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# Seeking serenity: living with HIV/AIDS in rural Western Canada

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## ORIGINAL RESEARCH

# Seeking serenity: living with HIV/AIDS in rural Western Canada

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## ABSTRACT

**Introduction:** The purpose of this naturalistic inquiry was to describe the experience of living with HIV infection in rural Alberta, Canada. Although the urban HIV epidemic has been well researched, the virus continues its spread into more remote populations where there is a need to understand and address its impact. Affected rural residents form a diverse and marginalized group that includes women, Aboriginal peoples, immigrants, injecting drug users, and men who have sex with men, yet there are few data available to inform appropriate health and social services and practice. A number of factors, such as stigma, invisibility, isolation, confidentiality, poverty, and risk behaviours, contribute to the rural experience, but have not been clearly explicated in the literature. This study was conducted in order to better understand the perceptions of health in a rural setting, the processes involved in accessing care, the challenges and benefits associated with rural life, and the relationship between personal beliefs and values and the nature of the disease.

**Method:** Semi-structured interviews were conducted with six HIV-seropositive individuals and one caregiver who were living or had lived in rural settings, as well as four AIDS agency staff from a small city. Participants represented varied backgrounds, ages, sexual orientations, exposure to risk behaviours, lifestyles, roles, and citizenship. A naturalist inquiry approach was used in order to explore the qualitative aspects of the experience. Interviews were recorded, transcribed, and analyzed. Documents such as poetry, letters, field notes and journals served to enrich the data.

**Results:** Participants identified the components of health as a sense of wellbeing, quality of life, and independence. Within the context of HIV infection, health was achieved through three processes: (1) accommodating the reality of the diagnosis into daily



life; (2) creating and engaging in supportive relationships and communities; and (3) reflecting on the meaning of one's life and future. Rural life had various meanings and implications for individuals, in terms of security, comfort, relationships, access to services, attitudes, dignity, and justice. Barriers and challenges to reaching health centred around a lack of skill and knowledge in human services workers, violation of confidentiality, difficulty associated with travel for medical care, and inadequate support for family caregivers. Participants suggested that the health of the community is reflected in the health of individuals. They expressed the hope that some day diversity would not only be tolerated, but would be celebrated by all members of society.

**Conclusions:** Rural residents perceive and enact health in distinct ways. Caregivers must understand that health usually represents a concern only after it has failed and self-initiated attempts to overcome problems have been unsuccessful. Participants in this study articulated their need to live in a society that acknowledges their diversity and honours their rights to access health and social supports in the community. Service providers may enhance care and promote health of this aggregate through education, attention to professional responsibilities, fostering resilient communities, and advocating for vulnerable members of society. Further research needs to be conducted in order to learn more about the relationships between HIV infection and rural living and the needs of people who live in such situations. With this knowledge, appropriate healthcare services can be developed and implemented to enhance the wellbeing and quality of life for individuals, families, and communities.

**Key words:** Canada, HIV/AIDS, qualitative.

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## Introduction

The purpose of this qualitative study was to explore the experience of living with HIV and AIDS in rural Alberta, a prairie province in Western Canada. The research was inspired by interest in and concern about perceived gaps in knowledge about the complex issues associated with this disease for HIV-seropositive rural dwellers. The HIV epidemic in North America, along with a large volume of research activity, was initially confined to large urban centres where the virus spread rapidly through the population of men who have sex with men (MSM) during the 1980s. In the early 1990s, the virus extended its reach into other settings and sub-groups of the population. Notable trends over the last decade include climbing infection rates among women<sup>1</sup> and disproportionate representation by Aboriginal persons<sup>2</sup> and immigrants (particularly women of childbearing age) from countries in which the disease is endemic<sup>3,4</sup>. Many of these individuals reside in, or are recruited for, specific employment (eg agricultural industry) to small towns and rural areas of Alberta. As the pattern and distribution of the illness undergoes these shifts, it is

important to examine the consequences for those individuals and communities who experience them firsthand.

Unfortunately, few Canadian data are available that describe trends associated with the spread of the infection to rural areas, or characteristics of life with HIV in such regions. However, it is recognized that high rates of mobility of Aboriginal persons between urban and rural areas increases the vulnerability of more remote communities<sup>5</sup>. Health Canada<sup>3</sup> reported that some risk behaviours, particularly those related to injecting drug use, are more prevalent in rural areas than in urban ones. Invisibility, isolation, and stigma are common in rural regions of Canada, and concerns related to confidentiality have a major impact on access to healthcare services<sup>6</sup>.

