Social Planning in Canada for Families with HIV Infection

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The number of Canadian families with HIV-infected parents has grown in proportion to the increase in infected women. In 1995, 19% of people newly diagnosed with HIV in Canada were women of childbearing age – more than double the percentage diagnosed earlier.1 Family HIV, defined as a situation in which mother, father, or both parents are HIV-positive, can be a multigenerational infection carrying a painful stigma and affecting all family members, not just those infected. Children and parents living in families with HIV/AIDS face many complex, highly stressful psychosocial issues, both immediate and long-term, as HIV threatens their security.2,3 As in other countries, social planning is required to address these issues.4,5

This article is based on a large multicentre study, funded by Health Canada, that investigated – for the first time – the psychosocial needs of families with HIV in Canada.2 The purpose of the article is to describe the plight of these families and to propose social planning measures to respond to their needs. It briefly describes the complex family problems arising from the presence of HIV, the difficulty in estimating the number of affected families, and medical advances in treating people with HIV infection. The concerns parents expressed during interviews are summarized and recommendations for social policy presented.

BACKGROUND

Complexity of the presence of HIV in families

When one or more family members are HIV-infected, families are affected in a variety of ways, the severity of which largely depends on three factors: 1) Family structure and life-stage tasks (e.g., each member’s sex, age, and role); 2) HIV status of each member: positive, negative, or indeterminate (in infants too young to be diagnosed); and 3) health status of HIV-positive members: asymptomatic, symptomatic, having AIDS-defining illness.

HIV status alone leads to complex family situations. One or both parents may be infected; all, some, or none of the children; or all family members. Sole parents, perhaps widowed by the death of their partner from AIDS, may head the families. When sole mothers or fathers, or both parents, are infected, concerns about the future care of the children, whether infected or not, are paramount. If only one child is uninfected, he or she faces the possibility of losing parents and siblings. Reports of the psychosocial impact of HIV on families describe its profound effects on parents, children, and extended families as well as on communities and institutions.4,5,9-20

The following example graphically illustrates how some of these issues affect families.

M., a woman in her 30s, had many lingering infections for several years. Eventually her family doctor suggested...
testing for HIV. She tested positive. Her husband and 6-year-old son were also diagnosed as HIV-positive, but two older children, girls aged 8 and 12, tested negative. In shock and despair, the parents decided they would not tell anyone about the HIV, fearing discrimination, especially against the children. M.’s health problems forced her to leave her job. As parents and children began to face the uncertainty of their individual and family futures, the father’s low earnings meant they were also living in poverty. The parents’ chief concerns were maintaining their health long enough to raise their children and arranging care for them if one or both parents became ill or died. They had no other family members living in Canada.

Difficulty in estimating number of families affected

How many Canadian families are caught in this distressing situation is unknown. All we have are estimates of the number of women with HIV and the number of children born to them. In May 1998, Health Canada estimated that at the end of 1996 the number of women in Canada living with HIV was 4,000 to 5,000. The current number of pregnant women with HIV averages 3-4 per 10,000 across the country. The Canadian Perinatal HIV Surveillance Program reported that the known number of infants born to mothers with HIV between 1984 and 1998 was 924. This figure includes only infants who came to medical attention: many mothers with HIV were unaware of their status, and therefore their children were not tested. Of the 924 children reported, 325 were confirmed to be infected. No national data are available on the HIV status of fathers and siblings of children with perinatal HIV exposure. Research is needed to determine the number of families with HIV, particularly the number of affected children.

Medical advances in HIV/AIDS care

Recent medical advances have contributed significantly to better health for many people with HIV who receive medical care and can obtain and tolerate the medications available. Most Canadians with HIV have access to a range of antiretroviral therapies. Success with combination therapies, including new drugs such as protease inhibitors, has helped many people remain asymptomatic or see their symptoms abate. However, the long-term effectiveness of these medications is unknown. Some people choose not to take them, others cannot tolerate their side effects or adhere to the strict routine required. Women diagnosed before or during pregnancy and who have access to information and treatment can choose to take medications themselves and accept them for their infants. Early identification and treatment reduce the risk of mother-to-child transmission from approximately 25% to rates reported as low as 8.3%, 5.5%, and 4.7%. Women delivering infants by elective caesarean section reduce the risk of HIV transmission substantially: recent studies showed that when caesarean section was combined with administration of zidovudine (AZT), the transmission rate was only 2.0%.

STUDY OF PSYCHOSOCIAL ISSUES

Methods

This article is based on a study of psychosocial issues in families in which mothers who were HIV-positive had given birth. The study excludes families where parents were unable to care for their children. The methodology is reported in detail elsewhere. Brieﬂy, in-depth interviews were conducted with 110 parents (75% of them mothers) in 91 families. The qualitative data thus collected were analyzed by a multidisciplinary team using a multi-step process to identify needs and concerns. The recommendations were developed through review and examination of these findings by groups of parents with HIV, a network of social workers specializing in working with families with HIV, and a consensus conference of professionals in leadership positions in public health, child welfare, home care, family services, and HIV patient care.

