

CANADIAN SCHOOL CHILDREN WITH HIV/AIDS: A FOLLOW-UP DISCUSSION

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ABSTRACT

It is important that schools are prepared to address the needs of increasing numbers of Canadian children infected with HIV/AIDS. Children diagnosed with HIV/AIDS experience psychosocial and neurological difficulties associated with infection; difficulties that have educational implications. Roberts (1998) described the school experiences of children and families with HIV and shared family recommendations for how schools can best accommodate and provide support for these children. However, many of these recommendations were general and could be applied to any number of childhood chronic illnesses. The purpose of the present article is to compare and contrast paediatric HIV with other childhood illnesses and thereby produce a more focused listing of recommendations. It is intended that this discussion will serve as a foundation for best practice guidelines for Canadian special educators as well as provide direction for future Canadian research in this area.

The available literature suggests that, as a result of improved treatments, the future picture of HIV/AIDS will resemble a chronic rather than terminal illness and that more and more children infected early in life will in all likelihood live to attend school (Roberts & Cairns, 1999; Singh et al., 1999). Roberts (1998) reviewed the stories of affected families as well as their recommendations for school systems. When analyzing these recommendations, it is clear that many are general tenets of good practice. A number of these recommendations would be useful for a variety of families, not just for families affected by HIV/AIDS. However, some of these recommendations are specific to this disease and are crucial in order to provide the best possible educational

services for this population. In this article, the author describes some of the most salient psychosocial and educational implications regarding children with other chronic health concerns and by way of comparison, shows precisely how HIV/AIDS is different. In doing so, the author elaborates upon the findings of Roberts (1998) and generates additional recommendations. Directions for future research are also provided. This discussion is meant to provide a basis for future Canadian educational policy discussions.

Brief Overview of the Roberts (1998) Study

The purpose of the Roberts (1998) study was to identify the perceptions of primary caregivers regarding quality of life experiences of HIV infected children and their families in Canadian public and separate schools. Qualitative methodology was selected to emphasize the voices of the participants: those primary caregivers who have first hand knowledge of interacting with schools when caring for a child with HIV/AIDS. Conducted in collaboration with the HIV Program at the Hospital for Sick Children, 17 self-declared primary caregivers of a school age child diagnosed with HIV/AIDS, living in Canada and attending (or having attended) public or separate school were interviewed. Together, participant and investigator explored the school experiences of the child affected by HIV/AIDS. The participant was initially asked, "What is school like for you and your family?" When necessary, this question was followed up with predetermined questions designed to tap into quality of life experiences, as well as to generate recommendations about how schools can best prepare to accommodate and support children with HIV/AIDS and their families.

Contextual Information Regarding Other Childhood Illnesses

In a discussion regarding the prevalence, severity, and impact of childhood chronic illnesses, Newacheck and Taylor (1992) stated that approximately 31% of children are affected by some kind of chronic health condition. Examples would include asthma and allergies. However, of this 31%, Newacheck and Taylor suggested that 5% would have an illness severe enough (i.e., cancer or diabetes) to interfere substantially with daily activities. These more serious illnesses can have a very serious impact on both the physical and psychosocial development of children and adolescents (Falvo, 1991). For example, Lavigne and Faier-Routman (1992), in their meta-analysis of 87 studies of children's adjustment to physical disorders, showed that seriously ill children can, among other things, demonstrate higher levels of anxiety, depression, noncompliance, and aggression.

Due to improving medical treatments, many children with serious conditions are living much longer (Harbeck-Weber & Peterson, 1996) and concerns regarding their long-term adjustment are paramount. Consequently, quality of life issues will become more important for these children (Harbeck-Weber & Peterson, 1996) and schools will likely see increasing numbers of students with serious health conditions in attendance. Considering the importance of school in the lives of children, Unsworth and Howard (1994) agree that for chronically ill children, "focused attention on educational goals must be a priority" (p. 74).

