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**Canadian Families With HIV/AIDS:
Quality of Life Experiences in Public Schools**

by

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ABSTRACT

In future, there will be increasing numbers of children infected by HIV/AIDS attending Canadian schools. It is vital that schools are prepared to meet the needs of these children and their families. Children diagnosed with HIV/AIDS experience psychosocial and neurological difficulties associated with infection, difficulties that will have educational implications. A review of the literature has shown that affected families have rarely had an opportunity to freely describe their experience when interacting with the school systems and that quality of life issues at school have been neglected. In response to these research gaps and grounded in Keith and Schalocks's (1992) quality of life model, this study's objectives were: (a) to identify the perceptions and experiences of the primary caregivers regarding interactions with the schools which have had an impact on the child and the family's quality of life, and (b) to clarify how schools can best prepare to meet the needs of children with HIV/AIDS and their families, and to accommodate and provide support for them. The study, guided by phenomenological methodology, identified 17 caregivers' perceptions of the quality of life experiences of HIV infected children and their families in Canadian public and separate schools. Recommendations were solicited from these caregivers in order to assist schools to understand how best to accommodate families with HIV/AIDS. The findings were discussed with reference to the available literature, showing how paediatric HIV/AIDS is both similar and unique in comparison with other chronic childhood illnesses. Throughout the discussion, recommendations were provided for school systems. Issues of family adaptation, ethical implications for school psychologists, and comments relating to the utilized quality of life model are offered. The limitations of the study and directions for future research are also discussed.

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A TRIBUTE TO BRUCE

A new star shines in the celestial array,
Its warmth beacons to the family below.
The light of Bruce's spirit touches us today,
You here all must feel its warm glow.

Symmetry of the galaxy,
Known by an engineer's mind.
As the winds of the world touch his face,
An intellect, a gentle nature, truly one of a kind.
In God's great plan, Bruce has his place.

Our world is left crystalline
When a loved one must leave.
But then, a comprehension of life's purpose becomes clear,
And we say, "No!" we must not grieve
But welcome life's mission that does appear.

To realize those who struggle
Should not be set apart.
Through Bruce's resurrected spirit, an understanding is new,
That we all in life's story must play our very own part,
With expression by all, not just a few.

Oh yes, a bright new star shines in the celestial array,
Its sparkle beacons to us all below.
We rejoice in this light Bruce sends to us today,
Because we are wiser from its special glow.

(Written by my mother, read by my brother,
at Bruce's funeral, March 1996)

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CHAPTER ONE: INTRODUCTION

All children today, wherever they are born, live in a world with AIDS. One thousand children, mostly in the developing world, become infected every day. One million children are HIV positive or have AIDS. Since the beginning of the pandemic, three million children have developed AIDS, and most have died. Nine million children have lost their mothers through AIDS. (Partners Around the World International, 1997, p. 6)

There are increasing numbers of Canadian children with HIV/AIDS in attendance at schools across the country. Yet, many schools are not aware of the presence of these children because a large number of caregivers exercise their right not to disclose the health status of their children. These caregivers are not confident of the schools' ability to deal effectively with paediatric HIV/AIDS in the classroom. Schools may recognize many of these children as special, but they may not fully understand the complexity of their situation. Children diagnosed with HIV/AIDS experience a myriad of psychosocial and neurological difficulties associated with infection, difficulties which have implications for the educational programming of infected children.

In the following chapters, I review studies of how HIV/AIDS affects children's physical, neurological, and psychosocial development. Specific gaps in the available research are identified, showing that affected families have rarely had a direct voice in the world of professional/academic research, and that quality of life and educational issues for infected Canadian children have been neglected. In response to these research gaps, and

guided by qualitative research methodology, the purpose of this study is 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 in order to emphasize the voices of my participants, those primary caregivers who have first hand knowledge of interacting with schools when caring for a child with HIV/AIDS. Together, and through intimate discussion, we explored the school experiences of families affected by HIV/AIDS. I 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. The objectives for this process of inquiry were (a) to identify the perceptions and experiences of the primary caregivers regarding interaction with the schools which have had an impact on both the child and their family's quality of life; and, (b) to clarify how schools can best prepare to meet the needs of children with HIV/AIDS and their families, and to accommodate and provide support for them.

In collaboration with the HIV programme at the Hospital for Sick Children in Toronto, 17 primary caregivers (i.e., mothers, fathers, grandmothers, uncles, foster parents) of infected children were interviewed at a location of their choice, in order to gain a better understanding of the school experiences of children and families affected by this virus. These caregivers resided in either Southern Alberta or Southern Ontario. They were from varied socio-economic and ethnic backgrounds. Although the stage of disease progression was often discussed, the mode of infection was not considered important to this discussion and was therefore not a focus of inquiry. Some caregivers, however, chose

to spontaneously disclose this information. Families were also invited to share their recommendations for school systems so that, in future, schools may be better able to accommodate these children. This research material will contribute to the interdisciplinary foundation of knowledge in this area, and provide direction for both national policy development and educative programming concerning paediatric HIV/AIDS in Canadian schools. When we are able to fully understand the lived experience of families with HIV/AIDS, we will be in a better position to address their needs.

In chapter one, I discuss the pathology of the AIDS virus and its modes of transmission. I also critically review the available research and the current school situation, highlighting the need for further research in educational areas.

Pathology of the HIV Virus

The human immunodeficiency virus (HIV) contaminates the cells of the human immune system by transcribing its ribonucleic acid (RNA) into the host cell's deoxyribonucleic acid (DNA). The resulting infection changes the configuration of the cell and forces infected cells to produce additional HIV virions. These virions spread through the body like dominoes, constantly adapting to the host's natural defenses and killing the body's immuno-cells. The end result is the complete decimation of the immune system. The body becomes defenseless against communicable diseases such as pneumocystis carinii pneumonia, cytomegalovirus, mycobacterium avium, herpes zoster and herpes varicella, and to certain cancers such as Kaposi's sarcoma (Beardsell, McKinnon, Meneilly, & Moody, 1995; Chaisson, Gallant, Keruly, & Moore, 1998; Stites & Terr,

1991). These opportunist infections, which ordinarily are easily resisted by healthy individuals are potentially deadly to people infected with HIV. The diagnosis of acquired immunodeficiency syndrome (AIDS) is usually made at the chronic onset of these opportunistic infections (Beardsell et al., 1995; Bruder, 1995) .

In adults, the time period required for HIV to progress to AIDS varies greatly, sometimes taking in excess of 10 years, depending on the individual's prior health and response to drug treatments. Some drugs act by hindering HIV's ability to transcribe its RNA onto the host cell's DNA, while others assist by boosting immuno-strength and treating the opportunistic infections (e.g., anti-bacterial and anti-fungal medications). Consequently, these treatments help to ward off infection and to slow down the replication of HIV. New drug treatments, such as the "AIDS cocktail," work by combining different protease inhibitors, further checking the ability of the virus to spread. The overall improvement in HIV/AIDS treatments has resulted in infected individuals staying healthy longer (Palfrey et al., 1994; Beardsell et al., 1995; Bruder, 1995).

In children, however, the situation is more complex. Most children are infected by their mothers peri- or post-natally (Beardsell et al., 1995; Bruder, 1995) and do not have the chance to develop their own immune system. In the past, many such children have developed opportunistic infections during their first two years of life and died soon after (Meyers, 1994). However, as children are responding well to the improved HIV/AIDS treatments, they too are now living much longer (Beardsell et al., 1995; Bruder, 1995). Boland and Oleske (1995) describe the ever-increasing chronicity of HIV infection in children:

The chronic nature of pediatric HIV infection is being increasingly recognized with advances in treatments and prolonged survival of children. Although there are a significant percentage of children who develop disease [i.e., full-blown AIDS] early in life and have a poor prognosis, with survival of only a few years, the survival of the group as a whole is much longer. In one large prospective study, it was determined that the cumulative proportion surviving at the age of 9 years was 49.5%, with a median survival of 96.3 months (Tovo et al., 1992). Of 202 living HIV-infected children currently being followed at the Children's Hospital AIDS Program (CHAP) in Newark, New Jersey, 96 are over 6 years old and 56 are over 9 years of age. (p. 26)

This increased life-span of children with HIV is not without complications. HIV infection can have a devastating effect on the human brain and central nervous system. In fact, it is estimated that up to 90% of HIV infected children suffer from neurological disorders (Hanna & Mintz, 1995). In most cases, HIV-related encephalopathy (neurological impairments affecting physiological and psychological functioning) is more pronounced in children than in adults (Klindworth, Dokecki, Baumeister, & Kupstas, 1989). Moreover, many children with HIV/AIDS also suffer from serious psychosocial stressors. These various risk factors have a serious impact on the developmental pattern of children infected with HIV/AIDS.

Modes of Transmission

Health Canada (1997a) documented the various ways HIV/AIDS can be transmitted, including sexual contact, injection drug use, receiving infected blood or

clotting factor, perinatal transmission, and occupational exposure. McIntosh (1994) described the estimated risk through the various modes of transmission. Receiving tainted blood products or organs was considered an extreme risk, perinatal transmission was considered a very high risk, sharing needles was considered a high risk, sexual contact was considered a moderate to low risk, and occupational exposure was considered a low to very low risk. To illustrate, McIntosh described how a needle stick from an HIV-infected patient resulted in infection in hospital workers only 0.4% of the time. Much of the concern, and perhaps even hysteria, regarding children with HIV/AIDS in school settings, as is discussed below in chapter two, centers around the risk of transmission to other children as well as to school personnel. If only 0.4% of hospital workers who have had direct blood to blood contact became infected themselves, it is evident that the risk of casual school contact is minimal. Moreover, risk of transmission in occupational settings can be well managed with the consistent use of universal precautions (established procedures for dealing with blood and other bodily fluids, the most notable feature being the use of rubber gloves). These precautions have been developed, and their use required, by federal Ministries of Health. They are used for the management of infection of all blood-borne viruses (i.e., the hepatitis strains), not simply HIV. Health and safety personnel at school boards are often given the responsibility of ensuring the use of universal precautions among teaching and support staff.

Current School Situation

My own recent experience teaching at a school board just north of Toronto, where, according to Health Canada (1997a), there is a high incidence of AIDS, indicates a general lack of preparedness in the educational community for paediatric HIV/AIDS in the classroom. For example, I observed that the use of universal precautions is not always consistent. At my former school, teachers were instructed in the use of universal precautions, but they did not always use them, nor was their use strictly enforced by school administration. Moreover, rubber gloves were not always readily available. At the elementary school level, there was a paucity of educative materials available to both staff and students regarding HIV infection. However, I was aware that the high schools had more information available. I did not have the opportunity to attend an HIV-related professional development activity, and the few suspected cases of paediatric HIV infection in neighboring school districts were informally discussed with feelings of alarm among teachers in the staff room. As the special education teacher, I would have been involved in the educational programming of these children. However, I was never informed of the school board's policy regarding paediatric HIV/AIDS. In fact, I did not even realize one existed. I have since been invited back to my school board to consult on matters relating to paediatric HIV/AIDS and, when openly discussing the issue, it is evident that there is still limited information and awareness about HIV/AIDS among teachers, administrators, and experts in special education.

The lack of security around confidentiality is also of considerable concern. I was informed that the HIV diagnosis of students whose families had chosen to disclose the information to the school district was recorded in the central computer data base and was readily accessible to support staff around the county.

My experience is congruent with that of other clinicians and researchers around the country who work with children with HIV/AIDS. They have observed inconsistent levels of knowledge and support in Canadian schools, and strongly encourage Canadian research endeavours in this area (D. DeMatteo, personal communication, May 9, 1997). In fact, recent Canadian psychosocial research has identified school-related issues to be a priority (Salter Goldie, DeMatteo, King, & Wells, 1997). Those clinicians and researchers working in this field (i.e., social workers, psychologists, physicians, etc.) acknowledge that most schools address HIV/AIDS prevention in health class, and that some schools have encouraged staff education. However, few schools have created an open atmosphere of trust whereby partnerships with affected families are facilitated. Moreover, policies regarding children with HIV/AIDS in the classroom are neither well defined, nor well communicated (Peterson & Brofack, 1997). Consequently, many families choose not to share their HIV/AIDS status with schools. A large proportion of schools may not be aware of infected children in attendance and of the related need for policy development and educative programming. It is clear that both the teaching community and the wider community need more information about the risk and management of HIV/AIDS transmission, as well as about the more general issue of paediatric HIV/AIDS in the classroom. In fact, the current study was a direct response to a need defined by

practitioners in this field at the Hospital for Sick Children in Toronto. It allows affected families to anonymously communicate their experiences and needs to the larger education community.

Available Research

To date, much of the research on HIV/AIDS has been conducted in the United States and has focused on modes of infection, disease pathology, pharmacological treatments, finding a cure and/or vaccine, and prevention of infection (Reidy, Taggart, & Asselin, 1991). There has also been research concerning the cognitive and physical implications of the disease and the side effects of medications used in treatment (Beardsell et al., 1995; Boland & Oleske, 1995; Cullington, 1989; Hanna & Mintz, 1995). This research has yielded important information and has clearly demonstrated that HIV/AIDS has a serious impact on the developmental trajectory of infected children (Klindworth et al., 1989; Cohen, Papola, & Alvarez, 1994). Much has been learned in the bio-medical area of HIV/AIDS, and this knowledge has led to significant progress in forms of treatment (Boland & Oleske, 1995). However, around the world, relatively little empirical work of a psychosocial nature has been carried out. What we do know about the psychosocial implications of paediatric HIV/AIDS has been documented primarily by health care and school professionals, but affected families have rarely had a direct voice in the world of academic/professional research. Moreover, there is a paucity of research, especially in the Canadian context, regarding educational and quality of life issues of infected children and affected families (Peterson & Brofack, 1997; Slater, 1989).

In chapter two, the most salient research and other literature relating to educational and quality of life issues of infected children and affected families is reviewed. The selected research covers work by educators, psychologists, social workers, and medical practitioners. Special emphasis is placed on discussion surrounding the right of children with HIV to attend school and their right to privacy. This review covers both Canadian and international materials.

CHAPTER TWO: LITERATURE REVIEW

Canadian Demographics and Epidemiology

According to Health Canada (1997a) there have been 15,101 confirmed cases of men, women, and children who have been diagnosed with or have died from AIDS. This number does not include those with HIV infection. Further, Health Canada acknowledges that there is a significant reporting delay, with one case on record having been delayed for 13 years before being reported. Health Canada has suggested that it would be reasonable to add a 15% correction factor to account for this reporting delay. That correction would bring the cumulative AIDS estimate to 21,620 individuals, with the majority of cases reported in Ontario, Quebec, and British Columbia.

While Canadian men make up the majority of diagnosed AIDS cases accounting for 92.5% of the current total, Health Canada (1997b) reported that "the total number of AIDS cases among adult women (delay adjusted) has increased from an average of less than 10 cases per year in the 1980s to nearly 170 cases per year in 1995-96" (p. 1). From a paediatric perspective, this statistic is particularly alarming since at least 78% of paediatric AIDS cases can be attributed to perinatal transmission (Health Canada, 1997c, 1997d).

