Preparing Counsellors for HIV Positive Youth: A model for curriculum development

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ABSTRACT

All counsellors will need to be equipped to meet the needs of individuals with HIV. However, this is especially true for counsellors working in the school environment. The arrival of children with HIV in school systems poses a challenge for school counsellors — a challenge for which they need to be well prepared. It is therefore extremely important that counsellor training programs include a component on HIV awareness in their curriculum. The purpose of the present paper is to outline the cornerstones of best practice that may serve to guide the development of such curriculum.

RÉSUMÉ

Tout conseiller doit être prêt à répondre tôt ou tard aux besoins des personnes infectées par le virus de l'immunodéficience humaine (VIH). Ceci est particulièrement vrai dans le cas des conseillers travaillant en milieu scolaire. Être prêts à accueillir en milieu scolaire les enfants porteurs du VIH constitue un défi des plus exigeants pour les conseillers scolaires. Il est donc extrêmement important que les programmes de formation des conseillers comprennent une section réservée à la prise de conscience du VIH. L'objectif du présent article est de mettre en lumière les meilleures pratiques fondamentales pouvant servir de guide à l'élaboration d'un tel programme d'enseignement.

Those living with HIV face a new reality. The last few years have shown great advances in HIV/AIDS treatments, which has allowed infected individuals to live longer (Altice & Friedland, 1998; Holzemer, Henry, Portillo, & Miramontes, 2000; Jeffe, Meredith, Mundy, & Fraser, 1998; Singh et al., 1999). And, the number of infected women of childbearing age is steadily rising (Health Canada, 1999a). Given that most children with HIV are infected by their mothers at or around the time of birth (Health Canada, 1999a), these changing demographics point to the fact that there will be more children with HIV and that these children will live longer and attend school. This trend poses challenges for school systems, and for university counsellor training programs. Professionals involved in the education system must be knowledgeable about issues pertaining to pediatric HIV/AIDS, and therefore instructors involved in related training programs must pass this information along to their students. This need is especially true in the field of counselling, as school counsellors play such an integral role in managing sensitive school matters. Moreover, counsellors outside the school environment also need this kind of specialized training as they too can be instrumental in helping families with HIV manage difficult and stressful situations.

The purpose of this article, is to provide practical guidance for the development of HIV/AIDS curriculum in counsellor training programs. First, we provide a brief overview of the Canadian demographics pertaining to HIV/AIDS. And second, we outline key aspects of pediatric HIV infection and describe how this knowledge can serve to guide professional practice.

Canadian Demographics and Epidemiology

The available statistics concerning HIV/AIDS have been questionable because of reporting delays and statistical sampling errors. It is, therefore, difficult to accurately predict how many children with HIV will in fact be attending Canadian schools in upcoming years. Even so, statistics maintained by Health Canada are offered in this section in order to provide the reader with some idea of how many Canadians live with HIV/AIDS.

Statistics provided by Health Canada (1999a) show that there was a total of 43,347 positive HIV tests and 16,236 AIDS cases reported from all provinces and territories of Canada from the beginning of the epidemic to the end of 1998. However, because of reporting delays and statistical sampling errors, Health Canada (1997, 1999a) believes these statistics to underestimate the true prevalence of HIV and AIDS. In actual fact, Health Canada (1999a) suggests that as of 1996 there were likely between 11,000-17,000 Canadians who carried the HIV virus unknowingly. Therefore, the actual numbers regarding HIV infection in Canada are likely much higher than the documented statistics indicate.

When looking at the gender differences in the reported statistics, Health Canada (1999a) reports that Canadian men account for 87.4% of the current total. However, Health Canada (1999a) also points out that the number of AIDS cases among females is steadily rising. In fact, the number of Canadian women reported to have AIDS has more than doubled between 1989 and 1998. This trend has tremendous implications for children as at least 78.6% of pediatric AIDS cases can be attributed to perinatal (i.e., mother to child) transmission (Health Canada, 1999a).

As of the reported (cumulative) statistics available in 1998, there were 243 Canadian children (i.e., youth under the age of 19) diagnosed with AIDS (Health Canada, 1999b) and an additional 1193 children were known by Health Canada to have been diagnosed with HIV (Health Canada, 1999c). Many more children are thought to be HIV positive but unaware of their infection.

Encouragingly, people with HIV are living longer without symptoms, and thus, HIV/AIDS is appearing more as a chronic than a terminal illness. These changing demographics suggest that more and more Canadian children will be infected with HIV and because of improving treatments these children will attend school. It is essential that school counsellors are prepared to meet the needs of these children and counselling training programs have a responsibility to train student counsellors accordingly. In order to assist in this aim, we suggest a model of best practice that outlines key aspects of pediatric HIV infection and also shows how this knowledge can serve to guide professional practice.

Three cornerstones of best practice in pediatric HIV/AIDS

We believe that there are three key aspects of pediatric HIV/AIDS which should be included in the curriculum of counsellor training programs: (a) ethical aspects, (b) physical and neurological aspects, and (c) psychosocial aspects. We will describe key topics associated with each aspect (i.e., issues), and second, we will show how this knowledge guides professional practice (i.e., implications).