However, children with illness may encounter special difficulties when it comes to school. For example, Olson (1988) described how devoting energy to acquiring educational skills may be especially difficult for children who are already channeling great amounts of energy into fighting for their health. Falvo (1991) described how learning is further compromised for children with illness when they are required to spend time away from school in order to receive medical treatments: treatments which also often leave them tired and weak. When turning to the literature on specific illnesses, we see many more school-related obstacles for affected children. To illustrate, Acton and Conte (1996) describe specific school-related academic and social concerns for children with cancer:

Many children with cancer have to leave school for varying periods of time depending on the severity of the disease and their reaction to treatment. Those children who miss school for a period of time may be behind academically and may be isolated from their peer group. Other students may be able to attend school during treatment. The problems faced by these students include their acceptance by other students given that there may be changes in physical appearance (balding, effects of surgery and/or radiation). (p. 10)

It is clear that children with cancer will likely experience difficulties when at school. Noll and colleagues (1990, 1991) demonstrate how social difficulties are particularly salient. In their longitudinal study, they reported that teachers described children with cancer as being less sociable and less likely to assume leadership roles when at school. Given the limitations for severely asthmatic children to engage in normal physical activity (Weinstein, Chenkin, & Faust, 1997), similar social difficulties can arise for these children when they are unable to participate equally in recess activities and in school sporting events. Moreover, considering the complex daily treatment regimens and dietary limitations of diabetic children (Harbeck-Weber & Peterson, 1996), it is easy to see how these children also may feel different and socially marginalized.

After considering the difficulties associated with school for chronically ill children, various researchers have provided teachers and schools with recommendations for how to best support these children. Tharp (1978) argued that communication and cooperation between school and family is of utmost importance. Moffitt (1985) reported the benefits of a multi-disciplinary team approach to supporting chronically ill children in the classroom as well as the need for teachers to create school environments which foster normal development during abnormal circumstances. Favrot and colleagues (1993) illustrated the joy and sense of normalcy experienced by sick children when school was brought to them via two-way teleconferencing systems. Moreover, Unsworth and Howard (1994) maintained that every effort should be made to maximize the time chronically ill children spend in the classroom and they urged teachers to "adapt, be flexible and maximize their time with students so that educational and social goals can be met" (p. 78).

Paediatric HIV/AIDS In Context: Similar Concerns

When considering some of the salient educational aspects relating to other chronic childhood illnesses, we see that the experiences of many other sick children are consistent with that described in the HIV/AIDS literature, and with that described by the families involved in the Roberts (1998) study. First, we see that medical treatments are improving in other fields and that the life expectancies for children with other chronic illnesses are improving. Educational, quality of life, and psychosocial concerns permeate the extant literature of other childhood illnesses. This is certainly also true for families with HIV/AIDS.

Psychosocial Concerns Relating to Paediatric HIV/AIDS

The available literature suggests that more attention must be given to the psychosocial impact of HIV/AIDS (Salter Goldie, DeMatteo, King, & Wells 1997; Reidy, Taggart, & Asselin, 1991). The results of the Roberts study (1998) are congruent with that conclusion. Families described how their relationships with others at school and in the greater community were central to their overall sense of quality of life. At times HIV/AIDS greatly affected this aspect of their lives and at other times it did not. Whether or not caregivers perceived that HIV/AIDS had a direct impact on this part of their lives, they described actively encouraging their children to socialize with others. It was important to caregivers that their children enjoyed friendships and participated in extra-curricular activities. In fact, one primary recommendation from caregivers was for schools to encourage children of all abilities to develop more positive social skills.

The literature tells us that families with HIV/AIDS are prone to feelings of anxiety, depression, and grief (Klindworth, DoKecki, Baumeister & Kupstas, 1989; Poguegnat & Bray, 1997; Maj, 1998). Families involved in the Roberts (1998) study spoke of their anguish and they described how positive social interactions helped to alleviate these problems. Many described the excitement their children felt when they could go to school to be with friends. It is essential that schools allow ample opportunities for children with HIV/AIDS to interact with others, and make accommodations for children with limited abilities. One caregiver illustrated how schools can make a positive contribution to the social interactions of children when she described the "circle of friends" which was organized for her daughter by the school.

Caregivers described their own social interactions with the school and their appreciation when schools opened their doors to them. The school climate can either facilitate or discourage parental involvement. Through their recommendations, caregivers wanted school staff to understand the importance of school in their lives and they explicitly stated their need for schools to create a warm and open environment in order to facilitate communication. It is clear that some schools succeeded in this regard and that this positive school climate left families feeling like partners in education. All schools can learn by this example. They can actively encourage parental involvement and create opportunities for families to interact with each other.