Health Canada (1997d) described this mother to child transmission as follows:

Perinatal (or vertical) transmission of HIV is the transmission of HIV from an HIV infected pregnant woman to her newborn child. Transmission can occur during gestation (in utero), during delivery, when the fetus makes contact with maternal blood and mucosa in the birth canal, or after delivery, through breast milk. Therefore, women of childbearing age (15-

44) are of particular importance since they may transmit HIV infection to their newborn children. (p. 1)

There are currently 158 children (delay not adjusted) in Canada who are known by Health Canada to have been diagnosed with or died from AIDS. Many more are thought to be infected with HIV. Although specific pediatric estimates are not available, a Health Canada report (1997b) estimated that by the end of 1996 "a cumulative total of 50,000-54,000 Canadians had been infected with HIV since the onset of the epidemic and that at the end of 1996, 36,000-42,000 Canadians were living with HIV infection (including those living with AIDS)" (p. 2). Importantly, this same report acknowledged that HIV infection was "especially" increasing among women.

Encouragingly, Health Canada (1997a) stated that the total number of AIDS cases is on the decline. This decline is partially attributed to improved medical treatments. People with HIV are living longer without symptoms, and the diagnosis of full-blown AIDS is occurring less often. HIV/AIDS is appearing more as a chronic than a terminal illness. Figure one compares the total number of HIV cases with the total number of diagnosed AIDS cases in Canada, since the onset of the epidemic (approximately 1979) to the end of 1996 (numbers provided by Health Canada, 1997a, 1997b).

The changing demographics mean that a significantly increased number of children attending Canadian public schools will either be infected with, or affected by, HIV/AIDS. (It should be noted that throughout the dissertation, the term "affected by HIV/AIDS" is used to describe children who belong to a family where an immediate family member is infected with the virus.) With the complex pattern of HIV/AIDS infection in children,

educators will need to understand the developmental impact of the disease in order to create the optimal learning environment. A review of the pertinent literature on the cognitive abnormalities and psychosocial factors associated with paediatric HIV/AIDS is provided in the following section.

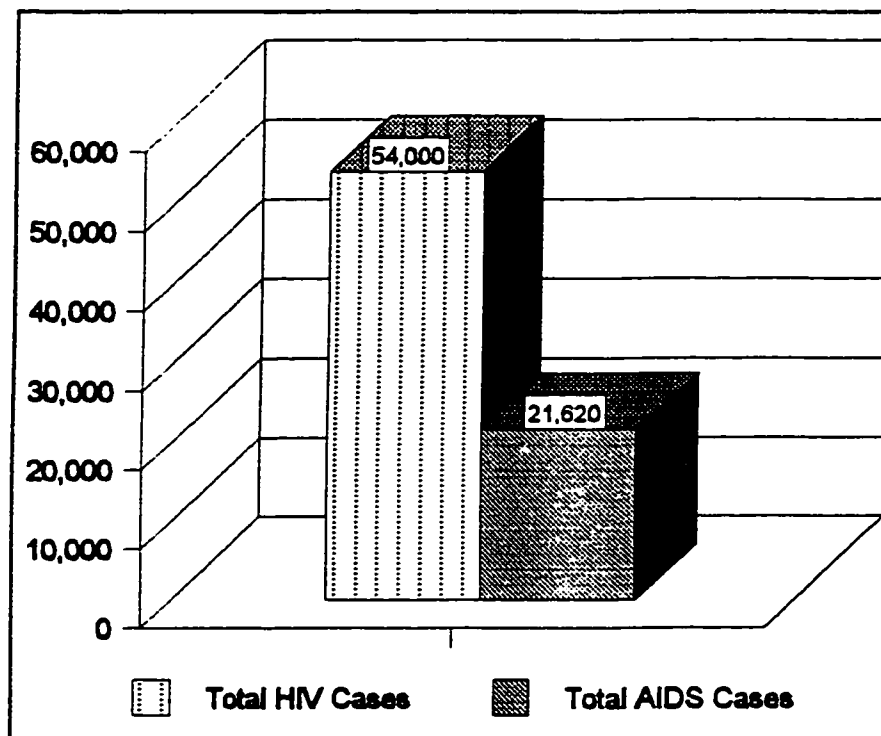


Figure 1. Comparison of the total number of reported HIV cases with the total number of diagnosed AIDS cases in Canada since onset of the epidemic (approx. 1979). Figures provided by Health Canada (1997a, 1997b) compiled to the end of 1996.

Cognitive Abnormalities Associated With Paediatric HIV/AIDS

Developmental abnormalities have been widely investigated in the field of paediatric HIV/AIDS. Besides fatally weakening the immune system in many infected individuals (especially children), HIV systematically attacks the brain and central nervous

system (Meltzer et al., 1998). Often, neurological signs are the first indication of HIV infection in children (Klindworth et al., 1989). The resulting neurological impairment, which can severely affect both physiological and psychological functioning, has been termed "AIDS dementia complex" or "HIV encephalopathy" (Spiegel & Mayers, 1991). In outlining the seriousness of this cognitive deterioration, Klindworth et al. suggest that "HIV-related neurological impairments and concomitant developmental disabilities are likely to present major societal problems. The education community must prepare to address AIDS as a complex bioecological problem with many associated and pragmatic issues" (p. 291).

Children who suffer from HIV-related encephalopathy present neurological impairment ranging from mild to severe and from static to progressive (Hanna & Mintz, 1995). Impairment tends to worsen with the progression of the disease. The types of dysfunction noticed by researchers and health care providers include: brain growth abnormalities, failure to achieve normal developmental milestones, loss of previously acquired milestones, mental retardation, soft signs (i.e., lack of coordination and balance, slight tremors, right/left confusion), and psychological disturbances (Hanna & Mintz, 1995). The specific constellation of neurological symptoms in infected children varies greatly. Concomitant risk factors, including poor nutrition and drug addiction, may also confound the situation and each child presents a unique picture (Meltzer et al., 1998). Consequently, involved practitioners need to constantly assess the individual child's cognitive abilities and plan remedial programmes accordingly (Diamond, 1989).

Neurological Research

Seven pertinent research studies were located and reviewed. Researchers affiliated with the Albert Einstein College of Medicine in New York are leaders in AIDS research, a reflection of the fact that approximately one in every 43 infants in the Bronx, New York, is born to an HIV-positive mother (Diamond, 1989). As such, four of their studies take prominence in this review. An additional American study and two European studies were also considered. Unfortunately, no comparable Canadian studies are available.

In one of the first studies of this population, Ultmann et al. (1985) in the Division of Pediatric Immunology at the Albert Einstein College of Medicine in New York, examined the symptomatology of 16 children with HIV/AIDS. The nine male and seven female children ranged in age from six months to six years. All but one of the children were born to mothers identified as engaging in high risk behaviors (i.e., IV drug use or acknowledged sexual promiscuity). At the onset of this ongoing study, a detailed medical history was obtained for each child and as the study progressed, the children were evaluated at intervals of one to three months using a uniform protocol of standardized achievement and intelligence tests. The results indicated that neurological functioning deteriorated with the progression of the disease. According to Ultmann et al. following the diagnosis of full-blown AIDS, "none of the children attained age-appropriate language and motor milestones. Three patients with AIDS actually lost milestones following the onset of opportunistic infections" (p. 566). Ultmann and colleagues go on to explain that "none of the AIDS patients was of normal intelligence and only one of seven patients tested as high

as the borderline range of intelligence; two were mildly retarded, and four were moderately to severely retarded" (p. 566).

In a follow-up study, again consisting primarily of case histories and cognitive testing, Ultmann et al. (1987) discovered that five children had died since the previous assessment and that the remaining 11 children demonstrated an inconsistent developmental pattern. Some children had progressed positively, some were static, and some had deteriorated. However, Ultmann et al. stated that "prognosis was poorest in those children showing a progressive neurological course" (p. 663). Due to the variable neurodevelopmental course, these authors stressed the need for individually tailored rehabilitation intervention.

Diamond et al. (1987) conducted a similar study following the developmental paths of 12 children ranging in age from three to nine years. Although the gender of these children was not given, it was mentioned that five of them were Black and seven were Hispanic. All of the children were from low socioeconomic status homes, and each had at least one parent belonging to a high risk group. As with the Ultmann et al. studies (1985, 1987) a detailed medical history was obtained for each child at the onset of the study, and the children were continuously evaluated using a uniform protocol, including standardized achievement and intelligence testing. In addition, and adding significantly to the results of the research, the researchers were able to perform computerized axial tomography (CAT) scans on seven of the 12 children.

The results of the intelligence testing placed two children in the mildly retarded range, six in the borderline range, and four in the average intelligence range. Specific

testing results showed that "visual-spatial perceptual based functioning was found to be more impaired than were abstract reasoning and verbally mediated skills in six (50%) of the patients. This pattern of impaired information processing was found irrespective of overall cognitive status" (Diamond et al., 1979, pp. 245-246). Abnormalities of gait and fine motor coordination were also observed, and the CAT scans showed "progressive cerebral atrophy and white matter low attenuation as well as calcification of the basal ganglia in cases clinically presenting with either rapidly or indolently progressive clinical encephalopathy" (p. 253). In observing the diverse developmental trajectories among the children, Diamond et al. (1987) also recommended individually tailoring rehabilitation intervention programmes: "These children will require frequent assessment in order to plan for their educational needs. Programming must take into account the particular patterns of deficits along with concomitant strengths" (p. 254).

Beginning in July 1983, Belman et al. (1988) followed the developmental patterns of 68 children infected with HIV/AIDS, using a similar approach to Diamond et al. (1987). Of these samples, 40 males and 28 females, 63 had at least one HIV-positive parent, while three children had received tainted blood during a transfusion. Thirty-four of the children died before the conclusion of the study, demonstrating a pattern of death occurring between one and 23 months after the onset of neurological deterioration. Belman et al. concluded that central nervous system dysfunction was a very common finding in symptomatic children, occurring in 61 of the 68 children studied.

The European community has also been profoundly affected by the AIDS pandemic (Houweling et al., 1998). Consequently, in the late 1980s, scientific

representatives from various European countries carried out an extensive review, in the same manner as the New York studies, of the developmental patterns of 203 children born to HIV-positive mothers. Thirty-nine of the subject children were HIV-positive, while 164 were antibody-negative. The findings of this "European Collaborative Study" (Cogo, Laverda, Ades, Newell, & Peckham, 1990) indicated that the neurological impairment of HIV infected European children was less severe than that reported in the United States. Fewer than 30% of the children with full-blown AIDS demonstrated neurological deterioration attributable to the HIV infection. In pointing out the inconsistencies between the American and European studies, the authors offered the following statement: "It is not yet clear whether this is a result of methodological differences in patient recruitment, to different viral strains, to other cofactors or to the level of social and health care available" (p. 406).

A subsequent European study yielded similar results. Tardieu et al. (1995) investigated a group of 33 vertically infected children who were being treated at a leading children's hospital in Paris. To be eligible for this study, the children had to be born to an HIV infected woman before August 31, 1985. The school records of the children were examined and psychoeducational tests were administered to 24 of the participants. (The caregivers of the remaining nine children refused formal testing, but allowed clinical and academic evaluation.) The test battery included special French language achievement tests, the Stanford-Binet Intelligence Test (3rd Revision), the Bender Visual-Motor Gestalt test, as well as selected subtests of the Wechsler Intelligence Scale for Children – Revised (French Edition). The majority of the children (N=22) demonstrated average school

performance, and the average intellectual quotient was within the average range (95 ± 11). However, 54 % of the children demonstrated below average results on the subtests which measured visual-spatial ability and time-orientation, and 44% of the children had speech-language difficulties. The overall results of this study support the earlier European study's claims that, in comparison with European samples, American children suffer from more severe neurological impairment. It is significant to note, however, that of the 57 children originally eligible for this study, only 33 were able to participate. There is some question as to whether the study results would have been significantly different, had all 57 eligible children been able to participate.

In a recent North American research article, Cohen, Papola, and Alvarez (1994) carried out a retrospective examination of 69 school-age children who were being followed by the Developmental and Family Services Unit at the Albert Einstein College of Medicine. Ninety-four percent of this predominantly male cohort, with ages between four and 14 years, were from either Black or Hispanic ethnic heritage and only 36% of the participants lived with a biological parent. The majority of the remaining children were living in foster care. The older age of some of the participants is encouraging, reflecting the benefit of improved drug therapies. This retrospective study suggested that cognitive impairment was more the norm than the exception for these children. Fifty-nine percent of the participating children demonstrated intellectual functioning in the borderline to severely mentally retarded range, with an additional 16% in the low average range. Fifty-seven percent of the children were being schooled in special education settings.

Cohen, Papola, and Alvarez (1994) also focused on some of the key benefits of drug treatments. Specifically, they noted that neurological deterioration appears to be inhibited by chemotherapeutic agents such as azidothymidine (AZT) and dideoxyinosine (ddI). In fact, in a review article, Cullington (1989) describes the power of these drugs to "reverse dementia in children" (p. 21). Although the toxicity of the drugs has put a limit on their use, the findings are encouraging for those children able to gain consistent access to drug treatments.

In conclusion, the results of the seven studies reviewed indicate that children with HIV/AIDS present a varied picture of neurological impairment, with the most severe pattern of disability possibly occurring in the United States. For the vast majority of infected American children, serious neurological deterioration is characteristic of the disease process. However, the validity of these results is hampered by restricted regional representation. We know a great deal about infected children in New York State, but relatively little about infected children in other areas of the United States and North America. What is the complete picture of neurological deficits for these children? Furthermore, we know that, especially in the United States, many children with HIV/AIDS have been exposed to concomitant risk factors. For example, a large proportion of infected children are born into highly impoverished environments. Their mothers are often IV drug users, and prenatal care can be exceedingly poor (Hopkins, 1989). Consequently, many infants are born malnourished and addicted to drugs. If they remain in the custody of their biological parents, early childhood health care may be

inadequate. It is difficult to ascertain, therefore, how much of the cognitive impairment is due to the HIV infection and how much is due to the surrounding risk factors.

In addition, it appears that no paediatric research has yet been published which outlines the cognitive abilities of infected children who are taking the "AIDS cocktail." The combination of protease inhibitors found in the "AIDS cocktail" has a profoundly positive impact on the overall health of infected individuals who are fortunate enough to gain consistent access to these medications (Palfrey et al., 1994; Beardsell et al., 1995), a fact that could very likely translate into less cognitive impairment.

Although these studies effectively review the neurological pathology caused by HIV in children, they offer little in the way of practical pedagogical recommendations. Specifically, how will these neurological implications affect the HIV positive child's ability to learn and apply new educational concepts? Given the specific pattern of neurological deficits, what is the most appropriate way to teach these children? A bridge between science and practice is needed in order to meet the real-life needs of infected children. Canadian neurological research studies would be particularly useful in order to accomplish this goal in the Canadian context.

