Gay Men's Focus Group)

d) Spirituality

- Living through visions throws me into spiritual aspect of life. (Aboriginal Focus Group)
- My mantra is: With my eyes I see, With my ears I hear, With my hands I feel, With my heart I understand. (Gay Men's Focus Group)

e) Living with Dying

- Have to live like we're dying. (Gay Men's Focus Group)
- Really start living when you hear about dying. (Women's Focus Group)
- "It seems like I'm being trained to face death." (Aboriginal Focus Group)
- Some misgivings about making a will, indicates a readiness to die, by writing it down. (Initial Focus Group)

E. Preferences for Palliative Care

A series of four questions were asked in the client survey in order to identify client preferences for caregivers and advocates in the event of HIV-related illness.

1. Who provided care? (If you have ever required care/assistance due to an HIV-related illness: N=32 or 65% of sample)
2. Who would you want to be your advocate when you become less able to function? (N=49)
3. Who *should* provide care? (N=49)
4. Who would you *want* to provide care? (N=49)

Table 17: Preferences for caregiver support in palliative care. Check all that apply. (N=49)

	Who did provide care? (N=32)		Who would you want to be your advocate? (N=49)		Who should provide care? (N=49)		Who would you want to provide care? (N=49)	
	#	%	#	%	#	%	#	%
Partner/Spouse	15	47%	16	33%	17	35%	17	35%
Friend	12	38%	14	29%	13	27%	17	35%
Parents/Family	7	22%	13	27%	13	27%	16	33%
Children	3	9%	3	6%	4	8%	4	8%
Medical Professionals	18	56%	16	33%	39	80%	35	71%
Other	8	25%	8	16%	10	20%	14	29%
Don't know/No Answer	-	-	2	4%	1	2%	-	-

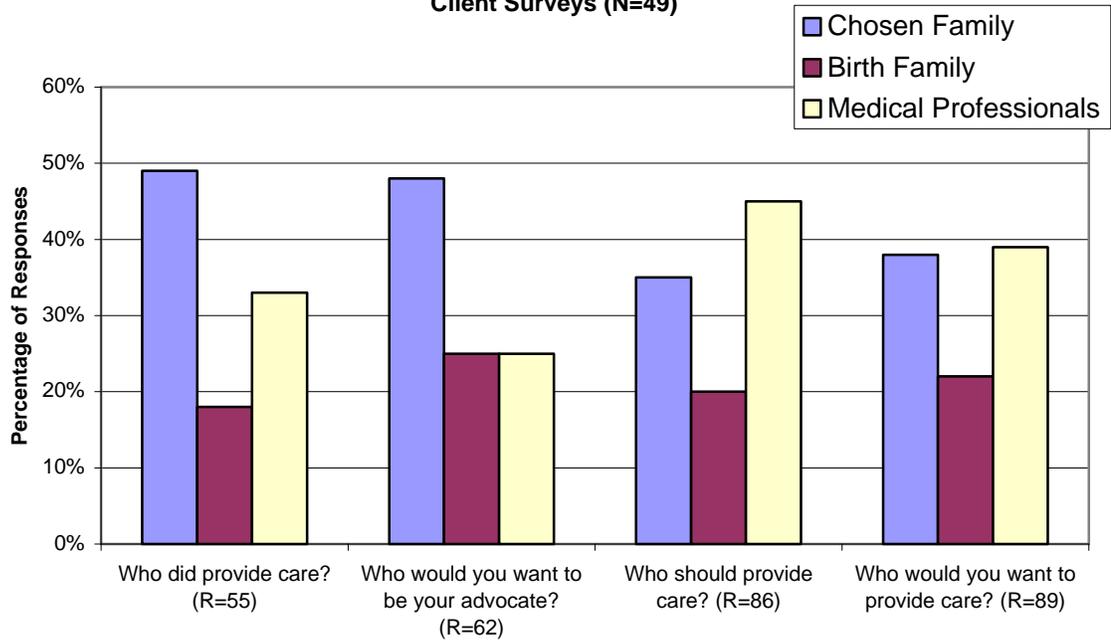
This table demonstrates that a high percentage of client survey participants believe medical professionals should provide care (80%), or would want medical professionals to provide care (71%). Only 56% of those who had received assistance for an HIV-related illness received it from medical professionals, and only 33% said they would want medical professionals to be their advocates when they are less able to function.

47% reported that their partners/spouses had provided care when they needed assistance, however only 35% thought that their partner/spouse should provide care. 38% reported that a friend had provided care, however only 27% thought that a friend should provide care.

In order to get another picture of this data, Partner/Spouse and Friend were collapsed to make the category “Chosen Family”, and Parents/Family & Children to make the category “Birth Family”, leaving three primary categories including “Medical Professionals”. Instead of looking at the number of participants answering each question, the total of each primary category was compared to the total number of responses to that question.

Caregiver Preferences of Clients

Client Surveys (N=49)



For those who had already required assistance for an HIV-related illness, chosen family provided care in most cases (49%). Members of the chosen family were also the preferred advocates of a large proportion of client participants (48%), however most (45%) thought medical professionals *should* provide care.

Despite this, patient autonomy and the physician's role in decision-making was often mentioned as a concern of clients:

- I would like to be treated as if I am an adult and not a child. (Client Survey)
- Palliative care begins when I say so. (Gay Men's Focus Group)
- The doctor's opinion is noteworthy. Mine is more noteworthy. (Gay Men's Focus Group)
- The doctor's opinion regarding time frame becomes something to bet against and beat. (Gay Men's Focus Group)
- Doctors playing God is not right. (Women's Focus Group)
- If someone told me I had 9 years to go, I'd tell them to fuck off. Doctor's opinion of how I feel is not the issue. It's not right for a doctor to put a time limit on my life. It just adds to the stress, so I don't ask how long I'm going to live. (Women's Focus Group)
- I value the doctor's opinion but I also value my own. The doctor's opinion is not the word of God. (Aboriginal Focus Group)

F. Informal Caregivers

I can't ask anyone to look after me. It's too hard.
Aboriginal Focus Group

When you look after someone who's dying, they teach you a lot.
Client Survey

1. THEMES FROM INFORMAL CAREGIVER INTERVIEWS

The themes that emerged from the Informal Caregiver interviews centred around the emotional and physical struggles in caring for a loved one who requires highly personalized and individualized care at home. Caregivers were highly motivated to provide this care.

In spite of the desire of most clients to die at home, home care and palliative care services do not adapt quickly enough to enable this goal to be reached, causing anxiety to caregivers who cannot succeed in meeting the preferences of their loved one. Constant care is only available to those who can pay for it.

The caregivers who had already lost the person they care for recalled the relief they felt along with the grief at the time of death. They were “burned out” after years of continually putting someone else’s needs ahead of their own and not getting regular respite. They were tired from monitoring and teaching and dealing with the fears of a discontinuous chain of home support workers. They were lonely as many of their friends had fallen away. They felt overwhelmed with constant responsibility coupled with too little knowledge about the symptoms, the progression of the illness, and techniques of physical care. They didn’t use universal precautions.

The caregivers feel responsibility as the primary advocate. Many of them live with HIV or some other debilitating condition themselves. It was stressful managing dementia, diarrhea and the insecurities and demanding behaviour of their loved ones. It was a financial strain for some of them. Closure didn’t always occur satisfactorily. Finally, caregivers living with HIV feared no one would be available to give them care and advocacy when they needed it, as they had provided. It was generally felt that a hospice would help address some of these needs.

Other themes include mental health issues, discrimination because of HIV, need for more support and respite, more consistent homecare, more information and training for informal caregivers, and lack of housing and hospice.

2. CASE STUDIES

As part of data collection, interviews were held with 6 informal caregivers, who had cared or are caring for someone living with AIDS. This is presented in a case study format, letting the stories speak for themselves. Identities and other details have been altered to ensure confidentiality.