Caregivers talked about their need to be treated normally, especially within the context of the school. This is consistent with what we know about other childhood illnesses (Moffitt, 1985). Caregivers want to be treated with kindness and compassion but not with excessive attention. In fact, treating families in a normal manner was one of the primary caregiver recommendations directed at school personnel. It may be difficult for schools to understand how much support is needed and what degree of support may be excessive. Creating an open atmosphere whereby communication between schools and families is facilitated would help schools better gauge the needs of children and families with HIV/AIDS. Moreover, caregivers described an appreciation of the everyday acts of kindness displayed by school staff. Some educators treat each and every family with compassion and respect and do so out of habit. Their heightened level of professionalism is commonplace and, as a result, no one family feels singled out. Caregivers recommended that all schools demonstrate this kind of customary thoughtfulness.

Unique Aspects of Paediatric HIV/AIDS

School and school experiences are important to many families, not just families affected by HIV/AIDS. Recommendations regarding social skills

development, the promotion of a warm school environment, the need for open communication between home and school, as well as the desire to be normal would be valid concerns for families with other chronic diseases. However, a number of things make HIV/AIDS unique in comparison with other chronic childhood illnesses. For example, HIV/AIDS is often defined by the stigma that surrounds it (Pequegnat & Bray, 1997; Myrick, 1998). Unlike others, this disease is contagious and the modes of infection are often connected with high-risk individuals. As a result, many affected or infected individuals encounter stigma.

Stigma

Stigma creates an obstacle for school-based interpersonal relationships. The available literature (Pequegnat & Bray, 1997; Myrick, 1998) discusses how families with HIV/AIDS experience social marginalization, and many families involved in the Roberts (1998) study described encountering moments of stigma. Although the participants involved in the study represented diverse ethnic and socio-economic population groups, those caregivers from minority backgrounds described feeling as though "all the blocks were stacked against them" and these perceptions affected the quality of their school relationships. One caregiver stated that she felt school staff could not get past her "face." In addition, and contrary to ethical practices, some families described being denied daycare placements and even the opportunity to volunteer at their children's school. One family revealed that a memorial which was erected in honour of their deceased child was desecrated. These experiences indicate that HIV/AIDS related stigma is prevalent in our society and remains a concern. It is significant to note that those families who had told others about their health status shared more experiences of encountering stigma.

Lack of Education Regarding HIV/AIDS

Most of the families stated their belief that stigma is grounded in ignorance. The people they have encountered have little understanding of the modes of transmission of HIV/AIDS or of how infection can affect everyone. Some described incidents where people questioned them as to how their children were infected with HIV/AIDS. One caregiver described being questioned openly in a busy school office by the school principal about her child sharing parts of his lunch with other students, implying a fear of HIV/AIDS transmission in this manner. The principal did this without discretion or thought as to potential embarrassment to the caregiver. It is clear that some school staff and even school leaders are not sufficiently educated about

HIV/AIDS. Many lack knowledge about the disease as well as the skill to interact with affected families in an ethically appropriate manner. Families made it clear that competence builds trust. Schools must continually strive to increase their level of knowledge and competence in all areas.

Disclosure

As a result of the stigma that surrounds HIV/AIDS, many affected families are wary about sharing this information. Unlike other childhood illnesses, families with children infected with HIV/AIDS may not be prepared to share this information with the school. In the field of paediatric HIV/AIDS, disclosure is an extremely important topic.

The caregivers who participated in the Roberts (1998) study reflected upon and carefully described the challenges associated with disclosure. Caregivers detailed experiencing stress when disclosing to others and using disclosure or non-disclosure as a protective measure. Many families chose not to share this information with the child, school, or greater community. The right to tell or not to tell must remain with caregivers in accordance with legal and ethical guidelines. However, based on interactions with school systems, the author believes that schools do not fully understand the need to devote attention to paediatric HIV/AIDS in the school setting. Schools do not realize the numbers of children with HIV in attendance and therefore many educators do not perceive this to be a pressing issue and in times of limited resources, they do not focus on it. Caregivers also observed this phenomenon and recommended that school personnel "open their eyes," "mobilize," and become more aware of the prevalence of HIV/AIDS infection among school age populations. Schools need to understand that there may be HIV/AIDS infected students in attendance, without their ever knowing it.