Psychosocial Factors Associated With Paediatric HIV/AIDS

The literature reviewed indicates that many, if not most, children with HIV/AIDS in the United States suffer from some sort of associated neurological impairment, and that this impairment has an impact on their development pattern. However, the literature also clearly indicates that virtually all of these children suffer from various psychosocial

stressors and that these risk factors also have a significant impact on their developmental patterns. In this section, the most recent literature concerning the psychosocial aspects of paediatric HIV/AIDS is reviewed, including two recent Canadian research studies which focus on this topic.

Impact on the Family

When examining the psychosocial impact of paediatric HIV/AIDS, it is necessary to examine the impact of the disease on the whole family. As mentioned earlier, most children with HIV/AIDS have contracted the virus from their mothers. This fact indicates that HIV will potentially have a significant effect on each member of the family, and thus the psychological and social strain of the disease will be felt by the entire family. This point is made by Mangos et al. (1990) in their review of the psychosocial impact of paediatric HIV/AIDS:

This disease has had profound impacts on the lives of the patients, their families, and the society in general. In the case of pediatric AIDS, the impact on the patient and his or her family are virtually inseparable ... the HIV epidemic, when it touches the life of a family by affecting an infant or child, challenges the family's structure and function as a unit. While this is true for any chronic disease affecting a child, it is particularly taxing in the case of pediatric AIDS because of the incurable, fatal nature of the disease and its association with societal stigmatization and intrafamilial psychological repercussions. (p. 40)

The familial patterns of children with HIV/AIDS demonstrate many risk factors are in place before the HIV infection. For example, there is an over representation of families

from disadvantaged backgrounds – especially in the United States (Pequegnat, & Bray, 1997; Myrick, 1998). Many of these families are impoverished and belong to an ethnic minority that may suffer from various forms of discrimination. Some of the mothers have turned to prostitution as a means of economic survival and some have also turned to intravenous (IV) drug use as a way of numbing the painful reality of their lives (Mangos et al., 1990). These families are then additionally burdened with HIV/AIDS. Most do not have the economic resources needed to ensure proper health care, nor do they have an extended family network to turn to in times of distress. The addition of the social stigma associated with HIV/AIDS makes it clear that many of these families are among the most marginalized in our society.

Attachment, Separation, and Loss

The situation for socially/economically marginal families becomes even more complex with the arrival of an HIV infected child. As Reidy, Taggart, and Asselin (1991) point out, "the child who is HIV positive, in his need for normal human nurturing and for the care necessitated by his illness, becomes doubly dependent and the natural caregiver who assumes his care becomes doubly burdened" (p. 331). Those families with previous burdens, weak support networks, poor coping strategies, and limited economic resources are required to care for some of the most needy of children. For many families, the situation is simply overwhelming. As Belfer, Krener, and Miller (1989) describe, the consequences of familial infection can be most devastating for the children:

The lives of these children are frequently complicated by the death of one or more parents or the presence of such active parental illness that their parents are unable to care for them. In some instances, the same circumstances that have led the mother to become HIV-positive have undermined her child caregiving capacity. This further leaves the child "at risk" emotionally. The stigmatizing aspect of AIDS complicates the development of alternative care programs such as foster care or even institutional care. (p. 462)

Belfer, Krener, and Miller (1989) state that many infected parents are devastated by their illness and life circumstances and are consequently not able to care for their children. These children are then cared for by extended families and/or social services (i.e., foster care). For many, the pattern of care is inconsistent. The child's ability to form a healthy attachment with a primary caregiver is often hampered. As the literature on attachment indicates, the absence of secure attachment may have a serious impact on the child's overall psychological functioning:

Throughout his writings on separation and loss, Bowlby (1969/1982, 1973, 1980) argues that, when faced with separation from their primary caregiver, children experience anxiety. In cases of prolonged or sustained loss, an intense mourning process, with its socioemotional, cognitive, representational, and biological components, ensues, and if continued beyond the normally expected period of grieving, is viewed as a reflection of an unresolved loss. Without the presence of a secure internal representational model of the primary caregiver, Bowlby believes that any loss would be experienced as paramount In terms of the development of internal representational models, the psychological unavailability of parents for long periods can be viewed as a powerful influence in shaping

expectations that attachment figures are unavailable and the self is unlovable. The implicit communication to the child is that he or she is unworthy of love – worthless and rejected – and that the parent is "lost" to the child. (Cicchetti & Toth, 1995, p. 388)

Anecdotal reports by Melvin and Sherr (1993) in the paediatric HIV/AIDS literature support the conclusion that infected children may suffer from insecure attachment. When describing a child with HIV/AIDS, they report that: "During the hospital stay the child made numerous superficial attachments to whichever adult would give him some attention. When he was re-united with his mother he showed limited emotional pleasure" (p. 38). This pattern of behavior is strikingly similar to the anxious-avoidant attachment style described by Ainsworth, Blehar, Waters, and Wall (1978).

Carlson and Sroufe (1995) indicate that these children:

Show little or no wariness of a stranger and generally are upset only if left alone. Avoidant infants do not show preference for the caregiver over the stranger. Most notably, when the caregiver returns following a separation, these infants fail to actively initiate interaction, are not responsive to caregiver attempts at interaction, and may pointedly look away or turn away from the caregiver. (p. 587)

It is important to note that the child's ability to form a healthy attachment with a primary caregiver may also be hampered by frequent and lengthy periods of hospitalization. Together with the stigma associated with the disease, this pattern may result in severe social isolation. As a result, children with HIV/AIDS, and other members of their family, often suffer from chronic loneliness. They may come to identify themselves as sick and not worthy of friendship:

As such children encounter loss, abandonment, or failure, the negative self-schemata held in memory cause these children to give heightened attention to the negative aspects of these stressful events and to attribute their occurrence to internal, stable, and global characteristics of the self. (Cicchetti & Toth, 1995, p. 395)

Anxiety, Depression, and Grief

It is not surprising to find that there are many references to depression and anxiety in HIV/AIDS literature (Klindworth et al., 1989; Pequegnat & Bray, 1997; Maj, 1998). First, infected families will often suffer from lethargy and other physical complaints which may have an adverse impact on their psychological integrity. For example, due to weakened health, many families with HIV/AIDS have to significantly alter their lifestyles. As a result, many experience feelings of loss. Second, once diagnosed, families are required to address many difficult issues. These issues include: death of themselves and other family members; stress regarding the organization of subsequent living arrangements for their children after they pass away; feelings of guilt for having infected loved ones; anger at family members, friends, and society at large for its lack of compassion; coping with the complications of a chronic illness (i.e., following a complicated treatment regimen); fear of exposing others to contagion; unemployment, financial disaster, and housing problems; and ambivalence centering around disclosure decisions (Friedman & Robertson, 1990; Mangos et al., 1990). These complex issues may create an atmosphere of stress in the homes of families with HIV/AIDS. They may be overwhelmed and view their future as hopeless. Children will not be immune from this stress. Moreover, younger

children may not have the cognitive capacity to fully understand their situation, and may experience confusion, while parents may be hesitant to discuss the situation with older children for fear of overwhelming the child and/or fear of the child sharing the diagnosis with others if the diagnosis has not yet been shared openly with the community (Klindworth et al., 1989; Spiegel & Mayers, 1991). The cumulative effect of these various family problems can be a factor in the psychological functioning of the individual adult or child.

Depressive symptoms in paediatric HIV/AIDS include apathy, social withdrawal, and anorexia (Speigel & Mayers, 1991). As Speigel and Mayers point out, it is sometimes difficult to assess whether the depression results from psychosocial or medical factors:

The relationship between depressive symptoms in physically ill children and true depression is not clear, and depression is in any case notoriously difficult to diagnose in hospitalized and medically ill patients. The depressive syndrome associated with chronic illness may have both psychological and physiological etiologic factors. Among the recognized causes of depressive symptoms are metabolic and endocrine disturbances and a wide variety of medications. Physical pain, prolonged isolation, and family dysfunction may mimic or contribute to depression. (p. 156)

Whether depression is caused by physiological or psychosocial factors, or a combination of the two, it remains clear that children with HIV/AIDS are at psychosocial risk (Maj, 1998). The stress associated with the illness will likely decrease the child's immuno-strength (Kiecolt-Glaser & Glaser, 1987) and thus leave the child even more susceptible to opportunistic infections. Moreover, as it is estimated that 80% of people

with HIV engage in suicidal ideation, it is probable that many older children with HIV/AIDS will either consider or attempt suicide (Krener & Miller, 1989).

In addition to depression, many families affected by HIV/AIDS experience grief. They grieve the loss of their physical integrity and the loss of their future as they imagined it. Many families also mourn the repeated deaths of intimate family members such as spouses and children. This grieving process can be hampered if the true diagnosis is kept secret. Siegel and Gorey (1994) examine the process of grieving an AIDS related death. They state that "the social stigma that has been attached to AIDS is perhaps the most frequently cited factor complicating the work of mourning" (p. S66). The stigma surrounding AIDS often requires families to keep the loss, or the reason for the loss, secret. Many are not able to grieve openly. Doka (1989) has described this phenomenon as "disenfranchised grief," and defines it as "grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported" (p. 311). Siegel and Gorey describe how disenfranchised grief impacts on the mourning process of the whole family:

Disenfranchised grief can exacerbate bereavement by intensifying strong emotional reactions typically associated with bereavement, such as anger, guilt, and depression. In the case of AIDS, family members may feel particular anger at the deceased for having a self-destructive lifestyle and for the potential shame he/she has brought upon the family. Two other factors, ambivalent feelings about relationships and concurrent crises, also tend to complicate the grief work. For example, ambivalence is common between family members and HIV-infected individuals. Whereas the family may love the infected individual and feel a strong sense of obligation to

assist him/her, they may also resent the burden and family disruption imposed by the illness and death. (1994, p. S67)

When children are being cared for by extended family members, they may sense the ambivalence of emotions and stress surrounding AIDS. They too may experience disenfranchised grief, and this experience may impact on their psychological integrity. Once children begin to understand the consequences of their own diagnosis, additional grieving is likely to ensue. The entire situation may present a frightening picture to children, especially if they have witnessed the physical and psychological decline of their parent(s).

Canadian Psychosocial Research

Reidy, Taggart, and Asselin (1991) describe caregivers' perceptions of their own psychosocial needs. A questionnaire designed to describe the perceived psychosocial needs of the natural caregivers of HIV infected children was developed and administered to 30 participants residing in greater Montreal. The participants, including 13 mothers, five fathers, and 12 significant others (i.e., aunt, grandmother, friend) were equally distributed between two ethnic groups: Haitian immigrants and French Canadians. The yearly incomes of the majority of participating families were well below the Canadian average at that time. The results indicated that the primary psychosocial needs assessed by participants included: (a) the need to maintain physical integrity; (b) the need to learn; (c) the need to act according to a set of beliefs and values; (d) the need to communicate; (e)

the need to feel worthwhile and useful; and (f) the need for formal support, support of an emotional nature, and support of an instrumental or functional nature.

The small sample size and the uniqueness of the study population hinder full generalizability of the results. Moreover, given the exploratory nature of the study, and the small sample size, the choice of research methodology may be problematic. By following a more qualitative paradigm, this study could have yielded more rich and meaningful data. This point is further supported by the fact that the open-ended question in the questionnaire identified most of the needs already included in the questionnaire, while also identifying new needs which had not at that time been discussed in the paediatric AIDS literature.

A qualitative research study focusing on the psychosocial impact of HIV/AIDS on families was recently completed by the HIV Research Team at the Hospital for Sick Children in Toronto (Salter Goldie et al., 1997). The purpose of this study was to identify the experiences and concerns of families living with HIV/AIDS, as well as to explore their current and future needs. Using a national network of collaborating researchers, the researchers conducted in-depth interviews with 110 caregivers at 13 paediatric hospitals or AIDS service organizations in eight provinces across Canada between January 1994 and April 1996. The results indicated five major themes which include: (a) the future needs of children, (b) living with uncertainty and coping with stress, (c) complex health and family relationship issues, (d) dilemmas of disclosure, and (e) social and community experiences of families.

The choice of qualitative research methodology allowed for the multiple voices of HIV/AIDS affected families to be heard. Moreover, both the magnitude and the quality of this study provide a strong foundation upon which additional AIDS related psychosocial studies can be based.

In summary, there are many psychosocial stressors ranging from social disadvantages to depression surrounding paediatric HIV/AIDS. These stressors need to be viewed within the context of the whole family to under the true impact on the child. Like the neurological complications accompanying HIV/AIDS diagnosis, these psychosocial factors will have potentially serious ramifications for the developmental pattern of the HIV/AIDS infected child. However, there remains a gap in this area of research. We still know little about the quality of life and educational issues which affect HIV/AIDS infected Canadian children.

School Implications

A key element in the life of most children is school. School is a place where children spend a considerable amount of time, as well as learn, grow, make friendships, and develop an understanding of the world beyond the context of their homes. When considering the needs of children with HIV/AIDS, we must consider their needs when at school. However, the mixing of paediatric HIV/AIDS and school systems has not been an easy one. There have been hot debates surrounding the right of infected children to attend school, as well as their right (and the right of the family) to withhold disclosure of the

diagnosis when in educational environments. In this section, a review of the ethical and legal findings surrounding these two contentious issues is offered.

Issue of School Admittance for Children with HIV/AIDS

As noted previously, recent advances in HIV/AIDS treatments are extending the life expectancy of many children with HIV/AIDS (Belfer, Krener & Miller, 1989), allowing many to survive well into their school-age years. These advances have brought the issue of school admittance to the forefront. The United States, especially New York State, has reacted with violence. There have been incidences where infected children have been banned from school, harassed, and even physically attacked (McNary-Keith, 1995; Murphy, 1990; Slater, 1989). While it may be easy to see how assault and harassment are unethical, the ethics regarding the issue of school attendance are less clear. Considering the high frequency of scraped knees and bloody noses on school playgrounds, should infected children be allowed to mingle with uninfected children? Would healthy children be at risk? According to a 1985 American Center for Disease Control Publication, in the vast majority of cases the answer to this question is an emphatic no: "Based on current evidence, casual person-to-person contact as would occur among schoolchildren appears to pose no risk" (cited in Murphy, 1990, p. 346).

Moreover, according to Section 504 of the 1973 Rehabilitation Act, all handicapped children in the United States are guaranteed full access to federally funded state educational programs. The Education of the Handicapped Act, passed two years later, states that all handicapped children will have "a free, appropriate public education

which emphasizes special education and related services designed to meet their unique needs," and "that the rights of handicapped children and their parents or guardians are protected" (cited in Murphy, 1990, p. 351).