Case Study #1

Ron & Bobby

Ron is a 40-year old bachelor, Italian, gay, who speaks Spanish, English and Italian, and lives in a prairie city in a house which he owns. He lived with the person he cared for, Bobby, for 7 out of 8 years they knew each other, until Bobby passed away at age 52 after 16 years of living with HIV. Ron got to know Bobby through a volunteer agency whose volunteers cared for people living with HIV in their homes. He said of his volunteer work: *“I got a high out of treating them (clients) properly and seeing they had a good time.”* He worked for a year as a volunteer, became Bobby’s friend, then considered moving in when the team’s assessment was that it was not safe for Bobby to live alone. Ron was on a disability allowance for a back injury and the agency paid him \$1000 a month once he moved in to provide full-time care. Bobby’s pension covered the bills.

Ron says: *“When I moved in to look after Bobby, I made a commitment that I would care for him until he passed away. Being gay, I had already suffered rejection from my ethnic community. Now, because I lived in the house, many people assumed we were lovers and that I had HIV. They were wrong on both counts. Because of Bobby’s psychiatric history it was hard for me to sort out what were psychological issues and which were signs of HIV dementia. Sometimes he was rushed to hospital with a seizure or other side effects of HIV meds, until his drugs were balanced. When I had to take him to hospital Emergency with a seizure, the nurses’ attitude changed immediately when I told them he had AIDS. That made me angry, so I tried to deal with seizures at home. Because Bobby was Number 1, I took on many of his feelings and symptoms of HIV. I felt lonely and had panic attacks... The last 2 years, Bobby went to a hospice for 2 weeks to give me respite. I’d come back from a holiday, and immediately, my energy would go down...I constantly felt burned out. I was diagnosed myself with HIV three years before Bobby died. When Home Care moved in, I lost control for 6 to 7 months. I got up every four hours to give him medicine. I lost 20 lbs in 2 months. In the last 2 months, every 8 hours a new home care person would come in and would wake me up to lift or change him or bandage his sores...most of them were afraid to touch him...I wouldn’t wear gloves because I didn’t want Bobby to think I was afraid. Sometimes Home Care wouldn’t come for a scheduled visit and wouldn’t let me know...friends helped me out, especially at the end. I feel I lost 7 years of my life and now I’m looking out for myself more.”*

Case Study #2

Jamie & Martin

Jamie is 36 years old and Martin was 29. They had lived together in a relationship for several years, and both were infected with HIV. Both were Aboriginal, received social assistance, and practised traditional native spirituality. Martin had decided early on after his HIV diagnosis that he was not going to take HIV treatment medications because he couldn't tolerate the side effects. In the last year of his illness, Martin had mood swings, was verbally abusive, forgot pots on stoves and left cigarettes burning. When Jamie was out, Martin would call an ambulance – Jamie said he “*was obsessed with hospitals*”. Martin would sleep all day and keep Jamie awake all night. Martin had headaches and back pain for which he took Tylenol and diarrhea for which he took Imodium. He couldn't walk steadily. Jamie experienced a financial strain with phone costs, cabs and ambulances.

A planning meeting with Home Care, caregivers and his clinic met to decide on the future. The plan was to have Martin go into a longer-term care facility, but it didn't happen due to “*change in staff*”. In the last six months, Home Care came in more often, from twice a week at first to once a day, to bathe and change him and prepare meals. In the last 2 to 3 months, Jamie developed a life-threatening pneumonia and was hospitalized, while Martin spent two weeks in a short-term AIDS housing shelter and then two months in the palliative care unit of a hospital, where he passed away.

In retrospect, Jamie says that Home Care had too many different individuals coming in. As a person with HIV himself, he found this stressful and he didn't get enough rest. He should have had Martin move into another care situation sooner, however Martin wanted to stay at home.

Case Study #3

Susan & William

Susan, 57-years old and a former nurse, is a ‘buddy’ for William, aged 59. William was in a long-term care palliative unit after being admitted in the spring, weighing only 95 pounds. He had been found by the Victorian Order of Nurses, living alone and alcoholic, and was found to have cancer of the esophagus and stomach, for which he underwent surgery. In the long-term care facility, he was tested for HIV, and was found to be positive with a CD4 count of zero. The HIV specialist told him he was dying. William told the doctor he would walk out on his own two feet – he could sign out of the palliative care ward, and once ‘escaped’ to a friend’s house for three days. The hospital placed him under the authority of the Public Trustee and William was placed on a locked unit for Alzheimer’s patients for a period of six months.

Susan, who had been connected to William through a volunteer service AIDS organization, became his advocate. Susan saw the nursing staff of the Alzheimer’s unit ignoring William. She also brought in pamphlets regarding HIV/AIDS and gave them to the nursing manager, who *“threw them back in my face, and said ‘I don’t appreciate you bringing in pamphlets.’”* The hospital social worker banned her from the unit, saying the hospital did not want to be liable if she was attacked by an Alzheimer’s patient.

Through Susan’s pressure, the doctor prescribed HIV medications and anti-depressants for William. She also pushed for a psychiatric review to establish William’s competency to make his own decisions and have him removed from the Alzheimer’s ward. In February, he moved to a public housing room he had found himself. Susan drove him around to find furniture. He now weighs 157 pounds, drinks 6 beer a day, cooks for himself, and has connected with his sister and family. Susan and William participate in each other’s family activities.

Case Study #4

Alan & David

Alan is 54, and has been with David, 48, for four years. Alan was diagnosed with HIV six years ago, and has experienced much loss. His wife left him after his diagnosis, and three years ago, his 26-year old son committed suicide. Alan is still grieving his son's death. Eighteen months ago, he suffered a small stroke which has left him with weakness on one side of his body.

Alan comes from a rural area and met David in a supportive housing project. David has dropped from 200 to 90 pounds in the past year, and has recently lost his driver's license due to vision loss. David wishes to die at home, but has been registered at a palliative care unit in a hospital. Alan foresees he will not be able to provide the total care required. David's memory is failing and he doesn't remember falling once or twice a night. Home Care comes in Monday to Friday to dress David. Alan gets help from friends to drive David to medical appointments, but has major needs for information and respite.

Alan wants to know the symptoms of HIV complications, and would like some training such as lifting techniques, including one-to-one explanations and written materials. Alan doesn't use precautions such as gloves, although he does a lot of cleanup of diarrhea because David refuses to wear diapers. Alan would like someone to come in to visit David once or twice a week, and give him a break. If he does go out in the evening, David will page him with something so 'urgent' that Alan has to come home. When David is gone, Alan fears that no one will be there to look after him the way he looks after David.

Case Study #5

Frank & Betty

Frank is a 61-year old Caucasian man who cares for Betty, a 48-year old Aboriginal woman. Betty was diagnosed two years ago after living a “*fairly chaotic*” life with drugs and alcohol. Fifteen years ago, Betty and Frank had a son together, who Frank raised on his own. Once Betty was diagnosed, she believed she would be bedridden in six months, and contacted Frank. He took on the responsibility of ensuring Betty had her medications and took them on time, and invited her to come and live with him and their son. Frank sees the arrangement as “*a friend helping a friend*”. She calls him her “*pill buddy*”. They are both motivated by the desire to prevent the progression of Betty’s illness to AIDS.

Frank has experienced some resentment of taking on this responsibility, but sees the situation as “*mutual care*”, as Betty’s humour and optimism have helped him with his depression and suicidal thinking. Still he felt very alone, especially at the beginning, and was “*exhausted, very emotional and got physically sick*” while playing the role of caregiver. He didn’t know where to get information and support.

Betty was in Intensive Care for two months, and he thought the medical people should have explained things to him more, such as test results, managing Betty’s care, and available resources like Home Care. He wasn’t using universal precautions and thought he needed more information about HIV transmission.

Betty liked to smoke marijuana frequently. At first, Frank didn’t want dope in the house, but when he saw how it helped the pain in her joints, he changed his mind, and now thinks it should be legalized. They are both currently receiving social assistance, however Frank is looking for work. He is concerned that if he gets into the workforce, there may not be enough support for Betty, and his commitment is to “*stick as long as I can*”.