The results of the Roberts (1998) study also indicated that many caregivers perceived that choosing not to disclose would result in giving up some of their rights. Caregivers who have chosen not to disclose described feeling as though they could not actively advocate for their children or ask schools about policies and educative programmes, as doing so would bring attention to themselves. As a result, many caregivers felt voiceless and ignorant, and these feelings significantly influenced their overall sense of quality of life. School information should be made readily available to families so that obtaining information is not viewed as burdensome or unusual.

Families that chose to disclose; however, experienced mixed levels of readiness on the part of the school staff. For example, some schools satisfied

the needs of families by ensuring open and frequent communication and accommodating families in times when school absences were necessary for medical treatments. However, other schools were less prepared and created moments of stress when, for example, a caregiver was questioned about a child sharing lunch items with others. Schools must realize that families take a risk when sharing this information even while anticipating that schools will be able to meet their needs and create an optimum educational environment.

Exercising Responsibility and Universal Precautions

Families discussed their rights and sense of empowerment relating to the concept of disclosure, but they also recognized a need to exercise responsibility. Caregivers have gone to great lengths to teach themselves and their children proper ways of handling blood. When at school, many children were expected to take care of their wounds and bring home the bloodied tissues in their backpacks so that caregivers could dispose of them at home in a way that was safe. Caregivers felt a need to protect themselves and their families, but they also felt a need to protect others. Many caregivers went to such lengths because they were not completely confident that school staff are properly trained in universal precautions: meaning that these precautions are utilized with all children, infected or not. Caregivers simply did not want to take the chance of others becoming infected by the blood of their children. These actions reflect the burden caregivers and children must feel. We could lessen this burden if we ensured the constant use of universal precautions in school environments: doing so would also be consistent with published American best practice guidelines (Crocker et al., 1994). Teachers should always have rubber gloves and first aid sets in their classrooms and should carry some of these supplies when in the library, the gym, the playground, or on field trips. Clark and Schwoyer (1994) discuss, for example, how teachers should ensure the use of precautions with all students in order to maintain a safe environment and so that they do not inadvertently breach confidentiality with identified students.

HIV/AIDS and Adolescence

HIV/AIDS is also unique from other childhood chronic illnesses because of its sexual implications and this has a special significance for adolescents with HIV/AIDS who are beginning to explore issues relating to sexuality. There is very little information about the experience of adolescents with HIV/AIDS in the available literature. The information that is available tends to focus on newly infected adolescents and their corresponding

high-risk behaviours but not on the adolescent infected during infancy (Bartlett, Keller, Eckholdt, & Schleifer, 1995). In the past, many children with HIV/AIDS did not live long enough to experience their teenage years.

One important contribution of Roberts (1998) is the documentation of the adolescent experience. Caregivers described encountering new types of challenges related to school and their infected children. It is difficult for them to help their teenage children explore issues of sexuality, and the obstacles associated with sexuality issues in some instances became the fuel for harassment from other students. Caregivers described the discomfort they and their children experienced as a result of sex education classes in the high schools. Many schools present educational materials on HIV/AIDS in an effort to prevent infection through unsafe sexual practices among teenagers. These presentations often use scare tactics and describe the difficult and fatal consequences of the disease. Schools may present these materials without realizing that there might be HIV/AIDS infected adolescents in the class. For a teenager already infected with HIV/AIDS, there is no doubt that such presentations can be frightening and stigmatizing.

In their recommendations, caregivers who participated in the Roberts (1998) study suggested schools be more aware of the need to use discretion when presenting delicate materials. School staff need to present HIV/AIDS information accurately, but with sensitivity. It is necessary to realize that there may be children in the audience infected with, or affected by, HIV/AIDS. Moreover, they should encourage other students to demonstrate similar diplomacy and sensitivity when interacting with people infected with the disease. Information about the scheduling and content of health classes should be made available to families so that caregivers of adolescents with HIV/AIDS may have an opportunity to prepare themselves and their children for discussing the materials to be covered.