The applicability of these statutes regarding children with HIV/AIDS has been upheld in American court. For instance, as McNary-Keith (1995) explains, the seminal 1986 New York lawsuit "District 27 Community School Board v. Board of Education" established the legal precedent. Based on information from the Center for Disease Control that no cases of HIV transmission have been documented through casual contact, New York City adopted a policy of full educational inclusion for children with HIV. This decision was challenged in court but the Supreme Court of Queens County upheld the policy, stating that the "HIV virus is not transmissible through casual contact in a school" (cited in McNary-Keith, 1995, pp. 74-75). Furthermore, the court also concluded "that students with AIDS are handicapped within the meaning of Section 504 ... [and] that their exclusion from public school would deprive them of a public education" (p. 75). The threat of infection in a school setting was deemed to be so low that the virus is not considered transmissible in these circumstances. Arguments that center around the fear of contagion are not supported by research evidence and therefore should not be used to ban children with HIV/AIDS from school (McIntosh, 1994).

When reviewing the Canadian legal situation, Kelly (1988), a legal theorist, outlines the rights of people infected and not infected with HIV/AIDS. He poses the question: "If there is a pupil or teacher with AIDS in the school, do parents have a right to require that the pupil or teacher be removed from the school?" He answers:

There is no such right. And again, unless the local medical officer of health prescribes otherwise, or unless the patient presents a demonstrable danger to those around him/her, there is generally no reason for removal of the AIDS patient from the school. (p. 84)

Thus, it appears that American and Canadian law uphold the basic right of HIV positive children to free access to public education.

Many theorists have embraced such legislation, arguing that these children have the right to a normal life and that interaction with others is extremely beneficial for their health and development (Lewert, 1988; Kelker, Hecimovic, & LeRoy, 1994; LeRoy, Powell, & Kelker, 1994). As Koop (1987) states:

Our infants and children with this disease must be afforded a normal and dignified life. They must be nurtured, helped to grow and develop, allowed to interact with peers, attend school and encouraged to enjoy and participate in all activities of childhood, despite the probability of a shortened life span. (p. 3)

The arrival of HIV/AIDS infected children in American schools has obliged theorists to develop best practice guidelines. One such set was developed by Dr. Allen Crocker, the Director for the Child Development Center, at the Children's Hospital in Boston. In his guidelines, he outlines the necessity of protecting the privacy and confidentiality of HIV/AIDS infected students in the school setting (Crocker et al., 1994). The premise of protecting the privacy of HIV/AIDS infected children has been supported by many other theorists (Harvey, 1994; Kelker, Hecimovic, & LeRoy, 1994; Lewert, 1988). This idea, however, has exacerbated the public angst with regards to HIV infected

children in schools (Clark & Schwoyer, 1994). Many parents, and at times teachers, feel they have the right to know the identity of students with HIV/AIDS (Harvey, 1994; Lavin et al., 1994). However, the school is often completely unaware of the health status of children in attendance (Lewert, 1988). Either the families have chosen to withhold the information, or children are infected without anyone knowing it. The act of withholding the diagnosis has led several states (including Illinois and South Carolina) to adopt legislation which forces medical professionals to report the status of HIV status of children to school principals (Harvey, 1994). Harvey argues that "these controversial statutes may conflict with other federal and state guidelines and professional ethics" (p. 18). There remains confusion. Should the school know if there is an HIV positive child in attendance?

Establishing a Safe School Environment

Some might argue that, on the one hand, although no cases of transmission have been documented from casual school contact, this does not mean in absolute terms that no cases of transmission have occurred. It would be prudent, therefore, to know the identity of infected children in order to use the utmost caution in their presence. On the other hand, it is known that the virus is difficult to transmit – there is only 0.4% chance of infection for a medical practitioner who is stabbed by a syringe contaminated with HIV tainted blood (McIntosh, 1994). Therefore, theories regarding possible transmission through casual contact are purely speculative (McIntosh, 1994) and contrary to current

medical knowledge. Such ungrounded speculation should not be used to rationalize the invasion of privacy of affected families, a privacy which Lewert (1988) shows to be vital:

The burden of living with an illness over which one has little or no control is compounded by the possible response of society should confidentiality be breached. The wishes of the family regarding the confidentiality of the diagnosis must be viewed as an inviolable right of the family. Often, it is the family's only measure of control over their situation. (p. 350)

Furthermore, since it is impossible to know for certain who is and who is not HIV positive (McNary-Keith, 1995), it would be prudent to use universal precautions with all students. Moreover, using universal precautions with just those students with confirmed diagnosis could inadvertently breach confidentiality. Clark and Schwoyer (1994) outline an incident in Kentucky where just such a breach occurred. Parents accompanying a class on a field trip observed a teacher using universal precautions (i.e., rubber gloves) when aiding a student. This special degree of caution alarmed these parents and they took their concerns to the principal, who attempted to remain within ethical boundaries of confidentiality by refraining from answering all of their questions. The parents subsequently assumed a diagnosis of HIV/AIDS.

A great deal can be learned from this incident. Using universal precautions with just a selected few would seem neither safe nor ethical. Furthermore, the argument that the identity of HIV infected students should be known in order to use extra caution does not hold up under scrutiny. Therefore, there is no logical reason to invade the privacy of these families.

Issue of Privacy and Disclosure

Canadian legislation also supports the protection of the privacy of individuals. When reviewing Canadian law, Kelly (1988) asks: "Do any of [the] pupils, teachers, principals, supervisory officers, trustees, parents, or the public at large, have a need or a right to know of the existence of the disease in a pupil or an employee?" (p. 83). He answers:

(1) Pupils generally have no need or right to know. (2) In the absence of duties *actually* requiring knowledge, teachers have no need or right to know. (3) In the absence of duties *actually* requiring knowledge, principals have no need or right to know. (4) In the absence of duties *actually* requiring knowledge, supervisory officers have no need or right to know. (5) Except to the extent that the report required to be made under the Education Act is brought before them personally, trustees have no need or right to know of the existence of AIDS in a pupil in a school; and, with respect of employees, they have no need or right to know. (6) Parents generally, have no need or right to know. (p. 83)

It would seem that Crocker's best practice guidelines (Crocker et al., 1994), regarding protecting the HIV/AIDS affected family's privacy, are equally appropriate for the Canadian context. An HIV/AIDS diagnosis does not wipe away the right of privacy for infected individuals. In order to ensure the privacy of HIV affected families, it is necessary to pay utmost attention to issues of confidentiality.

In sum, a review of the American literature regarding paediatric HIV/AIDS and schools reveals a rather chaotic sequence of events. The majority of schools were unprepared for its impact and school officials were forced to make difficult policy

decisions in their attempt to balance the right of people with HIV/AIDS against the right of a community to be protected against infection (Pozen, 1995). As indicated above, in a number of cases, children with HIV/AIDS were not allowed to attend school. In response, affected families petitioned the courts to protect their children's right to an education. Precedent-setting cases affirmed that HIV/AIDS infected children posed no significant risk to other children, and therefore, classroom exclusion was unjustified. A review of the pertinent Canadian law supports these findings. Moreover, there have also been questions regarding affected families' right to privacy. Some argue that schools have a right to know the health status of children in attendance, and there have been American laws created in order to enforce this sharing of knowledge. However, others argue that the right of families to privacy is essential and that, with the use of proper precautions with all children, the risk of transmission is negligible. There is no need, therefore, to invade the privacy of affected families. In Canada, the right of affected families to privacy is upheld. A large proportion of affected Canadian families have exercised this right not to disclose their HIV status to schools, and not surprisingly, their reasons for remaining silent center around fears of discrimination and harassment (D. DeMatteo, personal communication, May 9, 1997).

With the right of children with HIV/AIDS to attend school secured, it is essential that schools know how to accommodate the many needs of these children. Surprisingly, however, there is a paucity of literature, especially Canadian literature, which focuses on this area. Because many families choose not to share their diagnosis with schools, schools may not be fully cognizant of the number of infected Canadian children in attendance.

There may be a lack of educational research in this area because schools and other educational institutions misunderstand the need for it. However, if schools developed a more inclusive, respectful, and informed policy towards the acceptance of HIV/AIDS in the classroom, perhaps more parents would be inclined to share the diagnosis with the school. Schools would then be better able to meet the health and psychological needs of everyone concerned. Research is needed in order to help guide this policy and educative programme development.

Summary

The AIDS pandemic has had a profound impact on children around the world. The virus decimates not only the immune system of infected individuals, but their central nervous system as well. Moreover, this disease has affected many people who suffer from other risk factors. The result is a complex pattern of opportunistic infections, neurological impairment, and psychosocial stressors ranging from social disadvantage to depression surrounding paediatric HIV/AIDS. These stressors need to be viewed within the context of the whole family for the true impact on the child to be understood. The sum total of these factors will have a serious impact on the HIV/AIDS infected child's developmental pattern. Educational and psychological professionals will need to understand all of the factors influencing the developmental trajectory of HIV/AIDS infection in children to be able to accommodate their overall needs. Most importantly, this information needs to be disseminated to teachers so that they will be better able to understand the whole picture of the educational and social needs of children with HIV/AIDS in their classes. Research is

needed to delineate the most salient school related needs, from the perspective of caregivers, in order to help guide the development of educational policies and programmes. The development of policies and programmes needs to evolve alongside the changing reality of this epidemic.

In brief, based on the gaps in the research in this area, we need to know the answers to the following questions regarding children infected with HIV/AIDS in Canadian schools:

- 1) What are the school-related experiences of these children and their families like?
- 2) What are the implications for preparing schools and educators to meet the needs of children with HIV/AIDS and their families, and to accommodate and provide support for them?

CHAPTER THREE: METHODOLOGY

Purpose and Objectives of the Research

The purpose of this study is to identify perceptions of primary caregivers regarding quality of life experiences of HIV infected children and their families in Canadian public and separate schools. The objectives are: (a) to identify perceptions and experiences of primary caregivers regarding interaction with schools which have had an impact on both the child's and the family's quality of life; and, (b) to clarify how schools can best prepare to meet the needs of these children and their families, and to accommodate and provide support for them. A qualitative research methodology was chosen since the study's objectives center around the understanding of lived experience within a social context. The primary goal of this research is to discover regularities and discern patterns in the complete conceptualization of human experience. The in-depth understanding gained through this research study will contribute to a foundation of knowledge upon which educators may be able to design both policies and programmes reflecting the lived experience of Canadian families with HIV/AIDS. Specific recommendations from families directly affected is then provided.

The Current Situation with Canadian Schools

As indicated in the literature review, there is a paucity of research focusing on school related issues, especially for Canadian children infected with HIV/AIDS. Moreover, clinicians and researchers working with children with HIV/AIDS observe inconsistent levels of knowledge and support and strongly encourage Canadian research

endeavours in this area (D. DeMatteo, personal communication, May 9, 1997). Those working in this field acknowledge that most schools address HIV/AIDS prevention in health class, and that some schools have encouraged staff education. However, few schools have created an open atmosphere of trust whereby partnerships with affected families are facilitated. Moreover, policies regarding children with HIV/AIDS in the classroom are neither well defined nor well communicated. In consequence, many families choose not to share their HIV status with schools. A large proportion of schools may not be aware of infected children in attendance and of the subsequent need for solid policy development and educative programming. This study derives from a need defined by practitioners in this field and allows affected families to anonymously communicate with the larger education community.

Complications Encountered

Two complications were encountered which also guided the choice of research methodology and its procedures. Without the help of HIV/AIDS community health agencies, it is difficult to locate Canadian families affected by HIV/AIDS. Although the numbers of adults and children infected with HIV/AIDS in Canada is increasing, at present there is not a substantive number of school-age children in Canada infected with HIV/AIDS. The HIV team at the Hospital for Sick Children in Toronto is aware of about 500 Canadian children diagnosed with HIV/AIDS or born to mothers infected with HIV/AIDS. Of that number, a large proportion of the children born to infected mothers will not themselves become infected, and many of the children diagnosed with HIV/AIDS

are not yet of school age. In fact, the Hospital for Sick Children treats only about 30 school age children diagnosed with HIV/AIDS who reside in Ontario (D. DeMatteo, personal communication, May 9, 1997).

Second, most of these families choose to keep their diagnosis confidential and are not willing to share their HIV status with schools or the greater public. Access to participants for the present study was therefore facilitated through the HIV programme at the Hospital for Sick Children in Toronto. This paediatric HIV programme is one of the largest in Canada and has been involved in nation-wide research endeavours. Many of the families involved in this study are also involved in a larger research agenda at the hospital and the hospital HIV team presented the concern that these families may be overburdened by research requests. It was suggested that access be limited to caregivers in one face to face interview, one telephone interview, and additional written correspondence when appropriate. Due to issues of confidentiality, a group or school interview would not have been feasible.

Quality of Life

Quality of life issues are central to this study. When diagnosed with a life threatening illness, people become reflective about life and death. Similarly, when studying this area, researchers can either focus more on life or on death. It is with an emphasis on life that brings me to a focus on quality of life. Children with HIV/AIDS are alive, and I believe that as educators, it is crucial for us to better understand how we can help maximize their life potential. Moreover, from a health perspective, we know that a stress-

reduced environment is highly beneficial for overall well-being (Kiecolt-Glaser & Glaser, 1987, 1992). We must create an optimal environment which fosters positive quality of life experiences for children and families affected by HIV/AIDS.

Quality of life is a difficult concept to understand and there are various definitions for it. However, according to researchers interested in this field, “there is considerable agreement that the term refers to a concept which is multidimensional” (Felce & Perry, 1997, p. 57). Moreover, Felce and Perry explain how the term has developed as a unifying concept as “it may be defined to encapsulate developmental change in the individual and in their identity, the nature of their circumstances, experiences and lifestyle and their perceptions about themselves and their circumstances” (p. 57). How a person perceives the quality of his or her life depends upon various factors, and as such it is rooted in the interplay and unity of these life elements.

My specific understanding of quality of life is grounded in a theoretical framework which focuses on general feelings of satisfaction, well-being, social belonging, and empowerment (Keith & Schalock, 1992). Although multifaceted, Keith and Schalock argue that quality of life primarily involves these four basic areas. They base this theoretical conclusion partly on the quality of life discussions of Epstein and McPartland (1976) and Flanagan (1982). Keith and Schalock have used their theoretical model to develop a “Quality of Student Life Questionnaire” to statistically assess students’ “perceptions of [quality of] life experiences” (Keith & Schalock, 1994, p. 84).

When developing their questionnaire, Keith and Schalock (1994) conducted a principal components factor analysis through the administration of their questionnaire to

400 students. The purpose of this statistical procedure was to test their quality of life model. The results confirmed that the data produced by the completed questionnaire could be reduced to the four underlying factors of satisfaction, well-being, social belonging, and empowerment.

The decision to use this model, however, was not based solely on the value and power of the statistical tests used to confirm Keith and Schalock's conclusions. Rather, I was drawn to the model because of its face value and its simplicity. The idea that quality of life could be discussed within the framework of the four factors made sense to me.

My conceptualization of Keith and Schalock's quality of life model is illustrated in Figure two below. Quality of life is not solely reliant on one area, but rather relies on a fluid and transactional interplay of each individual area. For example, experiencing satisfaction is influenced by both social belonging and well being, and experiencing quality of life is impacted by how much personal freedom, or empowerment, is available. How we experience life is influenced by our quality of life.