Ethical aspects (issues). When considering pediatric HIV/AIDS, understanding the ethical implications associated with the disease is of paramount importance. The disease is unlike most other childhood illnesses because of the stigma associated with it, and because of the likelihood of multiple family members being infected (Mango et al., 1990). As a result of the stigma and ignorance about transmission, there have been hot debates around the rights of infected children to attend school and their right to keep their HIV status confidential (Pozen, 1995). Parents of infected children struggle with decisions around who and when to tell (disclose) and often decide to not tell anyone at all, including the children themselves (DeMatteo et al., 1999). School systems, therefore, may not realize that they have children with HIV in attendance. As a result, schools may underestimate the need to have appropriate HIV-related policies in place, and they may neglect to train their staff in issues pertaining to the disease — especially how to best manage ethical dilemmas. For example, how should a school deal with the fallout of a sudden disclosure from a child to classmates? What responsibilities or "duties to warn" does a school have if a youth with HIV is suspected of having sex with a classmate? How do schools handle HIV-related harassment? If a parent decides to disclose to the school counsellor, who does the counsellor inform or does she or he tell anyone at all? Currently, many schools are unprepared to effectively deal with such situations. Parents of children with HIV can feel frustrated at the lack of preparedness on the part of schools and may see this as another reason to withhold disclosure of the diagnosis (Roberts & Cairns, 1999). It is evident that the ethical issues surrounding the disease are complex and far reaching. Let us now turn to a discussion of how this knowledge affects professional practice (implications).

Ethical aspects (implications). When considering the ethical issues surrounding pediatric HIV/AIDS, it becomes clear that first and foremost counsellors need to understand how the virus affects the lives of those infected. Families living with HIV stress that greater education on the part of professionals working with their children would help to instill their confidence and trust (Roberts & Cairns, 1999). Such knowledge is necessary if counsellors are to practice in the most ethically rigorous manner possible. Moreover, with such knowledge counsellors can take a more informed and respectful stance toward the inclusion of children with HIV in the school system. In doing so, they should be well versed in the provincial/state legislation concerning pediatric HIV/AIDS, as well as in school policies pertaining to the disease. If no such policies are in place, it may very well be because schools have underestimated the need to formulate such policies.

Schools may need to be reminded that many HIV infected children are in attendance without the knowledge of school staff. If properly trained, new counsellors can help to educate their colleagues and advocate for the development of appropriate and respectful school policies. Imbedded in such policies should be a mechanism for helping staff to address ethical dilemmas. Given the complex and multidimensional nature of the disease, it may not always be easy to respond effectively to ethical dilemmas. Staff will need a way to navigate through challenging situations as they arise. The ethical decision-making process offered by the Canadian Guidance and Counselling Association (1999) is especially helpful and can be used effectively to deal with such situations. The basic steps of this process include:

Step One: What are the key ethical issues in this situation?

Step Two: What ethical guidelines are relevant to this situation?

Step Three: What ethical principles are of major importance in this situation?

Step Four: What are the most important principles, and what are the risks and benefits if these principles are acted upon?

Step Five: Will I feel the same about this situation if I think about it a little longer?

Step Six: What plan of action will be most helpful in this situation?

(Roberts, Pettifor, Cairns, & DeMatteo, (2000) provide an in-depth discussion of how to address ethical dilemmas specific to the field of pediatric HIV/AIDS.)

Physical and neurological aspects (issues). Many people are aware of the ways HIV attacks the immune system and thus leads to compromised health. Children may be affected by a number of opportunistic infections that may leave them weak and which may require repeated hospital stays (Beardsell, McKinnon, Mcneilly, & Moody, 1995; Bruder, 1995). It is clear how this physical impairment can affect school functioning. However, less people are aware of the way the virus affects the brain and central nervous system. The virus attacks neurological processes and the resulting impairment, which can severely affect both physiological and psychological functioning, has been termed "AIDS dementia complex" or "HIV encephalopathy" (Spiegel & Mayers, 1991; Wolters, Brouwers, & Moss, 1995). Children's cognitive functions can be altered and their ability to learn can be impaired. Specific problems tend to include language impairment and motor and coordination difficulties (Coplan et al., 1998; Drotar et al., 1997). Impairment is often variable from one infected child to the next, and certain medications can help children improve mental functioning (Cullington, 1989; Cohen, Papola, & Alvarez, 1994; Hanna & Mintz, 1995; Wolters, Brouwers, & Moss, 1995). Although the medications children with HIV take can be most helpful, the treatment regimes associated with such medications are complex and daunting, and many medications cause children to suffer difficult side effects (Altice & Friedland, 1998; Bright, 1999; Holzemer et al., 1999). Some families find that such treatments interfere with children's ability to participate normally in school and social outings, and as a result, some families do not strictly adhere

to treatment plans (Roberts & Cairns, 1999). This is of particular importance as missing doses can negatively affect children's health and creates the possibility for the virus to mutate and become resistant to certain drugs (Holzemer et al., 1999). Finally, when considering the physical implications of the disease, it is impossible to not consider transmission concerns. Although there is no cause for concern during casual contact with a person infected with HIV, it is still extremely important for schools to consistently use universal precautions (i.e., wearing gloves when handling bodily fluids). Anecdotal reports indicate that some schools do not universally use such precautions, perhaps because they underestimate the need to do so (Roberts, 1999).