Case Study #6

Lee, Evelyn & Linda

Lee, 60, and Evelyn, 55, are the foster parents of Linda, a 30-year old woman with severe physical and mental disabilities. Lee and Evelyn are Caucasian and Linda is Aboriginal. They met Linda when she was 12 years old and living in an institutional setting. She was totally blind, was tube-fed, wasn't toilet trained, couldn't hear and couldn't chew. She had no upper jaw and had slits for ears and eyes. Lee and Evelyn arranged facial reconstructive surgery "down east", resulting in Linda being able to hear and chew. They helped enrich her life through piano lessons, swimming, horseback riding, skating and a regular program for the disabled.

Ten years after her surgery, they noticed that Linda was fatigued and sleeping all the time. The pediatrician, who had cared for her all along, tested for HIV with a positive result. The parents called a meeting of 20 service providers at their home, including an HIV nurse, doctors, nutritionist, social worker, public trustee, teachers and volunteers. They and their two teenagers were tested, and one son moved out in fear.

Over the years, government Family Services has covered the cost of in-house teachers and caregivers who the parents select. They orient everyone in Linda's basic care and universal precautions. They feel the coordination of Linda's care would not have occurred had they not taken the initiative themselves. Linda remains healthy with no symptoms of HIV-related illness. Her viral load is between 1000 and 2000.

Lee and Evelyn need respite and a greater sense of privacy. As they age they have been looking for an alternate living arrangement for Linda, but there is no appropriate service or housing available.

G. Formal Caregivers

1. THEMES FROM FORMAL CAREGIVER INTERVIEWS

The case studies were analyzed as to common themes with a view to projecting needs for palliative care in the short-term and long-term. The formal caregivers from palliative care said that they had seen very few HIV/AIDS cases, with numbers ranging from less than one per year to one in the last three or four years.

Those formal caregivers who were seeing HIV clients were in community clinics, doctor's clinics, infectious disease clinics, walk-in clinics and Emergency, Acute Care and ICU departments of hospitals.

The new HIV infections are climbing in new groups – injection drug users, heterosexuals (especially women, often with children), and in younger age groups. Aboriginal people comprise the most quickly rising ethnic group. The newly infected are largely poor and probably do not see HIV as their primary concern. This may be another infection such as Hepatitis C, day care for their children, or their next fix. Basic needs and interpersonal relationships or lack thereof are often more important concerns than an HIV diagnosis.

The illness in these client groups is either chronic, particularly for those on new drug regimens, or presents in an acute episode, requiring emergency and ICU levels of care.

The complexity of needs in new clients is beyond the usual scope of the clinic-based physician/patient relationship, requiring a greater awareness of resources for referral and the development of improved communication and coordination with other caregivers. A new paradigm of palliative care is needed to respond to changing circumstances of clientele and treatment options. Continuing education is needed for both informal and formal caregivers.

2. CASE STUDIES

A total of nine in-depth interviews with caregivers in the formal health care system were conducted.

Case Study #1 – HIV Nurse in Tertiary Care Teaching Hospital

Prior to 1992, she had fewer than 15 patients per year, and was able to expand practice into community, into clients home and to provide education within hospital environment. Now, with as many as 180 patients, some who are seen on a consultancy basis, there is no time for a broad approach, and work is strictly confined to clinical care within a multi-disciplinary team.

Within the hospital, there seems to be a discrepancy between Palliative Care for HIV clients and others. For those with HIV, symptom management can appear to be aggressive treatment. The system of home support services, while limited in availability, seems to be improving in response to clients expressed desire to die at home.

Case Study #2 – Infectious Disease Specialist in Specialized HIV Clinic

This doctor works within a classical medical model team, comprised of physicians, nurses, technicians, and provides medical care to most of the HIV clients within his province. He attempts to present an evidence-based case to a client to consider what their condition would likely be without treatment. Fully one third of clients don't take antiretroviral medications, due to unstable living situations, a belief that it is too early for treatment, or have experienced side effects that limit quality of life.

He considers medical indications for referral to palliative care to be: failed conventional therapies, active untreatable illnesses, and low immunity. Treatment improvements have resulted in decreased demand for palliative care, which he sees as a honeymoon period, followed possibly by treatment failures and resurgences of "old" diseases such as CMV and dementia. The largely unknown effects of long-term therapy leaves many unanswerable questions for future care planning.

Case Study #3 – Palliative Care Physician

Her motivation to enter palliative care was the Sue Rodriguez case. She had the sense that Rodriguez chose euthanasia in the face of poor palliative care and intractable pain, and felt she may have made a different choice had a better palliative care system been available.

She identifies a major conflict within a palliative care approach that is very clinical and focussed on symptom management. A paradigm shift is necessary to consider the whole person, placing value on the actual caring. The main tool for good palliative care is communication. She attends up to 100 deaths per year within the system, but has seen less than one HIV death per year. Doctors are not trained to examine themselves in relation to clients, only to examine the client. Medicine is easy in that kind of relationship, but communication is difficult. The role of the physician is to assist the client in articulating the main questions, while the caregiver has to sit still in silence.

The main challenge in HIV care is chronicity of disease and difficulty in knowing when palliative care begins, in an environment that sees death from HIV as a system failure. HIV brings into sharp focus the kind of society we live in and what we really value. With complex issues of family dynamics and treatments, there is the opportunity to approach HIV in a more humane way, forcing caregivers to examine their own perceptions of normal family life and sexual relationships. It is difficult to maintain the continuity of palliative care outside the hospital where the players and dynamics are different. The situation may be normal for the client, where there is less medical control and other people besides the client need care.

Case Study #4 – Family Doctor in Community Clinic

She has worked 5 years within community clinics that have a concentration of HIV care. She now attends about 10 HIV clients, with a changing profile – formerly gay men, now women, IDUs, First Nations people, all poor. Only one patient is on active aggressive HIV treatment. Others don't want treatment, or don't see HIV as the main priority in their lives. Many are "street involved", wary of medical system, wary of any system. Her patients are largely solitary people, connected to specific networks for different reasons – ie. sniffer, tranny – but are very separated from the AIDS Service Organization network by choice.

Since 1996, fewer HIV-positive people are dying, with the push to aggressively treat HIV. Her patients access care as walk-ins or when acutely ill. There is little time for real dialogue. The subject of palliative care is rarely, if ever, broached. Discussion of palliative care requires dialogue with family and significant others. With solitary people, this type of discussion can't happen, as the network of people who would provide this kind of care doesn't exist. They may become acutely ill and a) end up in ICU, receive the most aggressive treatment and become "converts" to treatment (ie. Lazarus syndrome); or b) they die. Her patients never get to palliative care stage – they die with acute illnesses.

In her experience, it is difficult to do palliative care in HIV. The line between cure and death is precarious – the connection between HIV and palliative care may be antithetical by nature. This makes it necessary to put palliative care concepts into the acute system, at the beginning of relationship, with initial assessment. This may include dialogue about Living Wills and Advanced Care Directive as part of initial discussions, rather than at the end when hope is exhausted and treatments have failed. HIV requires a rethinking of where and when palliative care fits into acute care. She recognizes that talking about the eventuality of death with some patients possibly ignores their belief that God makes the decision about death, not us.

Case Study #5 – Orderly in Home Care System

He had only one hour of training related to HIV within a short course of home care training. He was a full-time (40 hours per week) home care provider to a wealthy PHA, as part of a small, closed team of care providers (HIV nurse, lawyer, accountant). Client was primarily concerned with stigma of HIV and had extreme need for confidentiality, as his own family members were not aware of HIV. Client depressed, suicidal, frightened by changing physical appearance. He would look in the mirror, become tearful and say: "horrible."

The worker was isolated, with little professional experience in caring for a dying person. When the client died, the orderly was unable to reach anyone else on the team. He called 911 – the emergency response team tried to resuscitate the client despite having the client's living will which indicated no resuscitation.

Case Study #6 – House Coordinator, Short-Term Housing for PHAs

She coordinates temporary housing for HIV+ people who need help with day-to-day life, or for "difficult" people who need community and family. They have capacity for 12 residents, and help with transition from hospital to independent living, from province to province, or from incarceration to community.

They have limited ability to provide 24-hour care. The staff have no training regarding the specific care requirements of HIV/AIDS.