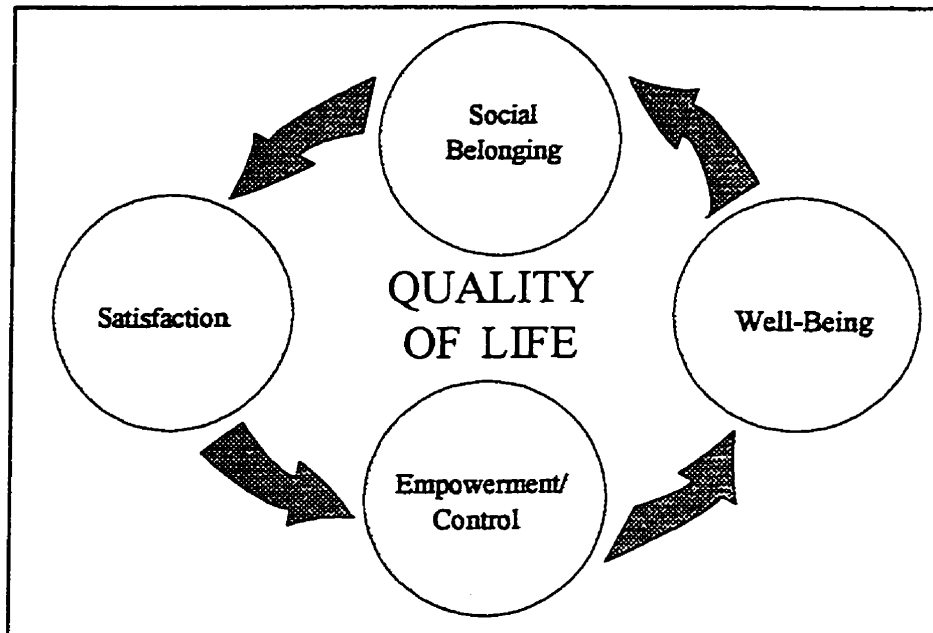


Figure 2. Transactional Quality of Life model based on Keith & Schalock, 1992. It should be noted that Keith & Schalock have not offered a pictorial conception of this model, rather this is my understanding of their theoretical model.

Tenets of Phenomenology

The most central tenets of phenomenology include (a) the importance of the quest to understand human experience, and (b) the importance of knowing experience in a holistic fashion. To illustrate, when addressing phenomenological psychology, Polkinghorne states that true knowledge is based on the understanding of meaningful experience:

Phenomenological psychology is a perspective that acknowledges the reality of the realm of meaningful experience as the fundamental locus of knowledge. It differs from mainstream psychology by holding that human

behavior is an expression of meaningful experience rather than a mechanically learned response to stimuli. (1989, p. 43)

Here we see how meaningful knowledge is embedded in the understanding of human experience. Polkinghorne (1989) elaborates on this idea when explaining the need to understand experience from a holistic perspective. He argues that experience cannot be reduced to itemized parts: "Experience is a reality that results from an openness of human awareness to the world, and it cannot be reduced to either the sphere of mental or the sphere of the physical" (p. 42). Without reduction, experience cannot be measured. In this regard, phenomenological psychology differs substantially from experimental psychology; it is not interested in causal relationships between independent and dependent variables, nor in identifying the average (mean) experience of phenomena: "It [phenomenology] is illuminated through careful, comprehensive descriptions, vivid and accurate renderings of the experience, rather than measurements, ratings, or scores" (Moustakas, 1994, p. 105).

Approaching human awareness from a whole and open perspective is further supported by the work of Colaizzi (1978). He supports these notions when highlighting the need to understand human experience within the context of the world. Contextual understanding is real understanding; context creates meaning. Colaizzi also speaks of wholeness and connectedness: "Human experience is always world-involvement experience ... human existence and the world constitute a unity, a unity so vital and basic that either one is absurd and inconceivable without the other" (p. 54).

Not only do we need to understand the essence of experience, we also need to understand the context of the world in which it took place. This holistic conceptualization

of human experience allows us to create meaning. It is this meaning which creates knowledge, and it is the search for this knowledge which is at the very heart of research.

After developing a complete and contextual understanding of human experience, the purpose of phenomenological research is then to describe this experience, allowing for the creation of knowledge to be documented and shared with others. Unlike other research traditions, phenomenology is committed to descriptions rather than explanations of participants' experiences (Moustakas, 1994). These descriptions are produced through an interpretive process; the researcher gives a part of him or herself to the analysis. The researcher and participant are intimately connected and the experience of expressing is matched by an experience of listening. Knowing is facilitated through this bond, a bond which is as much researcher as it is participant.

Stated succinctly, the purpose of phenomenological research is therefore to produce clear, precise, and systematic description of the meaning that participants and researchers make of lived experience (Cohen & Omery, 1994; Colaizzi, 1978; Haase, 1987; Polkinghorne, 1989; Tesch, 1990). Such research often uses natural language as a medium for data collection and presentation. Researcher and participant engage in intimate discussion, and it is the job of the researcher to create a climate in which full participant expression can take place. Moustakas (1994) describes important aspects of the phenomenological interview:

Often the phenomenological interview begins with a social conversation or a brief meditative activity aimed at creating a relaxed and trusting atmosphere. Following this opening, the investigator suggests that the co-researcher [participant] take a few moments to focus on the experience ...

and then to describe the experience fully. The interviewer is responsible for creating a climate in which the research participant will feel comfortable and will respond honestly and comprehensively. (p. 114)

This intimate discussion is usually recorded, listened to several times by the researcher, and then carefully transcribed. Once the taped interview is transcribed, the researcher systematically and comprehensively searches the written data for themes and patterns of experience. It is a written analysis of these themes, illustrated with the actual words of the participants, which are communicated to the reader (Colaizzi, 1978; Haase, 1987; Polkinghorne, 1989; Tesch, 1990).

It is clear that the qualitative researcher participates actively in the investigation and that data is created through the interaction between the researcher and participant. As such, the process of qualitative research is subjective rather than objective and that each qualitative researcher brings a unique perspective to the data even when studying the exact same participants. As such, reliability in the quantitative sense is not possible in a qualitative study. However, subjectivity does not equate invalidity. Validity or the truth value of a qualitative investigation is subject-oriented (Sandelowski, 1986). As explained by Sandelowski, validity is ensured by the participants' approval of the research results: "A qualitative study is credible when it presents such faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognize it from those descriptions or interpretations as their own" (p. 30).

Given the intimate interaction between researcher and participant, validity is further ensured when the researcher makes clear his or her own entering assumptions.

What the researcher brings to the investigation in way of experience and attitude is salient and should be clearly stated:

Since a major threat to the truth value of a qualitative study lies in the closeness of the investigator-subject relationship, the credibility of qualitative research is enhanced when investigators describe and interpret their own behavior and experiences as researchers in relation to the behavior and experiences of subjects. (Sandelowski, 1986, p. 30)

Through an honest and open interchange of ideas and experience, the researcher and participant begin a journey towards understanding the meaning of human perceptions and experiences. In essence, knowledge is created.

Choice of Research Methodology

A research methodology informed by phenomenology allowed me the privilege of beginning a journey towards a meaningful understanding of the lived experiences of this study's participants. I began each interview with the question: "What is school like for you and your family?" This uncomplicated question usually sparked an intimate conversation allowing a glimpse into the meaning participants make of their families' lives. I followed up with open-ended questions pertaining to the various areas relating to quality of life. These questions formed an interview guide (see Appendix A). However, I followed up with questions only after participants had as much time as needed to fully express their experiences of school from their own perspective. If a participant touched on one of the research question areas without prompting, further prompting was avoided. This semi-structured research protocol is in keeping with the tradition of phenomenology:

The phenomenological interview involves an informal, interactive process and utilizes open-ended comments and questions. Although the primary researcher may in advance develop a series of questions aimed at evoking a comprehensive account of the person's experience of the phenomenon, these are varied, altered, or not used at all when the co-researcher [participant] shares the full story of his or her experience. (Moustakas, 1994, p. 114)

Although informed by phenomenology, the current methodology differed slightly from traditional modes of phenomenological inquiry. In keeping with traditional phenomenological inquiry, caregivers were asked to describe their own lived experience when interacting with the school. However, they were also asked to describe their perceptions of their children's experiences. Given the difficulties of gaining access to this special population, I was not able to interview the children themselves in order to understand their own lived experience when at school. Nevertheless, caregivers' perceptions and observations of their children's lives constitute their external reality and the context in which they live and create meaning for their own lives. Caregivers have first-hand knowledge of caring for a child with HIV/AIDS and of interacting with school systems. They are in a key position to better inform schools about school children with HIV/AIDS. Their perspective has, for the most part, been neglected in the studies published to date. Therefore, better understanding of the perspective of caregivers is vital to the development of our knowledge of paediatric HIV/AIDS.

Researchers must work with the realities and limitations of any given situation. Moustakas (1994) clarifies this point:

Every method in human science research is open ended. There are no definitive or exclusive requirements. Each research project holds its own integrity and establishes its own methods and procedures to facilitate the flow of the investigation data. (p. 104)

As such, this study has been guided by the tenets of phenomenology but has had to establish “its own integrity ... methods and procedures to facilitate the flow of the investigation data” (p. 104).

Entering Assumptions

In recent years, a member of my family has been lost to AIDS. There was much secrecy and stigma surrounding the issue and the family experienced shock and pain. I was left feeling a great deal of anger and questioning a society which had caused such profound marginalization toward people affected by HIV/AIDS. As a teacher and school psychologist, I began to think of this particular epidemic from the perspective of children. These thoughts and emotions led me to undertake this research study and have been present during the process of enquiry. As a qualitative researcher, it is important that I clarify my entering assumptions explicitly and they are outlined as follows:

- (1) It is my belief that we are all God’s children and that discrimination toward any person is morally wrong;
- (2) It is also my belief that children are the most vulnerable and disempowered members of our society and they deserve more attention and recognition;
- (3) Children with HIV/AIDS have the right to attend school and to be loved and cared for by sensitive and knowledgeable educators;

- (4) I believe that it is the responsibility of those in positions of power to advocate for a morally responsible society; and,
- (5) Based on my personal experience and a review of the literature, I believe that caregivers of HIV infected children may have experienced a great deal of emotional pain, and that issues related to stigma and discrimination would likely be particularly stressful topics for them to discuss. In consequence, I was prepared to approach these issues with care.

Procedure

I interviewed 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. The purpose of the interviews was to understand the school experiences of these families, to identify issues related to the appropriate management of children and families in public school settings, and to clarify how schools can best prepare to meet the needs of these children and their families and to be able to accommodate and support them.

Contextual Information Concerning Participants

For reasons of confidentiality, precise demographic information regarding the participants will not be given. However, it is important to offer some degree of contextual information and as such this information is offered in a general manner.

If more than one primary caregiver lived in the nuclear family, the families decided who would participate in the study. Most often, I met with natural mothers. However, I

did also have the opportunity to interview a father, grandmother, uncle, and foster parent.

The families were from a variety of socio-economic backgrounds. Approximately two thirds of the families were Caucasian. The remainder were from an ethnic heritage.

Two of the families resided in Southern Alberta: One in an urban setting and the other in a rural setting. The remaining families lived in urban locations in Southern Ontario. Fourteen of these families lived in either greater Toronto or within a two hour drive of downtown Toronto. One family lived an approximate six hour drive away from Toronto.

The children ranged in age from 4 years to 18 years, with the majority of children in the pre- to early-adolescent age range. The oldest child had recently graduated from high school. The medical files of these children were not reviewed. However, information derived from the interviews indicated that approximately one third of the children were in advanced stages of the disease. One child had already died. Most of the children had concurrent health or developmental concerns, such as hemophilia or Down's syndrome. Eleven of the children were male, six were female.

Although the mode of infection to the child was specifically not asked, many of the caregivers chose to spontaneously offer this information. From the information volunteered by the caregivers, it appears that approximately two thirds of the children contracted the virus from a blood or blood product transfusion. It would appear that the remaining children contracted the virus from their mothers at or around the time of birth. Each of the children had lived with the disease for several years. It is significant to note that the representation of children with vertically transmitted HIV/AIDS in this sample

would appear to be lower than would be expected in the general population where most children with HIV/AIDS have contracted the virus from their mothers (Cooper, 1990, Reidy, Taggart & Asselin, 1991).

Pilot Study

Semi-structured interviews were conducted and recorded on audio-cassette with two primary caregivers currently residing in Alberta. Professionals from HIV/AIDS organizations working in collaboration with the Hospital for Sick Children's HIV team introduced me to these families. Someone familiar with the families first discussed the proposed study with them using a prepared letter of introduction (see Appendix B) and then requested permission for me to contact them directly. These interviews were conducted at a location of the participants' choice (i.e., in their homes or in my office). Using the interview guide outlined in Appendix A, these caregivers were asked about their school experiences and about their perceptions of their children's school experiences. Special emphasis was placed on questions about how schools can better prepare to meet the needs of HIV/AIDS infected children and their families.

These taped interviews were transcribed by a private secretary and then partially analyzed for themes and patterns of experience using a protocol analysis procedure influenced by Colaizzi (1978) and Haase (1987). This procedure of analysis included:

- (1) gathering a sense of each protocol's meaning through repeated listening to the interview tapes;

- (2) going paragraph by paragraph and extracting significant statements from each paragraph; and
- (3) formulating statements of meaning and/or themes from these extracted statements.

Themes represented labels of the most central meaning from each statement.

The two transcribed pilot interviews along with my notes and analysis were photocopied and shared with my doctoral supervisor at The University of Calgary. Each step of the data collection procedure and process of data analysis was discussed at length. The interview guide (Appendix A) felt natural to execute, it appeared respectful to families, and it led to meaningful discussions with participants. As a result, it was deemed appropriate to use for the remaining interviews.

Main Study

Using the same interview guide as in the Pilot Study, an additional 15 interviews were carried out with primary caregivers residing in Southern Ontario. Members of the HIV team at the Hospital for Sick Children in Toronto introduced me to these families. Team members (usually social workers or nurses) first discussed the research study with prospective participants using a letter of introduction (see Appendix B) as well as the hospital guidelines for informing parents about the study (see Appendix C). If families indicated interest, their permission was requested for a follow-up telephone conversation. If they agreed, I contacted the prospective participants by telephone in order to supply additional information and to arrange the meetings. As with the pilot study, semi-structured interviews were then conducted and recorded on audio-cassette with these

families at a location of their choice (i.e., in their homes or at the hospital). To conform with protocols of previous research studies conducted by the HIV team at the Hospital for Sick Children, research participants received a small stipend to acknowledge their time and contribution.

These taped interviews were also transcribed by a private secretary and analyzed according to the same procedure outlined in the pilot study section. In order to ensure the truth value of the data analysis, photocopies of the entire transcribed interviews along with my notes and analysis were sent by courier to study participants. A second interview was then conducted by telephone so that participants could provide feedback. During these second interviews, I took extensive notes and added to or modified the data analysis as needed.