In the USA, there is acknowledgement of the increasing impact of the epidemic in rural areas<sup>7</sup>. Contributing factors include higher levels of poverty, lack of psychosocial support systems, inexperienced caregivers, vast geographic distances to obtain services, and perceived lack of tolerance for diversity in rural areas<sup>8-11</sup>. Most HIV-seropositive people in rural areas of the USA tend to be young, non-white,



female, and living in poverty, and the majority contract the disease through heterosexual behaviours<sup>12,13</sup>, making this population very different from its urban counterpart. Furthermore, the first author's experience as a volunteer with an AIDS service organization that serves a small Alberta city and the surrounding ranching and agricultural region, indicates that many rural-born MSM return to their rural roots after years of urban living. Thus, the population of HIV-affected individuals who reside in rural areas is diverse. The unique array of and interactions among influences on rural life and health combine to ensure that the issues associated with HIV disease in such settings are multifaceted and must be addressed comprehensively in order to promote the wellbeing of this population. This exploratory study was conducted in order to contribute to our knowledge and understanding of this complex public health challenge.

## Method

The general objective of the study was to examine the experiences of individuals who live with HIV infection and/or AIDS in a rural context. Understanding of perceptions of health and rurality, the processes involved in seeking and receiving of care, the relationship between personal beliefs about health and life and the life-limiting nature of the disease was also sought.

A naturalistic inquiry approach was used in order to gain understanding of the meanings and realities ascribed by the research participants to the events and experiences of their lives<sup>14</sup>. Entry into the HIV-seropositive community was facilitated by the first author's volunteer work with an HIV/AIDS agency that served a largely rural population. After ethical approval was obtained through the University of Calgary, other HIV/AIDS agencies also agreed to recruit participants. Data were collected through face-to-face or telephone interviews which lasted from 60 to 100 min and were audiotaped for later verbatim transcription. Field notes and a reflective journal were maintained throughout the research process. In addition, letters, poetry, and other documents were offered by participants and served to enrich

the data, which were analyzed using the constant comparative method.

### *Participants*

A purposive sampling technique was used to recruit participants from Alberta communities outside of Census Metropolitan Areas (CMA), which are defined as municipalities with an urban core of at least 100 000 people<sup>15</sup>. Included were people who resided in locations not served by public transportation and who had to travel at least 10 km to reach the AIDS agency office and/or more than 100 km to reach a specialized HIV clinic and medical services. Initially, interviews were conducted with four individuals who were HIV-seropositive and living in rural locations. The three men identified themselves as belonging to the risk categories of MSM (Len and David) or injecting drug users (Jack), and were between the ages of 36 and 58. (The names of all participants have been changed). A 34-year-old woman (Kate) acquired the disease through blood products transfused during surgery in Central America, prior to moving to Canada. Because the goal of the study was to understand the experience of living with HIV, a woman (Leanne) who had been the primary caregiver for her brother during his illness and death from AIDS and alcohol abuse was also interviewed. In order to expand our understanding of the challenges associated with rural life, we included as participants two individuals (Brian and Ray) who had lived in rural areas but had since moved to large urban settings following a diagnosis of HIV. Following conversations with them, we returned to some of the rural participants to discuss the themes that had emerged from the urban residents. We also met with some of the AIDS agency workers at different points during the process to hear their perceptions of rural clients' experiences. By travelling in this circular and reiterative fashion, we were satisfied that the data were sufficiently saturated. Trustworthiness was further ensured through prolonged engagement with participants, member checking, and the conduct of confirmability audits by colleagues who were not involved in the study.



## Results

The experience of living with HIV was described by participants as a long and arduous journey. Reconciliation of life as an infected person with life before infection was a challenge for both individuals and their families. There was a process of learning to be an HIV-seropositive individual that involved awareness and acknowledgement of the medical diagnosis, examination of personal beliefs and attitudes about living with an incurable illness, and selecting strategies for coping with new circumstances. Each person faced the need to make decisions about what to do next, not only about the disease and its treatment, but also concerning such dimensions as lifestyle, relationships, and the future. These challenges are not unusual for many people who live with HIV; however, the participants believed that as rural residents their decisions were complicated by difficulty accessing services to support their choices, as well as by concern about the reactions of their communities should the diagnosis become public knowledge.