Case Study #7 – Regional Director of a Provincial Palliative Care Program

She has an eight-year history in palliative care, and has seen HIV in clinical practice since 1986. Until 1996 she saw up to one death per week, but has seen a decline in mortality since then. From 1996 to 1998, clients were more chronically than acutely ill. There was little demand for hospital-based palliative care, and increased demand for care at home, with a shift to hospice based care.

She works within a sophisticated home care program, where the family physician is encouraged to continue to provide primary care together with home care and palliative care services, and where nurses are specialized in provision of palliative care in the home. Palliative care doctors act in a consultancy capacity for symptom and pain management. Injection drug users are less likely to have a good support system for palliative care, and may be more likely to use hospice system.

Case Study #8 – HIV Nurse: Based in Tertiary Care Hospital

She has a 10-year history of working in HIV, with a client base of 60 to 70 patients. Ten of these would be seen as requiring palliative care services. She perceives a very clear shift over time in patient profile, needs, and team configuration (ie. who is involved in care).

She has always worked in a tertiary care situation within a classical medical team, and has been able to provide good, consistent care to a largely “compliant” actively-involved group of patients who were mostly gay, supported within families (with some difficulties), and within an activist gay community. They were grateful for care, and took very good care of themselves, using a range of non-conventional treatments to complement clinical care

Now there are fewer gay men. A group of clients is emerging who are radically different: women, frequently with kids, First Nations, substance users. They come to health care passively, and are not really interested in HIV. Their connection with hospital is often limited by other factors – transportation, communication (no phone) – which means she has to go through a third party to make connection or to follow-up. This limits compliance with treatment. Information is accessed by this new group of clients in a very limited way, and may not be accurate or complete. As a result, understanding of HIV is spotty and fragmented. They access care with acute illnesses that could or should have been prevented. More patients are living in poverty. Further complications are caused by frequently seen mental illness and substance use which limits care.

Increasingly complex treatment regimens make for very complex care, with much resulting confusion for care provider and client.

Case Study #9 – Palliative Care Coordinator, Home Care Division

Coordinates palliative care for whole province where each district has its own palliative care coordinator. She receives referrals from cancer clinics, doctors, community clinics, Infectious Disease Clinic which specializes in HIV. Palliative care team is comprised of nurses, doctors, social workers, bereavement coordinator, supported by a large contingent of well-trained volunteers. The whole system is supported administratively, and through continuing education (every nurse got continuing PC education). They are able to provide support to family and caregivers as part of the system.

She has had limited contact with HIV over the past few years, caring for 2 patients since 1992 outside of the palliative care system. VON teams care for HIV clients, with some links to palliative care coordinator.

Overall, the palliative care system is well coordinated, but has limited contact with or experience of HIV care.

H. Barriers & Service Needs

This section summarizes qualitative data from the client surveys, organization surveys, focus groups and caregiver interviews related to barriers experienced by participants and services needed by participants. Data was grouped in categories and edited for readability.

1. BARRIERS

Organizations were presented with a list of HIV/AIDS palliative care challenges and asked to indicate which are faced by their organization.

Table 18: Challenges Experienced by Organizations (N=33)

Challenge	#	%
Provision of culture-sensitive HIV/AIDS care ie. to Aboriginal clients and families	13	39%
Provision of HIV/AIDS care to people with addictions ie. IDUs	12	36%
Coordination of palliative care services with ASOs	11	33%
Information about HIV/AIDS symptoms and pain management	10	30%
Inadequate funding	10	30%
HIV/AIDS medications and side effects	10	30%
Provision of HIV/AIDS care to women	9	27%
Provision of emotional support and/or psychological counselling to PHAs and their families	9	27%
Legal issues (informed consent, mental competency)	9	27%
Complementary therapies in management of symptoms/pain	9	27%
Understanding sexual orientation issues	7	21%
Occupational exposure issues for service providers in HIV/AIDS palliative care (needle stick injuries, infection control)	7	21%
Ethical issues (assisted suicide, resuscitation)	7	21%
Obtaining basic HIV/AIDS information	5	15%

Several barriers to effective palliative care for those with HIV/AIDS were identified mostly by participants in the organization surveys. (Note: Unless marked, qualitative data in this section comes from the organizational surveys).

a) **Poor Communication & Boundaries**

- What bothers me the most about palliative care is the exchange of information from client to professional. It is often misconstrued due to terminology used (ie. condition disruptions, symptoms, feeling). (Client Survey)
- Nobody has time to explain much of anything. (Client Survey)
- Communication between team members is an ongoing effort to improve.
- Unclear division between VON and home care.
- Poor communication between urban and rural providers.
- Palliative care and HIV/AIDS is not discussed at the regional level.
- There is a need to maintain contact outside of the institution, but very little opportunity to do this. (Formal Caregiver)
- It is difficult to establish a communication system with others on team to describe the needs and wants of the client. (Formal Caregiver)

b) Stigma & Fear

- The stigma surrounding HIV/AIDS. (Client Survey)
- HIV/AIDS is scary to everyone.
- Among the gay population families sometimes feel ashamed. I anticipate there may be problems in the stigma many people still have towards this virus/illness. Special training and education will be required to overcome this stigma.
- HIV/AIDS is unique for its stigma in society. This means that clients, families and friends have to contend with guilt and shame in addition to fear and anger normally associated with life-threatening illnesses.
- Stigma in rural/small town community.
- Stigma and its implications for the client and significant others.

c) Complexity of Care

- Challenges of multiple diagnoses push the system. There are few advocates for comprehensive care within tertiary setting. (Formal Caregiver)
- Increased incidence of dementia. Complexity in providing care & symptom management.
- Multiple diagnosis. Complex regimens.
- Difficult to determine palliative care status. Patient may be terminal in disease trajectory several times.
- Complexity of the issues.
- Pain control with different opportunistic infections.
- The uncertainty of the virus. Our care teams have to be versatile in providing a palliative care situation but with new drug treatments, individuals may experience a degree of recovery (become asymptomatic again) but need other needs met.
- The balance between investigation, diagnosis and treatment vs. palliative care/pain management. Multiple diagnoses – ie. opportunistic infections, cancer and symptom control. Unpredictability of progression.
- Few people with this specific diagnosis means services must be put together case by case.

d) Lack of Confidentiality

- I spoke to an Aboriginal physician who works in Winnipeg and up north. He told me that it is not true that clients from reserves have problems with people knowing their HIV-status. On what planet?
- Anonymity is a challenge in a small rural setting.
- We need ways to protect or support individuals in small community without stigma of disease so people will be comfortable in small hospital setting.

e) Lack of Experience with AIDS

- Our community does not seem to require services for HIV/AIDS clients (or very rarely) as these clients tend to migrate to larger urban centres. Occasionally a client may return home for family support, but this has been rare in our rural community.
- Sorry, I don't know enough about the issues to make relevant comments but I would be interested in learning what we could do here at VON Manitoba.
- Our experience with HIV/AIDS patients has been very limited. It took some initial adjustment related to staff fears and concerns related mainly to it being a first time event.
- Because of the lack of knowledge of the illness and the life circumstances of many of the people who are street involved, care providers are currently ignorant of many HIV facts (ie. treatment/transmission etc.)
- Have not had HIV clients yet. I think difference would be to assure staff they are not at risk in caring for this client.