Unique Medical Components of HIV/AIDS

There are also medical components of HIV/AIDS that make it different from other childhood illnesses. Caregivers described how the illness presents itself in pervasive and unpredictable ways. Many of the children also faced concomitant risk factors such as hemophilia and developmental delay. As a result of the complexity of the health of their children, caregivers described a need to monitor their children with vigilance. Many have even organized their employment so that they may be available at all times throughout the school day in case their children require assistance. Caregivers also described worrying about their immuno-compromised children in a school environment

teering with germs and viruses. When discussing paediatric HIV/AIDS in the school system, the literature and the public reflect a great deal on the health risk to other children. However, it is clear that children with compromised immune systems may be at greater risk for contracting contagious illnesses when at school. Caregivers detailed their requirement for immediate receipt of information concerning outbreaks of contagious illnesses such as chickenpox or measles so that their children could undergo medical treatments to strengthen their immune systems. Caregivers were distressed when this information was passed on by other parents instead of by school personnel. Moreover, when dealing with immuno-compromised children, caregivers also described the need for schools to maintain a clean environment. In fact, ensuring a high level of hygiene throughout schools is one of the primary caregiver recommendations in Roberts (1998).

The available literature does detail the physical and neurological consequences of HIV/AIDS infection (Hanna & Mintz, 1995; Meltzer et al.) and the experiences of some of the families who participated in Roberts (1998) are consistent with these results. Some of the children experienced serious neurological problems and these difficulties influenced their school behavior and performance. However, there is very little information in the literature regarding how schools can modify their curriculum in order to accommodate the learning needs of these children. The situation is further complicated by the fact that school staff may be required to prepare programmes for these children without fully understanding their health concerns. In consequence, conflicts may develop between meeting the educational needs of these children and maintaining confidentiality. It is clear that this is a topic requiring further investigation by researchers and practitioners.

HIV/AIDS Medications

Although many children with chronic illness take medications, doing so for a child with HIV/AIDS can cause unique problems. Caregivers told of the many medications their children were required to take and how taking medications interfered at times with their children's socialization. For example, some families feared the consequences of allowing their children to participate in overnight school trips. Families who have chosen not to disclose did not feel comfortable having school staff administer their children's HIV/AIDS medications, like zidovudine (AZT), as doing so may give away the diagnosis.

Although medical procedures can be complicated, they do give families with HIV/AIDS much hope. Many caregivers described never expecting their children to live very long, yet many are surviving well into their teenage years.

With hope, families feel as though they are able to survive and dream about a future for their families.

Summary of Recommendations for School Systems

As previously outlined, one of the primary objectives of this article is to clarify how schools can best meet the needs of the children infected with HIV/AIDS and their families, and to accommodate and provide support for them. Unlike Roberts (1998), which provided some general and non-disease specific recommendations, below is a concise listing of recommendations specific to paediatric HIV/AIDS:

1. It is essential that schools allow ample opportunities for children with HIV/AIDS to interact with others, and make accommodations for children with limited abilities.
2. Schools must actively encourage parental involvement and create opportunities for families to interact with each other.
3. Schools must continually strive to increase their knowledge, competence, and ethical practice in all areas.
4. Schools must create an open atmosphere in order to facilitate communication with families. This would allow them to monitor the needs of students and their families.
5. Schools need to present HIV/AIDS information to students accurately, but with sensitivity. Schools should encourage all students to demonstrate diplomacy and sensitivity when interacting with people infected with this disease.
6. Information about the scheduling and content of health classes should be made available to families so that caregivers of adolescents with HIV/AIDS may have an opportunity to prepare themselves and their children for discussing the materials to be covered.
7. The choice to disclose a child's health status must remain with caregivers.
8. Schools need to be made aware that there may be students in the audience who are infected with, or affected by, HIV/AIDS.
9. School information regarding HIV/AIDS policies and educative programmes should be made readily available to families so that obtaining information is not viewed as burdensome or unusual.