### *Health*

Health was defined by participants as the ability to carry on with life, to care for oneself, and to remain independent. Quality of life was an important dimension and represented engaging in pleasurable activities and hobbies as well as taking responsibility for one's self and dependants. It was determined in part by the extent to which the individual could accommodate the limitations imposed by the disease, given in part the perception of barriers associated with life in a rural setting. Acceptances of the illness, along with determination to move forward, were essential strategies for achieving health.

### *Choices for living*

This domain comprised initial efforts to incorporate HIV into the participants' life stories. It involved interpreting and coping with physical symptoms and exploring options for treatment and lifestyle. Initial reactions to suspicion of

infection tended to focus on aspects of the physical self and were followed by confirmation and acknowledgement of the diagnosis; making decisions about lifestyle, behaviours, attitudes, and medical care; and examination of personal beliefs and practices. Some participants demonstrated little interest or ability in making health-enhancing choices; others made negative choices such as continuing with alcohol or substance abuse, while others made deliberate decisions to modify sexual practices, seek medical attention, and engage in other health-promoting activities.

Decisions about treatment were made more complex by the availability of antiretroviral drugs, the presence of other health conditions, lack of access to or absence of appropriate healthcare services, and compromised levels of motivation. Len, feeling a degree of coercion by healthcare providers into taking the newer drugs, resisted the pressure, citing the negative experiences of friends who experienced undesirable side effects. Instead he sought information about alternative therapies, such as herbal products, diet changes, and a more active lifestyle. David experienced some common but unpleasant side-effects of the drugs for a while, but soon felt better. Jack not only began a medication regime but relinquished his cocaine habit, joined Alcoholics Anonymous, and found strength in a positive attitude:

*[The HIV Clinic doctor] had plans of killing the bug, that's what he told me and I have faith in that. And I think with the proper attitude and the power of the brain I think this disease can be beat. I firmly believe that. . . . I have plans of being 102 years old. I got too much to live for and I love life.*

As participants accommodated their new realities, they acknowledged that the decisions they needed to make would affect the quality and length of their lives. These choices were complicated by the challenges of living in rural settings where many services were unavailable or inadequate and were accompanied by requirements for financial and other scarce resources.



## Creating community

This domain represented another level in the participants' progress toward health. Identifying personal needs for supportive relationships frequently began after acute medical concerns had been addressed. Some individuals chose to share the news with friends or family, while others kept it to themselves. Increasing awareness of the implications of his illness and the need to make changes prompted David to share his concerns with a family member:

*It was the time that I was, things were, everything was going wrong for me. I was like, I was really quite sick . . . to the point I was even suicidal and whatever, everything was going wrong for me. And I knew that. And I guess it was my reaching out for help from my sister, I kind of let her know that things are not going great for me.*

At the same time, David was concerned about repercussions from his neighbours if they discovered his sexual orientation or his HIV status, so he deliberately maintained a very low profile in the community. Mark was diagnosed early in the disease process, prior to the onset of symptoms, as a result of routine blood work for admission to a nursing education program. He chose to tell no one until he became ill with pneumonia 2 years later, at which time he advised his sister Leanne of his condition. Kate made the decision to tell others after sharing with her sister the agony of the diagnosis.

*Well she came here and I cried and I told her that and she said if I would tell other people that would make it easier for me. . . she thought other people would, I don't know, I'm not good enough in English, they would like, they would help me more if they know about it.*

Kate eventually told members of her church community and they responded with empathy, although she remained dreadfully lonely in her farmhouse on the prairie and

perceived the level of support from the community to be inadequate.

An important consideration for some participants centred around the question of where to live. Some were dissatisfied with their present location and were worried about the time when their health would deteriorate. The need for support from accepting, caring friends and family, as well for a healthy place to live, were identified as priorities. Past experiences and personal history played important roles in determining where a person chose to live. Most of the participants noted that if a rural location had been where they felt most comfortable during childhood and adolescence, then they tended to feel that they had 'come home' when they made the choice to return to a rural area. In contrast, after an unhappy adolescence in a small community, Ray chose to find a new home in the city, even though he found the city to be a dangerous place in some ways. Not only was his recovery from drug addiction enhanced through membership in Alcoholics Anonymous, he also was able to take advantage of support from other gay men in similar circumstances. He felt that his comfort level in the city was much higher than it would have been in a rural area. Brian also preferred city living and sought support from friends and the AIDS agency. He avoided going back to his home town, requesting instead that family members come to the city to visit him.