- Numbers of residents are very small so difficult to have expertise in house but also difficult to access from outside.
- Although we are led to believe that there are HIV carriers out in the community and surrounding areas we have not as yet come across anyone with AIDS. I anticipate the greatest gap will be getting health care professionals to feel comfortable in dealing with this disease.
- We have seen so few HIV/AIDS clients in the last few years. It's very difficult to determine where gays may be.
- Never had a case of HIV in this area that I'm aware of. I'm nurse in this area for 12 years.
- We have not as yet experienced involvement with HIV/AIDS clients on the palliative program. Some info is available but as yet I feel unable to address the needs without having had direct involvement with it.
- HIV issues have not been discussed yet. We have only began dealing with the cancer issues (which are more predominant) and expect to discuss HIV/AIDS in the future.
- As you can see we are in great need of branching out into the area of HIV/AIDS. Thus far we have dealt with other terminal illnesses ie. cancer, renal failure and congestive heart failure as well as death from the aging process. We have absolutely no experience nor knowledge in dealing with HIV/AIDS.
- Our society is very small. Often it is hard to keep up with the problems at hand, though we are well aware that we will one day have to deal with HIV/AIDS. We are willing to take that challenge on as well and are ready to start the learning process.
- Physicians readily consult when expertise needed beyond their scope of practice. This would be necessary as we've never had a case.
- Due to the lack of numbers the HIV/AIDS client is not particularly identifiable in our service.
- We have not yet had a palliative care HIV/AIDS client. It is difficult to know what challenges we'll face. We have provided palliative care for other reasons and would attempt to do our best with HIV.

f) Lack of Funding and Staff Resources

- Lack of money for resources, lack of provincial support, we are not ready to deal properly with the new HIV/AIDS populations.
- Big region, little expertise, little money, no hospice beds for HIV/AIDS
- Budget restrictions tend to limit services.
- Resources are limited and will remain referral agency at this time. Therefore can only refer to what already exists.
- Lack of staff available to provide daily care or 24 hour care if needed. Social worker, occupational therapy not available in all areas, have pastoral care.
- Lack of access to physician specialists.
- We are the private leg of VON and therefore all of our clients must pay for services or be referred by an agency that is paying. We are very interested in developing a palliative care team but funding is a definite issue. Our services include 24 hour nursing and home care workers.
- Infectious disease need to be consulted. Our facility doesn't have laminator flow hood. If medications similar to chemo drugs are required by patient, would have to be administered through Morden or PLP.
- We cannot provide 24 hour care with current resources.
- Funding continues to be our #1 issue. Donations and the incredible commitment and vision of the team keep us going. If this hospital were to be faced with providing HIV/AIDS palliative care, I am convinced the responsiveness to all the issues listed would be supported & addressed as the community, staff and volunteer base here have been extremely responsive & committed to growing the palliative care services.

g) Profile of PHAs

- Many service providers are judgemental of their clients' lifestyles.
- IDUs - many choose not to quit but have difficulty obtaining medications.
- Among the heterosexual population are usually past or present drug users so have emotional/social problems. This excludes person who contract HIV through blood transfusions.
- In some cases the family and lifestyle issues are more complex than those seen in the general palliative care population. These present special needs that must be addressed in the plan of care.
- This clientele tends to be younger so the needs would be unique.

2. SERVICE NEEDS

a) Family Supports

- There is a need for more palliative care for parents living with HIV/AIDS period. (Client Survey)
- More resources available to parents living with HIV/AIDS. (Client Survey)
- More resources regarding support for parents living with HIV/AIDS. (Client Survey)
- More recognition of parents living with HIV/AIDS and programs for them. (Client Survey)

b) Caregiver Support & Respite

- People are dying at home with very limited support, in an environment where the expectation is that whoever is in the home will provide all the care. (Formal Caregiver)
- Some way to get a break if you are looking after a person who is dying. (Aboriginal Focus Group)
- Support to caregivers. (Initial Focus Group)
- Care and support for care providers. (Client Survey)
- In-home respite care would be a major help with the caregiver making selection of the worker. (Informal Caregiver)
- More support systems for caregivers. (Informal Caregiver)
- No closure for caregiver. No memorial service. No connection with family. (Formal Caregiver)
- A support group with other caregivers to share ideas. "*Caregivers need buddies too,*" and breaks for recreation. (Informal Caregiver)

c) Home Care

- Need improved home care services such as IV/SSC treatments. (Organization Survey)
- Care at home (whole range of services). (Initial Focus Group)
- Home care ie.VON (Initial Focus Group)
- Friends to provide home care, with whole range of services, but have to be trained and knowledgeable. (Initial Focus Group)
- Location for palliative care should be at home if at all possible to set up. (Aboriginal Focus Group)
- Need easy quick access to homecare services and supplies (funded). (Client Survey)
- Increase nurturing care and funding in the community and homecare. (Client Survey)
- Overnight help for those living alone. (Client Survey)
- More in-home supports for parents living with HIV/AIDS. (Client Survey)
- Quick response for emergency care at home, ie. funding, transportation to and from doctor's appointments, volunteers or other members of team to stay with client for period of time during crisis or alone time. (Organization Survey)
- Increased home care. (Organization Survey)
- Create the conditions in home care to promote consistency in staff. (Informal Caregiver)

d) Hospice

- Day program and long-term palliative care. (Organization Survey)
- Hospice would be helpful. Some clients have no family and 24 hour nursing home care is not available. We depend on volunteers to fill the gaps. This has led to volunteer fatigue and hospitalization of the client. (Organization Survey)

- Availability of a hospice and respite care. (Organization Survey)
- Development of a regional hospice centre. (Organization Survey)
- There is a serious need to recognize that Manitoba requires specific HIV/AIDS hospice care units and not only in large centres. (Client Survey)
- Have one centre outside hospital for palliative care (hospice). (Organization Survey)
- Increased human resources to provide 24 hour support to all palliative patients. (Organization Survey)
- Hospice. (Organization Survey)
- More funding for residential programs for people living with HIV/AIDS. (Organization Survey)
- Classical institution-based palliative care likely replaced by need for hospice type care. (Formal Caregiver)
- A less institutional hospice setting is also needed. (Informal Caregiver)

e) Cultural Services

- Tribal council HIV worker. (Aboriginal Focus Group)
- Traditional healer on staff who could address treatment, language and religious barriers. An interpreter who could translate for medical people and family both. (Aboriginal Focus Group)

f) Basic Needs

- Financial support, transportation. (Initial Focus Group)
- Clothing. (Women's Focus Group)
- Baby-sitting. (Women's Focus Group)
- Emergency Assistance. (Aboriginal Focus Group)
- Food bank, shelter. (Aboriginal Focus Group)
- More supports through social services (Client Survey)
- Low cost/low maintenance housing for PHAs in order to: Ensure minimum housing standards for the economically distressed. Alleviate stress brought on by financial insecurity. (Client Survey)
- More financial help (consideration from social services for special diet and alternative therapies). (Client Survey)
- Support for transportation (financial, more reliable service, accompanied transport). (Client Survey)
- More money. (Client Survey)
- Funding for children and homemaking services. (Organization Survey)
- More personal care services for HIV persons. (Organization Survey)
- Clients require more planning around immediate day to day needs – pharmacare, social assistance, etc. In the past this time would have been spent planning end-of-life care. Now, it never gets to that point. (Formal Caregiver)
- People with need for basic shelter, food and community – not necessarily palliative care.
- Poverty is the main issue limiting quality of any care. (Formal Caregiver)

g) Drop-in Support

- Drop-in/support services. (Gay Men's Focus Group)
- Drop-in (Women's Focus Group)
- Drop-in (Aboriginal Focus Group)

h) Psychosocial Support

- The supervisors should go see clients more often and make surprise visits. (Informal Caregiver)
- Need increased psycho-social support due to complexity of disease. (Organization Survey)
- Plain old home visits from doctors/nurses, pain control, loneliness, aloneness. (Organization Survey)
- Ceremonies/retreats. (Initial Focus Group)
- Retreats/change of environment. (Gay Men's Focus Group)
- Counselling, psych care, mental health worker. (Gay Men's Focus Group)
- Recreation. (Aboriginal Focus Group)
- HIV+ care providers. (Client Survey)
- Companionship. (Client Survey)
- More programs for counselling. (Client Survey)
- More individual one-on-one support people. (Client Survey)
- More supports needed, mentally, emotionally, physically, spiritually for parents living with HIV/AIDS. (Client Survey)
- A friendly visit or go out places. (Client Survey)
- Make available social workers and counsellors that will visit clients and families in home. (Organization Survey)
- Funding activities of daily living. (Organization Survey)
- Someone to talk to after the death. (Aboriginal Focus Group)
- Prayer/spiritual healing, yoga/meditation. (Gay Men's Focus Group)
- Spiritual nurturance and assistance at time of death such as the way Buddhists help with going to the best spiritual state at time of death. (Client Survey)
- Careful attention must be paid so that palliative care does not become only medical and nursing care, excluding psychosocial and spiritual needs. (Formal Caregiver)

i) Support Groups

- Group for couples. (Women's Focus Group)
- Support group. (Aboriginal Focus Group)
- Chances to meet other AIDS patients. (Client Survey)
- Support groups. (Organization Survey)
- Special funding for development of support groups within the community. (Organization Survey)

j) Complementary & Alternative Therapies

- Alternative treatments to allopathic medicine (naturopathic, botanicals, herbs, meditation, creative activity). (Gay Men's Focus Group)
- Chiropractor, massage, reiki, touch therapy, acupuncture, (Gay Men's Focus Group)
- All alternative medicines. (Gay Men's Focus Group)
- Funding complementary therapies, extra money for nutritional supplements, vitamins. (Women's Focus Group)
- Include alternative physicians & therapists and access to their prescribed treatments. (Client Survey)
- Access to alternative therapies. (Client Survey)
- Make nutritional support (informational) an integral part of care. (Client Survey)

k) Medicinal Marijuana

- Marijuana, access to cheap, reliable source. (Gay Men's Focus Group)
- Access to cheap pot. (Initial Focus Group)
- Easy access to marijuana. (Women's Focus Group)