Characteristics of the study population

Participants lived in a range of communities from villages to large urban centres. About two thirds lived in cities. Most parents (66%) were born in Canada, including 9% of Aboriginal heritage, and more than one third of immigrant parents had lived in Canada over 10 years. Just over half (54%) had family incomes of $20,000 or less, while 13% had incomes of $40,000 or more. Nearly half (45%) reported at least some of the family income came from wages. Although incomes were generally lower than the national average, parental education levels were comparable: 61% had completed high school and 40% had some postsecondary education.

All the mothers and 63% of the fathers were HIV-positive. Thirty-six mothers (47%) and four fathers (two HIV-positive) were sole parents. In 18% of the families both parents were HIV-positive. These 91 families were raising 164 children. Eight children had died from AIDS, and two women were pregnant when interviewed. Thirty-two children were HIV-positive, and an additional 12 were too young for their medical status to be determined. Most children were 10 years old or younger, including 63% who were preschoolers.

Summary of parental concerns

Despite improved treatments that can shift HIV to a chronic rather than an acute or terminal condition, the following five areas of major concern, identified through qualitative analysis of the parent’s responses, still apply:

• The family’s future, centering on the needs of the children. Parents contemplated illness and possible death, and the impact of these events on their surviving children. Further problems were anticipated for children who were HIV-positive.

• Living with uncertainty. The stresses of living with HIV/AIDS were described as both cause and effect of health problems. Parents had developed a range of practical and psychosocial coping mechanisms to deal with these stresses.

• Complex issues of health and family relationships. In most families, more than one person had HIV. Parents spoke of focussing on the one most likely to become ill, and the difficulty in trying to meet the needs of all family members.

• Dilemmas of disclosure and living with the secret of HIV/AIDS. Parents talked about
the stigma they and their children faced and their fear of discrimination. Parents had to weigh carefully the risks and benefits, the timing, and the degree of disclosure. Each family had to make these decisions individually.

- Community and social experiences and concerns. Continuing financial pressures, including expenses and time off work associated with treatment, were critical issues. Parents spoke about the need for comprehensive HIV education for children and youth in schools, for the public, and for service providers, who were themselves often a source of stigmatization and discrimination.

**RECOMMENDATIONS**

Recommendations for action by national, provincial, and local governments address issues in six key domains:

1. **Stigma and disclosure**

   Education, advocacy, and protection of human rights are required to resolve the problems of stigma and discrimination, especially in supporting families with children in deciding about disclosure or non-disclosure of their HIV status. Both the public and professionals, such as teachers and social workers who regularly work with families, need education. This is critical, as infected children are living longer, enjoying better health, and entering schools and day care in greater numbers.

2. **Promotion and support of family health and well-being**

   Family members, whether infected or not, need access as individuals and as a family unit to coordinated medical and psychosocial care and financial assistance to enable them to remain together as long as possible.

3. **Integrated planning and transitions for the care of children**

   Families may need help to plan for the care of children and for the difficult transitions if parents become unable to provide care. We recommend providing more HIV information and counselling for children, parents, alternative caregivers, counsellors, and child welfare staff who work with families in these situations. We also recommend formation of a national working group to address the problems of families with HIV/AIDS, in part by building linkages that promote increased information-sharing, support, and integrated planning for the care of the children.

4. **Economic issues**

   Many families with HIV live in poverty. Children, parents, and alternative caregivers (often grandparents) require adequate resources for basic living needs and medical expenses. We also recommend flexible workplace policies to allow parents to work as long as possible.

5. **Issues of culture and racism that affect Aboriginal and immigrant families**

   Families of Aboriginal peoples, immigrants, and racial and cultural minorities have special needs related to the importance of cultural identity and the persistence of racism. These include:
   - culturally appropriate help to ensure full access to health care and social services
   - training for service providers on cultural issues and information specific to HIV in families
   - immigration policies to help families care for orphaned children in Canada or their country of origin
   - policies and services for Aboriginal families with HIV, dealing with fears of alienation and ostracism on reserves, movement between reserves and urban areas, poverty, access to treatment, and HIV education on reserves.

6. **Education, advocacy, research and policy development**

   Education, advocacy, research, planning, and policies are required to enhance understanding, increase support, and optimize quality of life for families living with HIV. Examples of needed action include promotion of counselling before and after HIV testing with support at time of diagnosis; development of a national resource centre to provide HIV information to children, families, professionals, and the public; and formation of a national expert working group on helping families with HIV and other life-threatening chronic illnesses.

**CONCLUSION: THE NEED FOR SOCIAL PLANNING**

Social planning brings families, government departments, and social service agencies together to conduct research, address problems, serve as advocates, and provide education on social issues. At present, however, parents and children with HIV have no social planning structure dedicated to their concerns.

How can the special needs of families with HIV be included in health, social, education, and economic planning agendas? By formation of a national organization for consultation, social planning, and policy development. It should include AIDS service organizations; agencies for health care, public health, child welfare, family support, and social planning; and income support programs – a combination of federal and provincial groups reflecting the issues faced by families living with HIV. Leadership and participation must come from many sectors: two key partners are Health Canada's AIDS Care Treatment and Support Unit and the Canadian AIDS Society. In addition, parents and children living with HIV have a wealth of knowledge and experience and are committed to participate in education and support strategies (with or without disclosure of their HIV) and to act as advocates for their current and future needs. The issues raised by family HIV show the limitations of our service systems and support the need for social planning through proactive family policy.31

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