For David, years of living in a succession of cities had made him miserable. By returning to a rural setting, he created a healing environment for himself. He found that his health status improved dramatically following his move and this he attributes to his decision to relocate:

*Well, I think it's because I live in a small community! Because my life is . . . responsibility for my two canines here, responsibility for myself basically in a space of freedom and a space of serenity. And I've really found my home to be very serene and I fit like part of the woodwork. And that's why I'm doing well, I believe that.*



Unlike most of the participants, Kate had little choice about where she would live. Her family preferred farm life, her husband worked as a farm labourer, and country life was all she had ever known. Limited financial resources meant that the family relied on a large garden and low rent. The unhappy consequence for Kate was the physical distance which separated her from neighbours, family and friends who otherwise might have visited more often and alleviated some of her loneliness. The communal rural lifestyle in which she had grown up and which would have afforded her the security and support she now needed so desperately had been left behind in her birthplace. According to Kulig and McCaslin<sup>16</sup>, this separation from extended family, combined with the unfamiliarity of a new country, has rendered many immigrants vulnerable to illness. In Kate's situation, the potential had become the reality. Living in a rural location proved an isolating experience for her and, combined with her physical disabilities, contributed to her sense of grief and uselessness as a mother and wife.

A client services worker interpreted the move to rural homes of persons with HIV/AIDS in this way:

*It's sort of like they come home to die, that idea. They want to be around their families again, they want to make some peace maybe, they're tired of the hustle and bustle of the life that got them where they are, they feel some anger sometimes towards the big cities, 'if only I'd come home sooner, maybe this wouldn't have happened'.*

Home seemed to represent security and safety for individuals who had exhausted their financial, medical, and human resources in the city. It was an interesting contradiction that rural communities and families had often been a source of stress and unhappiness for the HIV-seropositive individual, yet this was the environment to which the person returned in the end. The notions that home is where one's roots are and that home is a place where one feels secure and comfortable (as suggested by one of the agency staff) were supported by participants in this study. David's search for simplicity and serenity was over quickly when he realized that he could not

survive in the city. He suggested that people look for a setting that has some element of familiarity and about which there are some positive memories, even if there are also bad memories. A supportive environment was seen as facilitative of the process of achieving health, whereas a hostile environment was perceived as a barrier to health, although not an insurmountable or unavoidable one in all cases.

The potential for engaging in relationships and the factors to be considered in making a decision around this issue preoccupied many of the participants. The isolation of rural living was acknowledged by all participants and was carefully weighed as they chose where to reside. Another concern was the possibility that a person with HIV would be less desirable to someone looking for a companion or partner. Len perceived that some people avoided becoming involved with someone whose life expectancy was uncertain, and he worried that the number of individuals willing to befriend him would be severely limited in his small village. David made a conscious decision to avoid relationships because of their potential to cause stress and pain; he saw it as a way of protecting himself. Ray, on the other hand, clearly articulated the value of the connecting process. Long estranged from his family of origin, he made extensive use of his support network and surrounded himself with his 'family of choice'. His decision to return to the city was a deliberate and clearly expressed rejection of the remoteness of rural living.

### **Challenging destiny**

This domain provided the base from which participants viewed the course and meaning of their lives. Spirituality, an important aspect of the person's existence, was expressed in terms of a sense of inner peace and contentedness, and the conceptualization of HIV infection as an opportunity for growth and self-actualization. For some, religious values and beliefs played an important role in their lives and offered a degree of comfort. For the rural gay men in particular, whose upbringings had been in the Roman Catholic Church, contact with the institution was relinquished with the acknowledgment of their lifestyles and the subsequent



withdrawal of support. Both Leanne and Kate were disappointed to find that the support they had expected to receive from their church communities was sporadic and indifferent at times. Comfort and support was sought through closer relationships with other entities, such as a 'higher power' for Jack, nature for David, and friends for Ray.

Expressions of hope were frequent and varied and usually reflected the participants' new worldviews. Jack acknowledged an obligation to help other people who were trapped in the same lifestyle in which he had found himself. The concept of time for some participants epitomized something to be endured, while for others it expanded into a universe filled with hope. Unable to perform household chores, time weighed heavily for Kate. She counted the days until her children would be home for the weekend and her husband would be home for his one day off. Sunday, a day of attending church and visiting with friends, ended with Kate dreading Monday morning and the beginning of another long week. There was, for some participants, a definite connection to the world, the earth, and the cycle of life. David's deep connections with his environment were evident in his words, his gaze out the window during our conversation, and his pride in his gardens. Kate, David, and Len credited their rural backgrounds with their strong ties to the land and the rural lifestyle.