- l) Geographic Needs**
- No services available in North End [of Winnipeg]. (initial Focus Group)
 - More services in underserved and rural isolated communities. (Client Survey)
- m) Physicians & Specialists**
- Access to palliative care physicians with expertise in symptom control and management, (Organization Survey)
 - More doctors. (Client Survey)
 - Increased access to physicians with specialized training (Organization Survey)
 - Increased emergent response teams. (Organization Survey)
- n) Outreach & Advocacy**
- HIV/AIDS expertise for outreach in a personal care home setting, (Organization Survey)
 - Greater availability of one-on-one outreach support (emotional and informational). (Client Survey)
 - Advocates especially when in the hospital and in pain. (Client Survey)
 - Client advisory groups directing requests of other clients to proper channels. (Organization Survey)
 - AIDS network could be more visible. (Organization Survey)
 - More outreach to prevent need for palliative care. (Organization Survey)
- o) Education & Employment**
- Schooling. (Aboriginal Focus Group)
 - More comprehensive support like work and school changes. (Client Survey)
 - More training resources. (Client Survey)
- p) Volunteer Services**
- Build and nurture a larger volunteer base in community, which could be used for other health issues and concerns. (Client Survey)
 - More volunteers. (Client Survey)
 - More volunteers. (Client Survey)
 - Create a volunteer worker registry of people who would work with HIV-positive special needs clients. (Informal Caregiver)
- q) Medication**
- Access to narcotic pain control (heroin, cannabis). (Client Survey)
 - Help with medications. (Client Survey)
 - Pharmacy supplies of oxygen with minimal costs to individual and families. (Organization Survey)
 - Availability for funding of oxygen services. (Organization Survey)
 - Medications should be covered under Medicare (cost). (Client Survey)
 - Financial burden: Pain medication is covered for hospital patients, but not covered at home. (Formal Caregiver)
- r) Other**
- Legalize euthanasia. (Women's Focus Group)
 - Make funeral arrangements for other family members. (Women's Focus Group)
 - More direct government funding to ASOs. (Organization Survey)

I. Participant Recommendations

1. APPROACHES TO CARE

- At worst, you're treated like you're stupid for wanting to make choices.(Women's Focus Group)
- Case management meetings would help address advocacy issues. (Informal Caregiver)
- Difficult to reconcile personal aspects of caregivers in order for them to do the work of palliative care. They must confront their own "darkness" in order to do "whole person palliative care". (Formal Caregiver)
- A caring attitude is #1. (Informal Caregiver)
- More continuity of workers is needed. (Informal Caregiver)
- Each client is unique and different and requires individual assessment and will also require varied needs depending on family supports and financial state. (Client Survey)
- Understanding and caring safely for people with HIV/AIDS. (Client Survey)
- People need to be non-judgemental (Client Survey)
- Sensitivity and acceptance of individual's values and beliefs. (Client Survey)
- Sensitivity to public cultural beliefs. (Organization Survey)
- Palliative care should be more like a nursing home, ie. homey with informal atmosphere but with emergency equipment (Aboriginal Focus Group)
- Don't push treatment on people who don't want it. (Women's Focus Group)
- Allow the clients to plan the activities. (Client Survey)
- Compassion. (Client Survey)
- Listen to the person who is sick. (Client Survey)
- Recognize patients, not abandoning them and leaving them alone for hours on end. See patient as an individual. (Client Survey)
- Understanding (Client Survey)
- Dignity and control over decisions. (Client Survey)
- Allow people receiving the care to make their own decisions. (Client Survey)
- Active listening. (Client Survey)
- Flexible to adapt to each situation (Client Survey)
- Know the person well. (Client Survey)
- Understanding. (Client Survey)
- Teach compassion for family and patient. (Client Survey)
- Less seminars - more direct input for patients by patients. (Client Survey)
- Better professional understanding of people living with HIV/AIDS. (Client Survey)
- Comfort (no pain, companionship) (Client Survey)
- That people include the patient in everyday life. (Client Survey)
- More emphasis placed on issues surrounding rights to confidentiality and privacy, particularly in the rural environment. (Client Survey)
- Compassion (Client Survey)
- A sense of humour. (Client Survey)
- Love. (Client Survey)
- Be sure to provide a comfortable and pain-free environment. (Client Survey)
- A more homey atmosphere. (Client Survey)
- Non-judgmental. (Client Survey)
- Better anonymity measures. (Client Survey)
- Organization! Organization! Organization! (Client Survey)
- Good treatment (Client Survey)
- Recognition that palliative care can be a long process (ie. 6-24 months for many) and resources need to be available regardless of residential placement. (Client Survey)

- Better liaison with hospital. They provide the medical care. (Organization Survey)
- Start exploring options with clients when they are ready to, if they are ever ready to. (Organization Survey)
- Better connection with other agencies providing care (ie. AIDS Regina). (Organization Survey)
- Make social services (all departments) and health work together. (Organization Survey)
- Provide non-judgemental caregivers. (Organization Survey)
- I think in the area of HIV/AIDS, a health care worker working in the palliative setting must be in touch and truly honest with their own spirituality, sexuality. (Organization Survey)
- Increased need for palliative care whether urban, rural, hospital or home. (Formal Caregiver)

2. BROADENING PALLIATIVE CARE

- Referral from time diagnosed to time patient becomes palliative. Feel could make better use of program if patients referred earlier. If they happen to be cured in the meantime great, if not we are on board and patient is familiar with our program. (Organization Survey)
- A coordinated community-based regional program. (Organization Survey)
- Establishing broader services in community (ie. rapid response). (Organization Survey)
- Broadening diagnosis base if funding provided through provincial government. (Organization Survey)
- Range of services have to shift over a longer period of time (Initial Focus Group)
- Range of services over a long period of time (Initial Focus Group)
- Range of options from home hospice to institutional care, easy to acquire and flexible in range to adapt to changing situations. (Client Survey)
- That the time limit to stay in palliative be reviewed (people with AIDS can linger a long time). (Organization Survey)
- Recognition that this type of care requires additional resources. (Organization Survey)
- Clinical medicine approach is sharply opposed to whole person/system dynamic approach. (Formal Caregiver)

3. ACCESS FOR MARGINALIZED PEOPLE

- Fight marginalization and exclusion. Services should be available to all regardless of social and economic background. (Client Survey)
- Palliative care for IDUs (Organization Survey)
- More adequate research on women's needs, IDUs, aboriginal people. (Organization Survey)
- Appropriate detox and medical care for clients choosing to quit injection drug use. (Organization Survey)
- Care to those that are street involved/homeless.
- Pain control of morphine addicted IDUs. (Organization Survey)