After the second interview, a complete listing of themes from each participant was compiled. These lists were enlarged so that the writing was more visible and they were printed out on different coloured paper. Individual themes were cut into strips and sorted into various piles according to their most central meaning. At this point I was able to visually track common themes. It is interesting to note that themes either grouped together or did not fit at all. For example, at the conclusion of this step of data analysis there were a few individual themes (i.e., themes generated from a single interview) which did not fit into the emerging clusters. However, these themes did not appear particularly salient given the context of the interview. The remaining themes grouped together naturally.

At the least, a theme pile would indicate representation of approximately one third of the families interviewed. Often, the smaller piles represented families of a similar background (i.e., families of an ethnic heritage).

The piles represented theme clusters which were labeled according to their most central meaning. Finally, clusters were grouped together into categories. Again, each category included clusters of a similar meaning and categories were labeled according to their most central meaning. This final grouping is primarily for organization purposes. In this dissertation the category names mirror the four cornerstones of the quality of life model discussed, namely socialization, empowerment, well-being, and satisfaction. It should be noted that these names were not artificially imposed. The clusters naturally and logically grouped together in this way.

Tables of themes were produced to organize this data. Once organized, I integrated these themes into an exhaustive description of the experience (i.e., the essential structure of the experience). The essential structure along with the tables of themes were sent to each participant. In a letter to the participants (see Appendix D), I requested their feedback. I also provided each participant with a self-addressed stamped envelope in order to facilitate this communication. Out of the 17 participants, six responded and each response was positive and confirmed stated themes. It is important to note that no participant expressed concern about the comprehensive nature of the final analysis (i.e., none of the individual themes which were omitted caused concern to those participants who replied). Some extracts from this feedback include:

- (i) “Your summary is very concise and accurate. I hope that your thesis will be instrumental in setting school board policies and enabling children to learn in a very positive and supportive manner. Families and children [with HIV/AIDS] deserve the sensitivity of all of society but more definitely they need to see their schools practicing the principles that humanity can learn from.”
- (ii) “I have read over your summary and find everything to be dead on. You really took the care and time to listen to each of us and our needs. Thank you.”
- (iii) “Excellent work Jillian! I agree with your summation completely.”
- (iv) “An extremely comprehensive coverage of the emotional and practical problems we all seem to be facing to different degrees. Thank you for caring. I hope this helps reduce ‘stigma.’ I would like these children to be accepted as any child with another serious illness – with understanding and compassion and above all the total realization that they are and want to be thought to be thought of as an integrated part of their society.”

As I did not want to overburden these families, and as I wanted to conform with the access stipulation by the Hospital for Sick Children, no further contact with the participants was initiated.

Ethical Considerations

Every effort was made to ensure the highest level of ethical practice throughout the study. Ethics approval was obtained at both The University of Calgary and the Hospital for Sick Children (see Appendices E, F, and G). The subjects were informed of a) the aims and methods of the research, b) the detailed nature of their involvement, and c) the possible risks to which they may be exposed (see Appendices H, I, J, and K). Confidentiality was strictly maintained. Pseudonyms or numbers were assigned for all working documents used in the write-up. The only individuals who had access to the transcripts were the investigator and doctoral supervisor. No identifiable information (names, etc.) was included in the transcribed interviews. Tapes and transcripts were kept in a locked file cabinet. No identifiable records were (or will be) published, used for teaching, or presented at scientific meetings. The tapes and transcripts will be destroyed two years after completion of the study.

CHAPTER FOUR: RESULTS

This chapter is organized into three parts. In the first part the essential structure of the experience resulting from the analysis is outlined in text form and then depicted in Table one. This table shows the major categories and theme clusters.

In the second part of this chapter, the various theme categories and clusters are expanded. An at-a-glance table depicting a breakdown of the clusters and themes is offered under each of the categories. Quotes from the transcribed interviews follow and are used throughout to provide the voices of the families. It is important to note that the quotes selected were chosen because they best reflected the identified themes rather than to provide equal representation from the participant pool. Some participants were quoted more than others because of their ability to articulate their experiences. This does not mean that these themes applied exclusively to particular individuals, rather that the individuals quoted expressed their points most clearly. Participant quotes can be distinguished from my own interpretation in that they are either surrounded by quotation marks or indented.

The third and final part of the chapter consists of a listing of caregiver recommendations for school systems. A discussion of this analysis, together with my own recommendations for school systems, is provided in chapter five.

Essential Structure of the Experience

Seventeen families from very different walks of life are connected by a simple reality, the presence of a child infected with HIV/AIDS. The impact of this reality is pervasive and touches all aspects of the lives of these families. Of special interest to this study, is the families lived experience when interacting with schools. What is this experience like for them?

Through intimate conversation, caregivers shared their school experiences. They detailed their social context, and how they and their children related to others. Special emphasis was placed on the adolescent experience. Caregivers described how most children participated in a number of extra-curricular activities and were supported by friendships. However, the physical effect of the disease influenced their social choices. Although many caregivers were socially active, and participated in school events, many more chose to limit this aspect of their lives. They described a centering, a moving inwards toward family priorities. For them, relating to others, meant relating to their families, and specifically to their child with HIV/AIDS. Every day, as they attempt to maximize their life together, they chose to live. Caregivers also spoke of stigma and their striving for normalcy. Their children may be infected with HIV/AIDS, but they are alive and they deserve a normal life.

Choosing to live is an act of personal empowerment, and this general sense of choice and power surfaced many times during our discussions. The choice to tell or not to tell was of tremendous importance. Issues of disclosure affected the life of each and every

family. Oftentimes, this issue even related to discussions with the infected child. Sharing the diagnosis with others is often connected to sharing the diagnosis with the child. Telling is also connected to protecting. Families felt an overwhelming need to protect themselves and others. Sometimes this protection frequently surfaced as the choice not to tell. However, choosing to remain silent can result in a sense of voicelessness. Some families felt as though they were not able to ask about school policies and advocate for change, because doing so would require disclosure. This sense of voicelessness is lessened by participation in research and all families described their support of research endeavours in this area.

Families also described their sense of wellness. This description included moments of anguish and moments of hope. Caregivers told of their agony when they first learned of the diagnosis, a diagnosis which at times also physically implicated the caregivers themselves and other family members. They described the physical and neurological consequences of the illness on their infected child as well as the psychological impact on each member of the family. Whether or not other family members were infected with HIV/AIDS, they too were affected by the illness and many caregivers described connections among the wellness of each family member. Caregivers expressed hope about the improvements in medications and treatments. Many witnessed daily benefits of these medical advances. However, many also described the complexities surrounding medical treatments. Caregivers shared their concern for transmission to others and how they went to great lengths to minimize this risk. They also spoke of the need for, and expectation of, the use of universal precautions.

Families described their sense of satisfaction or dissatisfaction with schools and life in general. Although many families at times experienced genuine happiness, this happiness was viewed as fragile and tentative. They do not know what to expect tomorrow, so they take things one day at a time. Families do know, however, that they are most happy when together. They described strong connections to each other, and how these connections gave them courage and made them strong. When they grew together, they experienced hope and spirituality. Caregivers also discussed their need for human connections with others. Subtle, or not so subtle moments of kindness and compassion from teachers, principals, and friends helped to brighten their days and strengthen their desire to survive.

Families concluded our discussions with recommendations for the school systems. For example, they spoke of the need for effective programme planning in schools, programme planning which would include their children and be sensitive to their educational and psychological needs. They spoke of their need for competent leadership and open and supportive school environments. They described the importance of school in their lives and in the community, and how partnerships between themselves, schools, and community agencies would be beneficial. Most of all, they described the need for sound policy and HIV/AIDS educative programme development, as competence builds trust.

Each of the four main categories, socialization, empowerment, well-being, and satisfaction, are discussed below and illustrated on Table one. Tables two, three, four, and five illustrate the clusters and individual themes which comprise each category.

Table 1

Major Categories and Clusters

Categories			
Socialization (Social Context)	Empowerment	Well-being	Satisfaction
Clusters within each category			
-Interpersonal Relations of Child	-Issues of Disclosure	-Issues of Caregiver Wellness	-Perceptions of Child's Experience
-Interpersonal Relations of Caregiver	-Perceptions of Child Empowerment	-Issues of Child Wellness	-Experience of Caregiver
-Intimacy and the Adolescent Experience	-Empowerment of Caregiver	-Medications and Treatments	-Connective Experiences
-Normalcy	-Protection	-Issues of Transmission	-Human Touch
-Stigma	-Research		-Inner Growth

Note. Each cluster illustrated in this table is comprised of a number of related themes which are further illustrated in tables two, three, four, and five.

Category – Socialization (Social Context)

Relationship issues were central to the lives of families affected by HIV/AIDS.

Whether the relationships centered within the family or outside of it, they were thoughtfully considered and discussed within the context of this research. Families often brought up issues of stigma, and almost every family expressed the desire to keep their lives as normal as possible. For these families, as for most of us, a significant part of living is connecting with others and the quality of the connection affects the overall quality of life.

Caregivers noticed that many of their children's interpersonal relationships were developed at school. Their social development was also facilitated during participation in extra-curricular activities. They described how they and their children related to others in the school and community context. Some families experienced many opportunities for social interaction, whereas others did not. Occasionally families described how the illness created a social barrier.

The socialization category contains five clusters: interpersonal relations of the child, interpersonal relations of the caregiver, intimacy and the adolescent experience, normalcy, and stigma. The themes which emerged from the interview data were arranged within those five clusters and are further illustrated in Table two. They are then discussed and supported by quotations drawn from the interviews with the caregivers.

Table 2

Category – Socialization (Social Context)

Clusters				
Interpersonal relations of child	Interpersonal relations of caregiver	Intimacy and the adolescent experience	Normalcy	Stigma
Themes within the cluster:	Themes within the cluster:	Themes within the cluster:	Themes within the cluster:	Themes within the cluster:
<ul style="list-style-type: none"> - parental concerns & encouragement of child interpersonal relations - active child socialization - socialization & special needs - change in child socialization - limited child socialization 	<ul style="list-style-type: none"> - participation (or lack of) in social activities - involvement (or lack of) in school activities - change in socialization - centering 	<ul style="list-style-type: none"> - parental concerns regarding psycho-sexual development - effect of illness on psycho-sexual development - the experience of growing older 	<ul style="list-style-type: none"> - we are real - need for normalcy - exercising normalcy 	<ul style="list-style-type: none"> - open discrimination - fear of stigma - stigma through lack of knowledge - mode of infection related to stigma - subtle moments - cultural diversity

Cluster: Interpersonal Relations of Child

Children with HIV/AIDS experience a myriad of both positive and negative interpersonal relationships. Many caregivers described the importance of child socialization in the development of positive social skills. In fact, one caregiver described this as the most important aspect of her child's life: "And what we emphasize with [our child] is – it's not the academics – it's the social skills that count the most. Even if you can handle the academics, if you haven't got social skills, you haven't got anything."

Caregivers also described their concerns and worries about their children's socialization. They wondered, perhaps even worried, if their children would experience a sense of belonging if others knew about the illness. This worry included other children as well as the parents of these children. When one caregiver was asked to describe this worry, she replied: "I think it's more of an acceptance thing, like will my child be accepted if they really do know? And will they treat my child the same way?"

Another caregiver detailed how she advised her child to not share his diagnosis with other children. She worried that the other children were not mature enough to handle a situation as serious and complex as having a friend with HIV/AIDS: "I told him not to tell his friends yet because I said they might not understand and they might be frightened and scared and you might lose your friends. You don't know yet, you know."

Some caregivers had these questions answered in a positive way. For example, one caregiver described how her child was emotionally supported by his friends. He chose to share his HIV status with friends, and they stuck with him. "He's very popular which is

quite an interesting situation. I think that has helped him a lot because he has lots of friends and none of them dropped off.”

Another caregiver described how friendships persisted through times of disclosure and how these friendships helped the family: “We’ve had a tremendous amount of support, without anybody running away.”

One caregiver even mentioned unexpected support from children at the school. This caregiver was concerned that her children were not enjoying an active social life, so she went to great lengths to arrange a birthday celebration. Secretly she worried that perhaps not many children would show up. However, and to her surprise, it was an overwhelming success:

I mean, I’ll tell you. I had a birthday party for the kids, both of them last year at McDonald’s Playland. Twenty-four invitations went out. I was expecting maybe six [to come]. Twenty-four invitations went out and twenty-seven kids showed up!

Relationships were especially supportive when the child’s HIV status was not an issue; when friends remained close even after learning of the diagnosis. Caregivers also described how they felt supported by friends when these friends did not gossip about the illness: “In the school we just could tell that the small groups that he was addressing [about his illness] were not reporting back so that it became this overwhelming piece of gossip. It just did not happen.”

When able to socialize in a positive manner, many parents observed their children enjoying school. One caregiver described how interacting with friends gave her child something to look forward to:

Well, he enjoys school. I think he quite enjoys doing a bit of work, if he does it well, but he just loves the social side of school, you know, I mean, it was – the end of school [and it] was how many more recesses were there and how many more lunch times were there and how many more, you know, it's nothing to do with work. It's how many more and all these sort of things, social.

Positive relationships with others provide families with an enormous amount of emotional support and greatly influenced their overall quality of life. Moreover, participating in extra-curricular activities was also seen as beneficial for children. One caregiver described the many activities her child enjoyed:

So he skis and – in the winter he skis and he skateboards, right. He just loves – he has a ramp in the garage, four foot double sided what's it called? A quarter pipe, you know. Up one side, down the other side, turn around along the bar, a major attraction it is to the neighbourhood, he skateboards and he – well, he plays golf when he's got time and he can play tennis. What else does he do? He socializes.

Some families who have children with special needs (e.g., Down's Syndrome as well as HIV/AIDS) described the importance of active socialization for their children. Caregivers wanted their special children to be included and to socialize with all types of other children. In some instances, schools went to great lengths in order to encourage this kind of socialization as well as participation in extra-curricular activities. For example, one caregiver described how the school had organized a "Circle of Friends" for her child:

And at school what they are going to be starting is, like tonight actually, she's going to get a phone call from one of the students – and they are going to do this once a week that a different student calls her and just –

they call it a "Circle of Friends." So they're going to be starting that. And then, she will after a few months, she'll have to call somebody. Just chat on the phone.

This same caregiver described how her child was also going to participate in a drama production, and how the child's instructional aide was going to personally provide transportation:

[My child] is going to audition to be in the drama club. She's going to be in a play at the end of the year and she's so excited. It's "Fiddler on the Roof" and she has no idea what it is but she is going to be – she might be part of the crowd so she auditioned and the teacher's aide said the rehearsals will be after school and she said that she would drive [my child] home after. So – because the school is a ways and for me to – I would have to bring the other two kids and go pick her up and so this way she [the teacher's aide] said "Don't worry about her!" and [my child] is all excited and she's very – a very – like, she loves to perform and so she'll be great.