## ***Barriers and challenges***

Participants spoke at length about the difficulties and frustrations they had faced in the past or that they anticipated having to overcome in the future. One of the most frequently mentioned issues concerned aspects of the healthcare system. Awareness of gaps in public health care grew as individuals and families attempted to negotiate the health care bureaucracy, only to find that services were wanting. The inability of clinicians to assist Mark with his complex health problems; home care nurses who addressed Kate's physical needs only and who were unable to provide comprehensive services in rural areas; and Len's experience of driving miles to an outpatient department every 4 hours for a simple respiratory treatment that could have been done

at home, were all factors that contributed to a lack of faith in the healthcare system. There was frustration about a dearth of knowledge on the part of some hospital and home-care staff who were completely unaware of the needs of and care for people with HIV, and about strategies to protect themselves from infection. Family members had to arrange for healthcare employee education sessions so that that loved ones would be assured of at least minimum levels of competence among the staff. Several participants suggested that when the time came that they were unable to meet their own needs, they would prefer to die rather than be dependent on a system perceived to be uncertain and unreliable.

Rural residents agreed that physicians often lacked knowledge about HIV and AIDS treatments, but reported that prompt steps were usually taken to consult with specialists or AIDS agencies. There was concern that physicians relied at times on their patients for the latest research about treatments, resulting in feelings of unease and apprehension by participants. Most individuals had to travel long distances to attend HIV clinics and found the expectations of staff to be unrealistic and, at times, insensitive (eg expecting clients to complete a three-hour drive in time for an 8.30 am appointment). Len's requests that blood be drawn in his home community and forwarded to the provincial laboratory were declined due to the complicated arrangements associated with transporting 'dangerous substances'. He finally chose not to monitor his disease. Kate's husband had to take a day off work to take her to the clinic located 150 km away, resulting in a significant loss of wages and contributing to Kate's sense of being a burden to her family.

Most participants expressed concern about confidentiality with regard to healthcare services in a small town. There was a sense that the risk of intentional confidentiality breaches was high outside cities, and several individual shared personal examples of such violations. Ray described the experience of rural habitation as 'living in terror' because of his fear of indiscriminate disclosure by healthcare workers, a fear which prompted him to move to the relative anonymity of the city.



Another huge barrier to living well with HIV resulted from society's attitude toward the disease and the people who contracted it. The gay men in the study had been subjected to discrimination and violence for most of their lives because of sexual orientation, and they were certain that this hostility and lack of tolerance interfered with their abilities to gain access to the care and support necessary to achieve health. The emotional cost of concealing and pretending was overwhelming to these men and resulted in great pain. All of the substance-abusing participants were convinced that their coping strategies developed as a result of the pain and abuse they had suffered for most of their lives, and that perhaps these same strategies had led to infection with HIV.

Participants noted a positive relationship between their personal health status and the general health of the community as they perceived it. They felt better in a setting where openness and acceptance were demonstrated by other community members. Several people suggested that societal attitudes and awareness formed the basis of health. David, Leanne, and Ray indicated that differences should be celebrated and that tolerance could be accomplished through education and role modeling by parents for their children as well as increasing awareness and knowledge among healthcare professionals.

## Discussion

Although the group of participants represented diverse backgrounds and lifestyles, the lives and experiences of all were linked by common themes. Descriptions of life with HIV/AIDS focused on a core concept of health, defined by participants as the ability to carry on with life, care for oneself, and remain independent. The processes in which participants engaged as they worked toward improving their health revolved around that central core and included a range of activities and outlooks that moved the participants closer to or further from their goal of health.

According to Long and Weinert<sup>17</sup>, rural dwellers tend to define health in terms of their ability to function and

maintain productivity. Findings from this study strongly support this notion, as most participants opened discussions of the concept by talking about a sense of usefulness and contribution to family and community. Furthermore, the financial implications of illness were clearly articulated in terms of feeling a burden on family and community as represented by an inability to earn wages and meet obligations. It is important for healthcare workers to understand that health is viewed pragmatically and as something about which to be concerned only when it begins to fail. Interventions that focus on disease prevention or health maintenance may not have the desired impact, as health may not be the first priority for a population that is coping with more pressing day-to-day issues<sup>18</sup>.