4. TRAINING & EDUCATION

- Concerns regarding staff/volunteer education, adequate community experience and perhaps consultation with physician. (Organization Survey)
- Would require further education for staff to update on more recent care and management of symptoms etc. (Organization Survey)
- Direct straightforward information. (Initial Focus Group)
- Gross lack of education and knowledge that PHAs have to deal with. (Women's Focus Group)
- Client always has to educate the people they come into contact with. (Women's Focus Group)
- An educated staff that does not get burned out. (Client Survey)
- Need for appropriate education. (Organization Survey)
- Home Care Aides need more education including physical care skills and more professional nursing supervision. (Informal Caregiver)
- Teach caregivers that not all HIV/AIDS patients are drug users or have contracted the disease by being gay or homosexual. (Client Survey)
- People providing care need to be more knowledgeable and giving because of all the new developments and findings. There is lots to learn. (Client Survey)
- Having well-educated and confident staff on care management related to HIV/AIDS. (Client Survey)
- Work to enhance team membership and support. (Organization Survey)
- VON has funded a culture sensitivity workshop for its palliative care staff – presently in planning phase, not specific to HIV/AIDS. (Organization Survey)
- Organization could train family member to be primary care-giver (Aboriginal Focus Group)
- Information for partner/family (Women's Focus Group)
- Care providers should be knowledgeable (Initial Focus Group)
- We have to teach service providers about HIV. (Women's Focus Group)
- Knowledge about the sickness. (Client Survey)
- Teach caregivers about HIV/AIDS and not to be afraid of the disease. (Client Survey)
- Demystifying HIV stigma. (Client Survey)
- Increased education especially related to dementia, aboriginal issues and HIV/AIDS palliative care. (Organization Survey)
- Education (Organization Survey)
- More education to caregivers and professionals. (Organization Survey)
- Public education and awareness. (Organization Survey)
- Ongoing education for professional and volunteers and communities, especially high school students. (Organization Survey)
- Develop consistent training for all health professionals, caregivers and volunteers in palliative care. (Organization Survey)
- Better training (Organization Survey)
- Training and education of health care professionals. Training and education of clients and family. (Organization Survey)
- Increased education for palliative care providers. (Organization Survey)
- Create diverse training to cover multiple issues re: addictions, mental health issues etc. (Organization Survey)
- Conference which would not only include education for palliative care teams, but also information for other health care workers who care for them as outpatients, in order to ensure continuity of care. (Organization Survey)
- Provide education and training to home care attendants specifically on HIV/AIDS palliative care – include training programs for certificate or palliative care certificate courses. (Organization Survey)

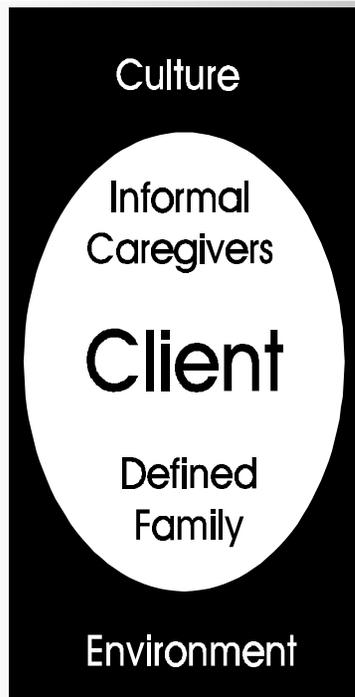
- More education to families of persons with HIV. (Organization Survey)
- Increased understanding of HIV health-related issues by professional caregivers. (Organization Survey)
- Conferences/workshops which not only include pain medication but complimentary therapies and their appropriate use for pain/symptom management. (Organization Survey)
- Provide informed caregivers. (Organization Survey)
- Increased education. (Organization Survey)
- Have in-services every 6 weeks on a variety of topics including HIV/AIDS. (Organization Survey)
- Limited HIV information. (Formal Caregiver)
- More HIV in-servicing is needed for institutional staff. (Informal Caregiver)

Part VI

Recommendations

A Dynamic Model of HIV/AIDS Palliative Care

Broad range of palliative and supportive services



- Communication
- Mediation
- Coordination
- Continuity
- Adaptability
- Education
- Autonomy
- Mobility
- Accessibility



Diagnosis

A. Broadening Palliative Care

Lessons Learned – Palliative care in the context of AIDS should be seen as whole-person care of the living, not an exclusive resource of the dying.

- The natural history of HIV is characterized by periods of wellness with episodes of acute illness, leading in some cases to chronicity. Care needs may be episodic and demand intermittent palliative care. Patients may require palliative care services, and still be expected to recover.
- Aggressive antiretroviral treatments have an impact on the progression of illness, but may also have a severe impact on quality of life. As well, long term effects and effectiveness of these drugs is not known.
- Emerging epidemics of newly infected and affected populations are having and will continue to have a considerable impact on HIV care, including palliative care, and systems must adapt on an ongoing basis.
- In the context of HIV, palliative care is most clearly defined as an integrated element of supportive care provided at varying degrees of intensity over the course of the illness.

RECOMMENDATION #1 – Earlier Connection

Palliative care services should take the lead in establishing connection to patients living with HIV earlier in the course of their illness, providing information about their services and philosophy using a culturally sensitive approach.

RECOMMENDATION #2 – Diverse Access Points

Palliative care services should take the lead in establishing connection with diverse access points, including tertiary care, primary care, outpatient facilities, addictions treatment programs, prisons, and drop-in programs.

RECOMMENDATION #3 – Broader Need Assessment Base

The need assessment base for palliative care should be broadened to include HIV patients in different and fluctuating levels of wellness, and provide a range of services over a longer period of time, remaining responsive to the episodic nature of HIV illness.

RECOMMENDATION #4 – Linkages with HIV Primary Care

A concrete two-way communication strategy and formal linkages should be created between primary HIV care and palliative care services in order to facilitate the integration of palliative care services throughout the continuum of HIV care.

RECOMMENDATION #5 – Increased Funding & Staff Resources

Given longer life expectancy of PHAs, increasing client loads, complexity of care and need for training opportunities, increased funding will be required in both palliative care networks and HIV community care. In order to recruit, retain and sustain the level of energy, creativity and flexibility required for individual personalized HIV care, a comprehensive, reliable resource base is required.

B. Approaches to Care

1. OUTREACH

Lessons learned – Services need to be mobile, brought out of the normal venue of service delivery, and into the range of client access. Outreach, home visits, and the general mobility of service providers are key to accessibility of services for diverse groups of PHAs, and should prevent clients “falling through the cracks” of service provision. Outreach in HIV prevention acts as “radar” in a primary care context. Outreach in the context of HIV care, including palliative care, could follow a “Community Health Representative” model, including the brokering of systems (eg. Housing, Welfare, Justice), the mediation of cultural differences, and a resource for connecting people and communicating between stakeholders. (*Community Health Representative or CHR is a role established by Health Canada in the 1960s on First Nations reserves, in which a local person was selected by the community as a translator and mediator between the people of the Aboriginal community and the medical system.*)

RECOMMENDATION #6 – Outreach Workers

Outreach positions should be created or enhanced whose primary role is to communicate between HIV+ clients, their caregivers, and systems, including palliative care. These positions should reflect the demographic profile of the population being reached.

2. CULTURAL MEDIATION

RECOMMENDATION #7 – Cultural Mediation

Aboriginal people should be hired to play the role of cultural mediators between Aboriginal PHAs, their families and systems, including the palliative care system. Such a role would include communication in the first language of the PHA, negotiation with formal structures, and access to cultural services.

3. CASE MANAGEMENT

Lessons Learned: Case management is an effective way to communicate among service providers regarding client and caregiver needs. Provision of palliative care may shift over time and require a reconfiguration of primary players, both informal and formal.

RECOMMENDATION #8 – Case Management

A comprehensive case management strategy should be developed for HIV clients that is interdisciplinary, integrated, adaptable and client-centred.

4. CONFIDENTIALITY

Lessons Learned: Confidentiality is often a primary concern of the HIV+ client, and requires specific strategies built into communication systems such as case management and record-keeping.

RECOMMENDATION #9 – Ensuring Confidentiality

Palliative care workers should get specific training on confidentiality issues related to HIV and AIDS, and explicit instruction on where information about clients can and cannot go.

C. Meeting Service Needs

Lessons Learned: Services in palliative care must be flexible, responsive and continuous with acute care in times of need, and continuous with supportive and primary care in times of wellness.