Physical and neurological aspects (implications). When counsellors understand the physical and neurological implications of the disease, they are in a better position to ensure that their professional practice meets the needs of infected children. They will be more able to consider the health needs of children when helping to design individual education plans. Given the complex health needs of infected children, it will be very important to maintain open lines of communication with parents and health care providers. This is important in order to ensure that the overall needs of children are well thought-out and also so that schools can more easily pass along information about outbreaks of contagious diseases (i.e., chicken pox, etc.) that can be potentially devastating for children with weakened immune systems. Moreover, when considering the variable and unpredictable nature of HIV-related neurological impairment, it will be important for schools to assess children's abilities often and to integrate the information into individual education plans (Diamond, 1989). Schools should let parents and health care providers know immediately if cognitive skills deteriorate as this may have implications for treatment planning. Finally, schools must ensure that staff members are properly educated on the use of universal precautions, and they must ensure that such precautions are indeed used universally through staff in-servicing and consistent enforcement of school policy.

Psychosocial aspects (issues). Pediatric HIV/AIDS is like no other childhood illness because of the stigma that surrounds it, and because of the likelihood of the virus affecting multiple family members (Mangos et al., 1990). When considering the ways in which HIV is transmitted (i.e., primarily through IV drug use or unprotected sexual intercourse), we see that the majority of individuals infected are among the most marginalized people in our society (Pequegnat & Bray, 1997; Myrick, 1998). These people must deal with a multitude of risk factors in addition to HIV/AIDS such as poverty, life on the street, social isolation, etc. It is, therefore, not surprising to note that many people with HIV/AIDS, including children with HIV/AIDS, face depression and anxiety (Speigel & Mayers, 1991; Maj, 1998). Even though HIV is becoming more a chronic than a terminal illness, some people with HIV/AIDS still experience shortened life spans. Families must then also deal with various periods of grief and loss (i.e., at time of diagnosis, during period of diminished capacity, and at death). Children with HIV may not only go through repeated hospital stays, but may also lose their primary caregiver. Their care may become unstable and inconsistent.

Hence, those caring for these children need to pay special attention to these children's ability to form healthy attachments to primary caregivers. With improved medical treatments and prognoses, it is not unlikely that young children with HIV will grow into teenagers with HIV. This brings a whole new set of concerns to affected families, as they must now deal with complex issues of sexuality (Roberts & Cairns, 1999). In addition, teenagers who are not infected with HIV are at risk for becoming infected if they engage in sexual risk behaviours. Schools will need to consider how to provide all teens with the information needed in order to prevent infection. It is clear that the psychosocial problems surrounding HIV/AIDS are complicated and daunting (Roberts, 2000a). Counsellors working with affected families must appreciate these issues if they are to provide appropriate service.

Psychosocial aspects (implications). In order to meet the psychosocial needs of children with HIV/AIDS, counsellors will first need to be organized and proactive. They should ensure that each infected child has a case management team in place; including a case manager, the child's counsellor, and respective educators. The case management or individual education plan should be designed to meet the holistic needs of the child, with emotional and behavioural needs given the same priority as educational needs. Simply put, all children-but especially children with HIV-will not meet their academic potential if their emotional needs are not addressed. Schools must also plan for children who will require extensive psychosocial support, with the probability of long-term counselling being required. And, schools should pay attention to the stigma surrounding the illness-especially in regard to transmission-and do everything possible to support the peer relationships of infected children. When considering the complexities surrounding adolescence and sexuality, schools will also need to ensure that their curriculum includes appropriate components on HIV/AIDS and prevention. Affected families stressed the need for such health classes to be respectful and accurate as it was difficult for their children to listen to factually inaccurate presentations and/or presentations which focused exclusively on the terminal aspects of the disease (Roberts & Cairns, 1999). Again, it must be stressed that there may be HIV positive adolescents in attendance without the school's knowledge. Finally, given the amount of time children with HIV/AIDS spend in school, counsellors are in a tremendous position to inspire hope in children and families with HIV/AIDS. They can begin to do so by being knowledgeable, prepared, and respectful. (Roberts, 2000b, provides additional information about school implications regarding pediatric HIV/AIDS.)

In summary, as more and more Canadians become infected with HIV, counsellors will need to be well trained to meet the specialized needs of these people. However, this is especially true for counsellors working in the school environment. Given the unique role counsellors play in managing sensitive school matters, they are in a key position to provide leadership in preparing for the arrival of school children with HIV. In order to be effective in this role, counsellors will obviously need to be well prepared. This means that counsellor training pro-

grams should incorporate HIV education into related curriculum. The purpose of the present article is to guide the development of such curriculum. We not only provide an overview of the knowledge counsellors should possess, but we also link this knowledge to guidelines for practice.

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