Another caregiver described the many developmental delays her child experienced as a result of the cognitive implications of the disease and how, despite these set backs, her child deserved the opportunity to interact with other children:

But it's important because I know where she's not the kinds of kids – she's four years old but she not acting like a four-year-old, but I know she's speaking things, she's learning, she's very bright in a few things, you know, and be aware of everything though. And so I don't think it would be fair to her to keep her away from other kids so she can participate. You know, give her the chance at least to participate with other kids.

Caregivers also took steps to encourage active socialization. One caregiver described how she tries to find an extra-curricular activity her child would enjoy: “So, you know, I’ve asked the kids if they would like to, you know, take skating lessons. I’m just trying to find out from him, if there is anything I can sign him up for.”

Some caregivers described how the illness negatively affected their child's level and quality of socialization. Sometimes these social barriers were of a physical nature and at other times they were of an emotional nature. No matter the nature of the barrier, the illness created a social obstacle for some children and this interference influenced their general sense of quality of life.

One caregiver described how her son experienced a change in his ability to socialize with other children as well as his ability to participate in extra-curricular activities because of the physical implications of the illness:

He had a lot of friends before he got sick. A lot of friends. Being honest, our phone at home never stopped but now because he's not able to participate in sports, [my son] lost his sense of balance, [he] has a ten-speed bike at home that [he] can't remember how to ride. He's not good in sports anymore. It's all that part of the brain that was affected and so, you know, at school he's limited to what physical contact he can have.

Constant immune-related health concerns also presented a social barrier. When asked if her young child spent time playing with other children in the neighbourhood, a caregiver responded that these activities were minimized. The caregiver was concerned about her child's health when interacting with other children: “I am scared, you know. I

think I over-protect her. She's – she can get cold or flu or – she was with pneumonia last year in hospital.”

Moreover, medical regimens created barriers for certain kinds of socialization. An overnight school trip was anticipated by one family and the caregiver worried that her child may not be able to participate because of the pills he has to regularly take. Asking a teacher to administer zidovudine (AZT) would likely “give away” his diagnosis, a diagnosis which many parents are not prepared nor willing to share. The fact that other pills are engraved with the label “HIV” directly on the caplet further complicated the situation. Caregivers described how the pills “label themselves,” and how this created a social obstacle for overnight extra-curricular activities. One caregiver described this dilemma:

Now they're coming up to a school trip that's for a couple days, overnight. Like, he's gone to friends' houses and we'll just skip that dose and he'll get the morning dose later. Now what do you do with the school trip? Oh, he's on medication, he can't carry his own medication and hide it. I mean, I guess you could if you were in high school and you knew what's going on and you don't want to disclose to your friends. And if you get caught then I guess you have to [disclose], but at 13 you can't. So, he can't go on this trip.

Another caregiver described how her daughter's illness interfered with her ability to socialize with others. This child was not well enough to spend as much time with other kids as she would like and this was a disappointment for her: “[She does not socialize] as much as she'd like to. She'd like to be a real social animal, but no.”

Some caregivers who had socially active children worried about their children's ability to socialize in the future. Although their children were well at the time of the interview, the caregivers realized that they may not always be so healthy:

So he participates in everything his friends do. Now I think it might get more difficult, if he's sick, you see, and I hope we're not going to get to that situation whenever – you know, we'll cope with that when it comes but hopefully his friends will still be there. But obviously there won't be so many coming around so often to do the things that he does with them, things like skateboarding on the ramps in the garage, if he's not feeling well. And some of them will disappear. I expect the ones that do that with him. I don't know what sort of – I mean, how mature do you expect a friend of a child to be to go and spend time with a child who's not well. That will be hard, that's hard I think for any child.

Caregivers witnessed both positive and negative elements of their children's interpersonal relationships with others. Some children were well supported by others in their lives. Many even experienced loyalty in friends after sharing the diagnosis. However, some caregiver's acknowledged the interference of the illness and medical regimen in their children's ability to socialize normally with others. Many caregivers were left with persistent fears as to whether this part of their children's life was rich and fulfilling, and if it was at present, would it continue to be throughout the progression of the disease.

Cluster: Interpersonal Relations of Caregiver

Caregivers, too, experienced a variety of both positive and negative interpersonal relationships. They described how the process of relating to others both inside and outside

their family was central to their quality of life. They described in detail this very intimate aspect of their lives.

Many caregivers described how they enjoyed active socialization, especially when interacting with the school. One caregiver, a former teacher also diagnosed with HIV, described his enjoyment when welcomed into his child's class to volunteer.

But they're happy to have me come in there and volunteer and I mean that's surprising in a way. You know, someone might think, well, geez – you know, they might say, well, why have somebody there with HIV, if they don't have to be there? It's an unnecessary risk. Somebody might look at it that way. They might look at it and say, well, we don't want this guy coming in and he's like on medications all the time talking to our children or there's all – but they're saying, oh, he's a teacher and we can use him as a volunteer, like come on in.

Some caregivers also described how they felt a sense of belonging when participating in support groups for parents of children with HIV/AIDS. Many felt a tremendous connection with others in a similar situation. Sometimes these support networks were organized in a formal way, and sometimes, as explained by this caregiver, they were created in a more informal manner:

The other thing that sometimes is nice is, I guess it's not with school but it is, you meet other families and we hooked up with another family who's seeing the same people at clinic and setting a rapport and this was all within a year after we found out and they found out. We went on a trip with them.

When interacting with others in a positive way, caregivers described joy, happiness, and a sense of belonging. However, not every social interaction was a positive

one. Some caregivers described negative social experiences. Many caregivers acknowledged how the illness affected their personal social lives and some described how the illness prevented them from interacting with the school. Others described how they observed a change, sometimes a deliberate change, in their interpersonal relationships with friends. Some caregivers described how interacting with others affected by HIV brought the issue "to the front of [their] brain" and was therefore avoided. Almost every family interviewed described a centering of family as a result of the illness. Families chose to spend the majority of their free time together, and when together many felt strong, happy, and peaceful.

One caregiver described how, in the past, she was very active in her child's elementary school. She would spend time in her child's classroom on a weekly basis helping the teacher out with odd jobs. However, as she described, when she learned of her son's illness, spending time at the school was too painful as it brought up feelings of loss:

Anyway, when I was working with those children I kept thinking, well, you know, you couldn't help it when each child came to see me. "Here's this cute little child with his rosy future, touch wood" and you know. It was just very painful to see all of these children and to know that yours had this terrible thing to cope with and I couldn't do it. I tailed off after a while and I think they thought I was unreliable and everything but I just found I didn't want to do it anymore. Isn't that awful? So, I sort of dropped off my involvement in the school, you know. I did the odd thing but I didn't do volunteering at the school. It was too painful.

Another caregiver, who has chosen not to disclose her son's health status, described how she actively avoided the school. She did not want to become too

conspicuous, because then the school would have more opportunity to question her about her son's fragile health. For her, it was easier to stay away:

I'm always scared of what they [the school personnel] are going to confront me with. I dread, I dread when the school calls. I – you know what – I don't go to them. I'm just trying to stay away. I'm trying to stay in my own cocoon. It's easier to just stay in my own little world.

It is also difficult for some caregivers to interact with other families in similar situations. This kind of interaction brings the sadness to the forefront of their consciousness.

We do not participate in group programs. I've never done – they offer our hemophilia clinic or the chapter organizes weekend retreats and things like that. I don't need a retreat. I'm fine. You know, I mean it's nice to know it's out there and what not, but when I do things like that it puts – it puts the process in the front of my head and I need it here in the back [motions]. And so I don't – we don't participate with a lot of the available things out there.

Social awkwardness transcended the school and clinical environments. Some families described how they even chose to limit their socialization with friends. As one caregiver described, deciding to move to another city where they were unknown as a family was the only way for her to cope with socially awkward feelings after learning of her son's illness.

At – in a personal level, we definitely decided – We decided seven years ago, voluntarily to slow down socially. And, you know, I don't know that that's always easy, but you can't. The thing that was happening with us socially where we lived before we moved, was that we weren't laughing the

same way the others were laughing anymore anyway, so that our friends were – seven years ago – then getting into buying cottages and, you know, spending the weekends drinking and laughing out of – then you get bored and you do stupid things. And we just weren't – we knew that wasn't going to be what we were going to be doing.

Families felt a natural desire to center themselves; to draw each other in. It is as though families want to maximize every moment they possible can by spending it together. They are each other's priority. To them, life means being together.

Cluster: Intimacy and the Adolescent Experience

Families described new kinds of challenges when their HIV/AIDS infected children reached adolescence. Many families did not expect their children to live to see adolescence, and consequently were not prepared to discuss issues of sexuality with them – a topic which had new meanings when HIV/AIDS is brought into the equation. Adolescents with HIV/AIDS experience the same kind of sexual awakening as other adolescents, however they are not as free to explore this side of themselves. This difference can cause many difficult situations for both child and caregiver.

One caregiver described her angst when realizing that she would have to deal with issues of sexuality with her adolescent. The situation felt frightening and complex when HIV/AIDS is brought into the situation: “So, high school now this is a whole new ball game, you know, because at the beginning I used to think we wouldn't have to cope with all this sex bit.”

Many caregivers of adolescents described their concerns for their children's sexuality. How were they going to cope with it? Were they going to experience intense feelings of loss? One caregiver described her empathy for her child as well as her worry about her own ability to deal with the complexity of HIV and adolescence:

You're probably going to think about it [sex] a lot if there is some reason why you think you'll never be able to get married or never be able to – you know, you don't know what the future holds. You hope some miracle will come along but at the moment you think obviously no mother is going to be very happy if their daughter goes out with someone who's – you know, they'll be all worried who's HIV positive. But even kissing a girl, you see, will be a big thing. I mean the parent of the girl might not like that. If I was a parent of a girl I would have to be realistic. I probably wouldn't like that either. So it's a bit difficult, isn't it? And I don't know how that's going to be handled and I don't know how to help him with something like that. So this sort of – although you don't go to school for sex obviously, but you do see girls there all the time and these things are going to be things in his mind.

Issues of sexuality could also be a target for harassment among teenagers. They can be keenly aware of the sexual implications of being HIV positive. One caregiver described how her child was humiliated in front of a group of adolescents about the sexual difficulties he may face.

And then one day in the middle of the term last year my son came home and he said – he was a bit upset and a bit annoyed. Well, this boy [the son's friend] had – on the bus, he's a very – he's a nice boy but he has trouble controlling his temper sometimes and his outbursts and unfortunately, he can be a bit mean, and he's learning to cope with it and he does very well

sometimes. But it got away with him this day and he didn't think what he said on the school bus in front of everybody. He said, well, he said, if ever I'm really mad at [my son] or, you know, I just tell him he can never have sex, you know, in front of the whole school bus. So that upset my son I think more than he cared to show.

Caregivers described how many schools taught students about HIV/AIDS, and how adolescents with this virus encountered more detailed information about the disease in high school sex education classes. Caregivers found that information about HIV/AIDS was often explicit and presented in a negative way. Adolescents were warned about promiscuity and how it can lead to deadly consequences. For a student already infected with the virus, these lectures may be especially difficult to listen to. School staff may present this information to classes and not realize that there may be infected students in the audience. One caregiver warned, "Be very careful because you don't know who is in the room." Another caregiver shared her concern about sex education classes:

Actually, the children have a large amount of time spent on this AIDS education. So they get a lot of education and I am a little worried about what's going to happen to my child sitting in the classroom when they do this. You know, how he's going to feel about it because he'll be sitting there too.

Growing older brings concerns other than those related to sexuality. As children grow into adulthood, many experience new implications of the illness. For those who were infected in infancy or early childhood, the disease may be at a very advanced stage, and consequently it may be difficult for some adolescents to keep up with their friends. One caregiver described how difficult it was for her family to watch her son's close friends head

off to university, and for her son not be able to join them. Although she encouraged her son to apply to university and he was accepted, in the end he was not well enough to attend. In many ways it brought the full impact of the disease to the surface.

We deferred a year and we had to call last year to cancel that for medical reasons. And again, we ended up disclosing at the faculty of music because I, you know, it was hard to explain that – it was just hard to explain that we never knew whether we'd really be able to get to [the university] or not. Because the doctors were still saying keep him safe and I'm still saying, "Why? You know, this guy's – he's brilliant! You know, let him." I want to let him go. It was very clear for the doctors that he wouldn't be able to do it.

It is clear the HIV/AIDS brings new challenges to children as they grow older. It may be difficult for adolescents to fully realize the sexual implications of the illness. They may be unsure whether they will be able to enjoy intimate relationships with others. Intense feelings of sadness and loss may result. Moreover, the sexual consequences of the illness may create new opportunities for harassment by other adolescents, and awkwardness in health class. It is normal for teenagers to think about sex during this stage of development and it must be a tremendous blow to realize that those people with HIV may not be able to fully explore the sexual side of their lives. Growing older also brings other kinds of challenges. Those adolescents infected early in childhood may experience devastating aspects of the disease by adolescence and in consequence, they may feel marginalized from their friends. It is not surprising that most families described their intense feelings to simply be normal.

Cluster: Normalcy

Given the psychosocial and neurological problems associated with paediatric HIV/AIDS infection, it is not surprising that families expressed an overwhelming desire to live as normal a life as possible. Normalcy was often defined by families as the way others treated and reacted to them and sometimes by the way they treated and reacted to themselves. Some of the families' lives were in turmoil, but many families were able to ensure a high degree of normalcy.

During almost every interview, caregivers made a point of showing me a picture of their child. It was as though they were trying to instill a sense of "realness" and "normalcy" in my mind. Understanding the normalcy would help me understand their experience: "I want you to know who he is, just even if you see his [photo] you know. I think it's important to have him here."

Another caregiver described how her child portrays his illness. He does not look sick, he does not act sick, nor will he easily allow the sickness to overcome him. When the caregiver spoke these words, she spoke them with pride, and the words gave her hope: "[Our son] does not look like he should be HIV positive and a hemophiliac. He just doesn't. He's the utopia of a normal healthy kid."

Some caregivers also noticed that their children did not identify with the illness on an emotional level. Although HIV/AIDS was discussed in the home, a strict treatment plan followed, and universal precautions was used whenever necessary, one caregiver described

how her child often forgot he was HIV positive: "With the HIV and AIDS, [my child] doesn't even think of himself in terms of it sometimes."

Another caregiver described how her child was cognizant of being different. This was a very awkward and uncomfortable realization for him. Deep in his heart all he wanted was to be the same as the other children at school: "His desire is to be just like the rest of the kids there."

At times, the words of caregivers demonstrated their level of acceptance. Many knew their children were infected with a deadly virus, but truly accepting this fact was a difficult task. Some just did not think about it: "The HIV, as far as I'm concerned, is a non-issue."

Other caregivers understood all too well the consequences of HIV infection. Although they could put on a normal face and portray a normal life, deep inside a thought persisted – perhaps their child would not grow up. According to one caregiver, this worry never left her:

And it's not to say that I don't get annoyed, that I don't try to treat him normally, that I don't try to be normal with him. It's just that deep down it affects you so much that you don't – you can't leave it.