- A range of needed services has been identified by participants in this research. Some of them may be unconventional in nature and function, and some may be seen as outside the traditional scope of palliative care.
- Particular aspects of care (ie. acute, supportive, palliative) are segregated within the current framework, with a quality of exclusiveness or competition for resources that leads to fractured service and poor communication. Value must be given to the quality of complete care.
- Current funding and human resources are insufficient to meet all the needs identified in this study. More people need to be hired. Right now, there are too few people doing too much. This makes the system inflexible because clients can only access a small window of a caregiver's time. More time for conversation and relationship development is needed.
- Informal caregivers often carry the bulk of the responsibility for care but these caregivers have few resources. More strategies need to be developed to support these as informal caregiver networks.

1. MAKING SERVICES ACCESSIBLE

RECOMMENDATION #10 – Transportation

Enhanced access to funds for transportation are required in order to promote accessibility of services among those living in poverty.

RECOMMENDATION #11 – Child Care

Mothers living with HIV require child care in order to access services available in the community. This should be seen as respite for the client and supported financially.

RECOMMENDATION #12 – Services for IDUs

Injection drug users may require a specific configuration of HIV palliative care services, and innovative models should be developed in order to promote accessibility for this underserved population.

2. CLIENT & CAREGIVER SUPPORTS

RECOMMENDATION #13 – Respite

Palliative care services should develop increased access to broad respite services for caregivers, with attention paid to the specific needs of HIV+ caregivers and HIV+ parents. Opportunities for rest, discussion, de-briefing, learning, and recreation should be elements of respite for informal caregivers. Respite care should be available in the client's home, with respite caregivers chosen by the client.

RECOMMENDATION #14 – Hospice

A hospice environment designed specifically to accommodate the needs of PHAs should be modelled and created in prairie cities. Rural hospitals can be encouraged to provide a hospice-

oriented unit which utilizes principles and policies of hospices. The specific needs of women, Aboriginal people and substance users must be considered and built into the design of these environments. Respite sites should be factored in for those living at home.

RECOMMENDATION #15 – Home Care

More resources need to be made available to increase access to home care services for poor clients. Home care service providers need more training in HIV/AIDS care. As well, more continuity in staff is required in delivering care.

RECOMMENDATION #16 – 24-Hour Backup

Caregivers in the home setting need backup on a 24-hour basis and a network of service providers should be developed and scheduled as part of the case management team to provide this essential support.

RECOMMENDATION #17 – Basic Needs

People with HIV should be provided with enhanced access to basic needs such as nutritional supports and financial supports on an ongoing basis throughout fluctuating levels of wellness.

RECOMMENDATION #18 – Temporary Housing

People with HIV need increased access to temporary housing in times of illness or transition (from prison, addictions treatment, hospital, etc.). An open door policy is needed to accommodate the episodic nature of HIV.

RECOMMENDATION #19 – Drop-in Support

Drop-in support accessible to diverse groups of PHAs and their caregivers should be made available in a sustainable way. This non-clinical environment could play many roles in providing support services, act as a base for outreach and access point for palliative care services, and be a continuous thread through fluctuating levels of wellness.

RECOMMENDATION #20 – Increased Volunteer Support

Increased attention should be paid to the recruitment, training and sustainability of a large and stable base of community volunteers comfortable with and experienced in providing support to HIV+ people and their caregivers. In-home paid caregivers for family members should be considered in home care planning and budget development.

RECOMMENDATION #21 – Medication Support

Pain medications are covered when provided in hospital, but not always when used at home. This should be reconsidered.

3. CULTURAL SERVICES

Lessons learned – A high level of satisfaction was found among Aboriginal clients regarding participation in Aboriginal ceremonies and consultations with traditional healers, however access to these services was limited.

- Conventional/allopathic approaches to palliative care and HIV is along a linear continuum. This may be antithetical to the Aboriginal traditional circular approach in which death is an accepted and acknowledged part of life.

RECOMMENDATION #22 – Cultural Awareness

Given the increased number of Aboriginal HIV+ clients and the projection of future increases within this population, it is essential that traditional Aboriginal understandings and approaches to living and dying be considered in palliative care service delivery and reflected in care provider training.

RECOMMENDATION #23 – Cultural Services

Increased partnerships between palliative care services and traditional cultural services need to be developed in order to facilitate access to these valuable services. More resources should be allocated to Aboriginal-directed cultural service development and delivery.

RECOMMENDATION #24 – Research

Funding should be established for research, consultation and implementation of culturally relevant approaches to HIV care, including palliative care, specifically for Aboriginal people.

4. PSYCHOSOCIAL SUPPORT**RECOMMENDATION #25 – Professional Support**

Increased access should be made for clients and caregivers to counsellors, psychologists and psychiatrists, in order to address mental health issues, grief and bereavement and issues of multiple loss.

RECOMMENDATION #26 – Peer Support Groups

Increased access should be made to support groups for clients, caregivers, and family members affected by HIV.

5. COMPLEMENTARY THERAPIES**RECOMMENDATION #27 – Complementary Therapies**

Complementary and alternative approaches to HIV care (massage, reiki, therapeutic touch etc.) need to be supported financially in order to increase quality of life and decrease pain and suffering. Formal caregivers should receive training regarding complementary therapies in their regions and awareness regarding access and perceived benefit of these therapies in alleviation of pain and suffering.

RECOMMENDATION #28 – Access to Marijuana

Special Access to medicinal grade marijuana should be enhanced for availability to clients receiving palliative care and other HIV services.

D. Training & Education

Lessons Learned – Given the lack of HIV experience among many service providers across the prairies, it is important to start the process of education as soon as possible, in order to make the palliative care system more accessible to those with HIV, and to prepare caregivers for the complex care involved in HIV.

- Clients, informal caregivers and formal caregivers have specific and particular needs for skills development.
- Informal caregivers need task-specific training tailored to their needs.
- Shifting realities for the care of HIV+ people requires the development of both core skills and continuing education for care providers. An interdisciplinary approach acknowledges the value of care and caregiver in an integrated model.

RECOMMENDATION #29 – Information for Clients

A responsive, culturally appropriate program for educating clients about HIV progression, treatment options and legal issues should be developed and delivered either through enhanced physician time, or those playing an outreach or cultural mediation role.

RECOMMENDATION #30 – Information for Families

A responsive, culturally appropriate program for educating families of PHAs about HIV progression, treatment options and legal issues should be developed and delivered by those playing an outreach or cultural mediation role.

RECOMMENDATION #31 – Training for Informal Caregivers

A “train the trainer” approach to education for informal caregivers regarding skills in personal care and emotional support should be taken. This could be a function of enhanced home care services, in which home support workers receive education of the care approaches to HIV clients and in turn, teach the in-home caregiver.

RECOMMENDATION #32 – Certificate Program

A certificate program in HIV/AIDS palliative care should be developed and delivered to health care workers in the prairie provinces in order to build the skills and knowledge base of formal care providers.

RECOMMENDATION #33 – Continuing Education

A coordinated regional (or even national) program of workshops, conferences and in-services related to palliative care for those with HIV should be coordinated for service providers, volunteers, informal caregivers and clients, with the goal of improving standards of care. Topics should include emerging populations, addictions, mental health, Aboriginal issues, women’s issues, pain and symptom management etc.

Conclusion

As a modern people, we take offence at things that we cannot explain. We are convinced that answers can be found through the considered application of mind and money, and we have succeeded in great measure. The mortality rate of HIV/AIDS is falling in every region. But confounding this success is the emergence of new and unstable epidemics in different populations all over the country. What have we learned from the first wave and the gay men who have fought and died, and who still live and fight? Certainly the issues are the same as they were twenty years ago – hostility to those infected, indifference in the face of new infections, the arrogance of science in “managing” the problem – but what have we learned since then?

We approach death with similar impatience. It is, of course, unavoidable, but surely, surely it can be delayed. If not, then at least it should be sanitized and removed from the context of life, transformed into a modern specialty. And then, let us all work harder to avoid these awful failures. Because we have indeed failed to cure HIV. And people continue to die.

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Appendix

Survey of Clients
Focus Group Discussion Guide
Formal Caregiver Interview
Survey of Organizations