The ability to accept and adapt to isolation and distance is another characteristic of rural residents<sup>19</sup>. Great value is placed on self-reliance, as was apparent in the participants in this study. There was a tendency to comply with standard instructions provided by healthcare providers, or to avoid the intervention altogether, rather than to advocate for strategies relevant to their own situations. Healthcare providers must be prepared to adapt usual protocols to meet the needs of clients, and to monitor closely their progress to ensure that the extra effort required of individuals is not overwhelming the resources available to them. In addition, because rural communities are often perceived as 'fishbowls', it is critical that strict attention be paid to the need for privacy and confidentiality<sup>20</sup>. Several authors have reported that the difficulty associated with maintaining confidentiality in rural areas is particularly problematic<sup>21</sup>; the issue becomes more critical when the stigma of HIV is included in the equation<sup>22-24</sup>. Healthcare providers must provide leadership in striking a balance between human rights, tolerance, and nurturing caring attitudes within the community.

Most participants described the financial hardships associated with their rural existence. All relied on seasonal employment income or government disability pensions which typically fell far short of the cost of living and did not reflect the increased expenses associated with travel, communication, and non-insured equipment and



medications. Rural dwellers in Canada tend to experience lower incomes when compared with their urban counterparts<sup>25</sup>, which affects their ability to access resources necessary for healthy living. Poverty is an important determinant that directly and profoundly influences capacity for health and must be addressed in order to create equitable opportunities for wellbeing in all settings.

Kendall<sup>26</sup> described two trajectories along which persons with HIV infection may journey: (i) wellbeing; and (ii) illness. Within the former, a synergistic community of friends and families was built and nurtured through the vehicle of human interaction, and represented spiritual bonding. Illness, on the other hand, was characterized by spiritual and emotional despair accompanied by a lack of inner peace. The ill person experienced self and others as fragmented, with alienation and fearfulness exacerbated by self-destructive behaviours. There were striking similarities between Kendall's informants, and the perceptions expressed by individuals in our study. Kate expressed a profound loneliness and lack of intimacy in her life, and saw no future for herself. She often spoke of her sense of isolation, living as she did far from friends, family, and neighbours. David, on the other hand, deliberately and carefully secluded himself from all but a few individuals by moving to a rural community where he was unknown. He eventually came to the realization that contracting HIV had been a good thing for him, in that it had caused him to examine his life and reject those things that did not contribute in a positive way to 'simplicity and serenity'. Infection with HIV provided an opportunity for spiritual reconnection to his rural roots, with the result that his life gained new meaning. Interestingly, some individuals felt that they were healthier at the time of the interviews than they had ever been. This state of wellness was attributed to a change in lifestyle, setting of new goals and priorities, a more suitable environment, avoidance of stressors, and appreciation of the important things in their lives.

## Conclusion

The findings of this research provide an introduction to the lives, issues, and concerns of members of rural communities who cope with HIV infection and disease on a daily basis. The most crucial need is the one articulated by participants themselves: to create a society in which the experiences of HIV-seropositive individuals may be legitimized and their diversity celebrated. To live in a community that respects rights to privacy and confidentiality, while supporting the needs and addressing the issues of those who need it most, was the dream voiced by our participants. To participate in a community that truly cares about the welfare of its members and does not merely tolerate their invisibility was the hope expressed by the HIV agency staff. To know that one can count on the spiritual, physical, emotional, and social support that one needs when a loved one is dying was the plea of a family caregiver. These simple human requests for justice and dignity challenge the healthcare provider at a professional level, as well as a personal level, to consider health and wellbeing in its broadest context.

Many questions are generated by this initial investigation. Although this particular study was limited by the number of participants and the lack of generalizability of results, there are clear indications that the concerns raised are as difficult as they are real. Marginalized groups of HIV-infected individuals, including those who live in rural areas, are perceived to have few resources yet they are at great risk for complex health problems, only one of which is HIV. Issues related to rural settings, such as poverty, late diagnosis, and relative lack of access to health care services indicate that prevention, treatment, and harm reduction will be formidable challenges in the near future.

In addition, participants in this study comprised a group of individuals who were generally well and reasonably independent. Exploration of the experience of 'being ill' in a rural setting would yield important information for practice. More data are needed about the attitudes and perceptions of health care providers and community members toward



people with HIV infection. The conduct of rural research is itself challenged by increased investment of time and resources related to travel, vast spatial distances between participants, and the need to form relationships with a large number of partners in order to reach a reasonable number of participants. However, study of the structure and processes of communities which embrace and care for HIV-seropositive people would offer vital information about the health of community members and of communities themselves, and would enhance our understanding of health promotion strategies for populations. As the nature and scope of HIV disease continues to change and adapt to new circumstances, so must the responses of all community members. We hope that this study will contribute to that quest for greater understanding.

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