10. Schools must develop a greater awareness of the issue of HIV/AIDS and be prepared to meet the needs of the families they serve.
11. School personnel must endeavour to establish and maintain working alliances with caregivers. They must also develop their own knowledge and competency concerning issues and procedures relating to HIV/AIDS in the school environment and foster relationships of trust between schools and families affected by HIV/AIDS.
12. Schools must promptly provide families with information regarding outbreaks of contagious illnesses in the schools and make every effort to ensure a high level of hygiene throughout school environments at all times.

Directions for Future Research

The results of Roberts (1998) help us to understand what school is like for children and families struggling with HIV/AIDS. Caregivers clarified ways in which schools can prepare to meet their needs as well as the needs of their children with HIV/AIDS, and to be able to accommodate and provide support for them. However, we still do not know all that we need to about this topic in order to provide the optimum school environment for families affected by HIV/AIDS.

We know very little about what school systems and their personnel perceive they may be doing to meet the needs of these families. What are their policies for managing paediatric HIV/AIDS? There exists no published review of HIV/AIDS school policies across Canada. The results of Roberts (1998) indicate that families affected by HIV/AIDS would be very interested in this information; however, they are hesitant to ask for it directly. An in-depth review article, in which all school systems or a random selection of them are studied, would help us understanding the various questions associated with school HIV/AIDS policies. Some questions include, for example, what do school systems in British Columbia, Ontario, and Quebec, provinces with the largest reported number of HIV/AIDS cases, have in common and how do they differ? How do they train their staff about HIV/AIDS? How much money is set aside for new and on-going training?

What school systems perceive they may be doing, and what their written policies say, may be quite different from what they are actually doing. A survey of school systems across the country could be followed by in-depth interviews with school personnel. For example, it would be useful to interview teachers who are aware of a child with HIV in a classroom and teachers who

do not have such an awareness, in order to compare perspectives. These interviews would allow us to understand how much training teachers, and other school staff, receive concerning issues of paediatric HIV/AIDS. Such interviews would also provide information concerning what teachers think about their school system's policies.

Medical professionals who work with school systems have a great deal of experience with school-age children infected with HIV/AIDS. They are in the unique position to help schools understand the myriad of health and emotional concerns these children may encounter. Although most of the research published in this area is written by medical professionals, we know very little about the school experiences of medical professionals who work in Canada. I suggest that interviews with medical professionals also be a focus for additional research in this area.

As more children are born to women with HIV/AIDS, and become infected, grow older, and attend school, researchers will have more opportunity to study this area from the direct perspective of the children. Children are the ones who spend 6 hours of each day, 10 months of the year in a school environment. A better understanding of their own lived experience would help us develop a more complete understanding of paediatric HIV/AIDS. It would be beneficial to interview a cross section of children of many ages and levels of health and ability, in order to complete this kind of research. In addition, these direct child studies would be enriched with educational assessment. How do their health concerns affect their ability to learn and apply knowledge? Moreover, how can school staff best meet their educational needs while ensuring strict confidentiality?

There are many children who are not infected, but who are nonetheless profoundly affected by HIV/AIDS. These children include the siblings, sons, and daughters of infected individuals and for the most part they have been neglected in the research published to date. When considering HIV/AIDS from the family perspective, as recommended by the literature, it is important to understand the experience of each family member (Mangos et al., 1990). Research methodologies which allow for the participation and contribution of non-infected family members are therefore needed.

In conclusion, the author discussed the results of Roberts (1998) with reference to the available literature, showing how paediatric HIV/AIDS is both similar and unique in comparison with other chronic childhood illnesses. In doing so, disease specific recommendations for school systems were generated and directions for future research highlighted. It is intended that this discussion will serve as a foundation for best practice guidelines for Canadian special educators.

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PARENTS' PERSPECTIVES ON THEIR ROLES IN FACILITATING THE INCLUSION OF THEIR CHILDREN WITH HEARING IMPAIRMENT

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Abstract

The purpose of this research was to examine the roles of parents of children with hearing impairments who had undergone auditory-verbal therapy and who had been integrated. Data were collected through questionnaires (N=41) and focus groups (N=24). It was found that parents had four critical roles in supporting academic and social integration: teacher, advocate, support group member, and facilitator of friendships.

Introduction

Over the last two decades, educators have looked increasingly to the regular classroom as the first choice in the placement for children with disabilities. It is felt that an inclusive classroom setting, the academic and