Equality was also important to caregivers. Some worried that perhaps their children would face situations where they would experience a level of respect disproportionate to that of their peers and that they would experience stigma and discrimination. One caregiver described how she wished she could create a rule, a rule whereby everyone was treated fairly: "I really think that it should be made that a child that

has a terminal disease that should be respected just like all the other kids and have the same rights as a child that is negative.”

Some families described the actions they took to instill a sense of normalcy with their children. One caregiver described how she has never treated her child, nor allowed others to treat him, in a special way: “We’ve never – he’s never received toys or gifts or things like that because he’s positive or that he’s a hemophiliac. He has never won a battle because of those issues, let me put it that way.”

Another caregiver described how she struggled with the medical advice offered to her by experts in order to manage her son’s hemophilia and HIV-related immune difficulties. Her family had been told constantly to limit the physical exertions of her child. However, for this caregiver, living means living normally.

[Normalcy] is very important because we’ve been given so many – so many times we’ve been told, you know, he can’t do this or he can’t do that. “Don’t let him do that,” and we just said, forget it. Doing what we want. We take the medicine. We’ll take precautions. But he skateboards, he rides horses if he wants. He does whatever he wants to do.

Above all else, being normal was important to caregivers. They wanted their children to experience normalcy and they tried to exercise this whenever possible. Being normal meant having others, as well as themselves, view them in a normal way. It occurred to me suddenly when analyzing this data that when most of the people I know wish – for example, they wish to win the lottery. However, when these families wish, they wish to have what so many take for granted.

Cluster: Stigma

It may be a gross understatement to say that feeling normal was difficult for families who also experienced stigma. This disease is set apart from most others and is perhaps most well known for the stigma that surrounds it. At the beginning of the pandemic, those with alternative lifestyles (i.e., gay men or IV drug users) were the segment of the population most affected. Many people with conservative and/or rigid outlooks expressed the belief that these people "got what they deserved," or that this was "God's punishment for bad behaviours." However, HIV knows no boundaries. Soon the medical community noticed HIV infection in women and children, but the stigma associated with infection did not dissipate substantially. The caregivers involved with this study were highly cognizant of this stigma and they were hurt by it. Some experienced open discrimination whereas others observed subtle moments of stigma. Many families who chose not to share the diagnosis with others did so because they feared discriminatory consequences. Some caregivers believed that society perceives the mode of infection to be highly correlated with stigma. Oftentimes they were asked directly how their children became infected. Families from culturally diverse backgrounds felt as though the "blocks were stacked against them." Not only was the colour of their skin different, but they were also affected by HIV/AIDS.

Some caregivers experienced open discrimination. For example, one caregiver described how her child was refused a spot in a nursery school programme. Although the nursery school offered excuses for this refusal, perhaps for fear of legal consequences, the

caregiver was left with the feeling that her child was banned from the school because she was HIV positive:

When I went to daycares and they say yes, yes, yes, okay. But then they send me a letter and they say there is so many kids to place and we don't have room for them, you know. Giving excuses, but I know what kind of excuses that. Is because she is having AIDS because I tell them right away the situation, right, because I don't like to hide it to anybody. But they seem – they say everything is okay but then they send me a letter that says no.

Stigma can surface in the most despicable ways. One caregiver, who has already lost a child to AIDS, described how his family was honoured by their small rural community with a memorial site. However, the site was soon vandalized:

Well, there was an incident with that garden after she passed away they planted a bunch of flowers in the garden and they put a plaque there and it was – we don't know why it was vandalized but it was vandalized about, I don't know, a year after. But we don't know if it was because of what she had.

Stigma creates anger. One caregiver described how his wife (who is open about her HIV status) was discriminated against by the school. She went to great lengths to free up time so that she could be a volunteer driver for her son's class when they went on field trips. It was important to her son that she be involved. However, the school refused to allow other children to drive in a car with her. They feared the possibility of blood mixing in case of an accident. This incident left the family feeling angry and set apart from the

rest. Most of all, it left their young son feeling bad, for reasons he was not able to understand.

And then actually what happened then with that school, they started – we started – we had a problem with them because of driving on field trips where [my wife] offered to be one of the mom's driving kids on a field trip. And the first time it happened, it was just like an accident supposedly, but with [my son] ending up being in the car with mom by himself, you know. And then so we asked, we said, well, can we make sure that there's some other kids in the car with us next time, and when they made the list up for the drivers and so on for the next field trip, again it was [my wife] and [my son] for this field trip. And so they asked about that and they were like – basically said they had a problem with there being positive kids and negative kids like in the car in case of an accident, that kind of thing. And it got to I think – so it was basically – now [my son] could have gone in another car with the parents or with the principal and with other kids but they didn't want to have other kids in the car with [my wife] and they're saying that's not being discriminatory, like, excuse me. I would be really pissed off, if I was [my son].

Families were aware that the stigma that surrounds HIV/AIDS is heavy and pervasive. Families were left fearful and hyper-vigilant about avoiding possible avenues of stigma within their community. Often these fears resulted in families choosing not to share their health status with others. One caregiver described this fear: “Nobody knows because it's my thinking and Hemophilia Society that nobody declare that [HIV status] because everybody live in the community if you know what I mean? If you declare in the community, the people hate you.”

Most caregivers expressed a belief that lack of education in the school and greater community was the primary reason for stigma. Much of this stigma centers around fear of "catching" the disease. Many people are simply not educated in the ways HIV/AIDS is transmitted. Some fear contagion in ways that are highly improbable if not impossible. One caregiver described the complete lack of education she observed in the general community. To illustrate, a comment was made by the caretaker of her child's school:

There is a total misconception, ignorance. For instance, just the other day one of the caretakers in the school was saying that when he was up north he was afraid of getting stung by a mosquito in case it could carry AIDS.

Another caregiver described similar ignorance about HIV/AIDS transmission. The school principal worried that other students may catch HIV/AIDS if they ate the same salad as her HIV positive son:

Another time when I was in for something completely different, at the office. I was signing in something or giving something in, he [the principal] said, "Oh, by the way." He was there and he said, "Oh, by the way, I was going to phone you today. I nearly phoned you today because [your son] was in the lunchroom and I noticed he was sharing his salad with people, you see." So I said, "Oh, yes." And he said, "Well, I wondered if that was a good idea, you know." And I said, "Well, were they using the same cutlery or anything, you know?" And he said, "Well, no, I think they were using their fingers, you know, taking a bit each, you know." So, I said, "Well," I said "there's absolutely no danger." I said, "Even if they were using the same fork," which they weren't, which I don't think is hygienic for anybody to use the same fork, I said, "There's no danger in something like that, you know." He said, "Oh, well." But the fact that he said that shows he doesn't understand.

Caregivers also described how they felt when others made careless comments.

Sometimes people joke about AIDS or make disparaging comments about infected people without realizing that they are doing so in front people living with the virus:

Actually, a week after we found out about [our son's HIV status], I went to a party, a Christmas party, and they were making jokes around the table and one lady who would be devastated if she knew she made a joke about [my son], you know. So joking she said, oh, but don't let [someone with AIDS] put a band-aid on your finger, you know. I mean some totally thoughtless joke, but I mean I wasn't stupid. I realized it was silly, you know. But she would have been mortified if she knew what I was going through right then. And she's a very sensitive lady and – but I mean – and she's a teacher, but you never think, you see. You go out and you say these silly, thoughtless silly jokes at someone else's expense, you know. It's thoughtless.

The way people have contracted the virus is correlated with the amount of stigma they experience. Many caregivers described how other people asked them this question directly. One caregiver related a story which illustrates this phenomenon:

So the first question will be, well why? How [was] this person infected? At the World AIDS Conference last July, it was so amazing when this lady with white hair, grandmother, went up and gave her story and so – but I'm not much for drama, you've got enough drama, you don't have to be looking for it. So you're sitting there listening to another sad story and you've heard so many sad stories and – but, you know. So you listen to the whole thing and the end of her presentation was, of course [she said], "You're all wondering how I – how I was infected," you know, and that was so – she gave her little – her very meaningful, not little, very meaningful story and then she said, and you're all wondering in the back of

your minds – And we were, I mean, you are, you do. That's the first thing you want to know.

Other caregivers described how they also believed that their ethnic background worsened their stigma; it was as though they felt “all the blocks were stacked against them.” Sometimes, this feeling of discrimination prevented caregivers from interacting with the school. Selected quotes from caregivers of colour illustrate this point.

You see, for some reason. I don't know. I'm 39 years old and I feel like I well dress. I don't dress seriously but I dress to present myself as a mature woman, you know. But they looking at my face. They just look at my face I believe and think that – I don't know.

I guess they do have parents' meeting but I tell myself that I'm a woman of colour and I don't think – I don't go to the parent meetings. I never do because I feel it will be one against everyone. You know, I don't want the discrimination. I don't want – especially because we have two things against us. First, her – our condition, you know my daughter and my condition, and second, our race.

It would be fair to say that HIV infection and stigma go hand in hand. When affected by this illness, it is difficult to relate to others without some thought or experience of stigma. Stigma can be experienced in a variety of ways and its legacy leaves a cloud of fear around the lives of many of the participants involved in this study. This stigma whether feared, experienced directly, or experienced in a more subtle manner, greatly affected the overall sense of quality of life for these families.

Category – Empowerment

Caregivers described their overall sense of empowerment within several different contexts described in the five clusters entitled issues of disclosure, perceptions of child empowerment, empowerment of caregiver, protection, and research. Those clusters and their related themes are depicted in Table three below. The clusters are then discussed and supported by relevant quotations drawn from the caregiver interviews.

The caregivers described their perceptions of their children's level of empowerment. HIV/AIDS infection can leave families feeling powerless against the consequences of the illness. It is not surprising, therefore, to observe the importance caregivers placed on their ability, and on their children's ability, to choose.

"Choosing" was especially important when it centered around sharing the information with others. As indicated in the previous socialization section, caregivers described a need to avoid stigma as well to ensure a high level of normalcy for their families. Many families worried that these needs would not be met if others knew about their children's health status. As a result, many caregivers chose not to disclose.

Caregivers also discussed their sense of empowerment and their perceptions of their children's empowerment in school, and other contexts. They described a strong desire to protect their families from harm. Moreover, caregivers discussed how participation in research studies allowed them a louder voice.

Table 3
Category – Empowerment

Clusters				
Issues of disclosure	Perceptions of child empowerment	Empowerment of caregiver	Protection	Research
Themes within the cluster:	Themes within the cluster:	Themes within the cluster:	Themes within the cluster:	Themes within the cluster:
- stress and disclosure	- encouragement of child empowerment	- “meta” responsibility of caregiver	- protection of child	-importance of research
- disclosure or non-disclosure as protective measure	- choices of child	- need for information	- protection of self	-participation in research
- connection between disclosing to child & disclosing to others	- child empowerment equal to same age peers	- need for involvement	- protection of others	- hope
- connection between disclosing to others and physical integrity of child	- child responsibility	- feeling voiceless		
- connection between disclosing to others and physical integrity of child		- exercising empowerment		
- controlled disclosure experiences				
- fear regarding accidental disclosures				
- benefits of disclosing				

Cluster: Issues of Disclosure

One of the single most important issues to families was disclosure. Caregivers thoughtfully and carefully described the manner in which they shared, or did not share, their child's diagnosis with others. Although some families were open about their child's HIV/AIDS status, the vast majority were not. Many children did not know about their diagnosis, and some families even chose not to share their child's health concerns with members of the extended family. The reasons caregivers gave for their secrecy centered mainly around discrimination. They believed they were protecting their families by remaining silent. Interestingly though, some of the families who had disclosed to the school and greater community, did so in order to prevent backlash. The question of "to tell or not to tell" is an extraordinarily complex one.

Most caregivers described intense feelings of stress connected with the idea or act of disclosing, especially to the school. Many families were unsure whether or not it was necessary to share this information. One caregiver described how the issue of disclosure to the school was the foremost question on her mind when her child began school: "The only issue was, you know, was not to tell or to tell."

Another caregiver, a foster parent, described the confusion she experienced with the question of disclosure. Members of the governmental foster agency were even unsure of the legalities around this issue. This foster parent disclosed to the secretary and the principal, and then upon instruction from the foster agency, asked them to not share the

information with anyone else. The principal, however, felt it was his duty to inform the teacher. This story illustrates the challenges around disclosure:

[Our foster son], last year attended junior kindergarten at the [school] here in [our home town]. Prior to enrolling [him], the day that I enrolled him, I phoned [the governmental foster agency] to find out if I had to tell the school about his HIV, and they said, "Oh, yes! Absolutely, you have to, you know, otherwise we'll be in trouble, you know, if you don't and something happens." So, I went up and I enrolled him for kindergarten and I told the school secretary that I had to talk. I told her that I had to speak to the principal and this was why and she said that's no problem. She said he'll be very understanding, there will be no trouble about this issue and she told the principal. And then I came home and the phone rang, it was [the governmental foster agency] saying you can't tell the school. And I said but I already did. I said I told the secretary and she told the principal. And they said you phone her back and tell her not to tell anyone else – tell her and the principal not to tell anybody else in the school because we're not allowed to tell the school. They didn't know that. So I did. And [our foster child's] principal told his junior kindergarten teacher because he felt that she's his staff member and that she should be aware.

Regarding the question of disclosure, some families were more concerned with protective issues rather than legal matters. Some caregivers chose not to disclose because they believed doing so they would place their families at risk:

It's very hard, you know, because I don't like to lie. But I do it because I have to protect my children. I don't want the discrimination.

To me, I just see all these doors closing.

This would certainly be a weapon in someone's hands.

Some caregivers believed that they needed to protect their children from the scorn of other children and perhaps even from the scorn of school staff. However, most caregivers who chose not to share this information, did so because of their concern about other parents: "There are parents in the school that I would rather chew my arm off than tell."

Most caregivers chose not to tell because they believed that this was the best way to keep their children safe from scorn and discrimination. However, some families worried that if their secrecy was discovered the consequences would be even worse. They chose to disclose in order to preempt backlash:

We did disclose later on at one point. Like after we had been there for a while just because we were doing something which might – that was going to be in the press and just in case there was any sort of backlash or anything that they should know about it.

For many caregivers, disclosure to others was connected with disclosure to the child. As the following quote illustrates, some children are aware that they are sick, but they do not know the exact reason why. Some caregivers chose not to share this piece of information with their child because of the fear that their child would share the words with others:

My oldest son has asked many times what's made him sick and I have told him that it's just something that couldn't be helped. The reason I do not tell the children this is because they are still so young that I know that if I mentioned the words, they would also say it.

One caregiver described how disclosure was made to the school because his young child was aware of his HIV status and might share this information in a casual way:

At that point, it was – actually, I think it was more for the reason at that point that we told them, was because at that point our son actually was aware of his diagnosis, not to the great detail that an adult would be, but enough to say that he had the HI virus and that it was in his blood and that kind of thing. We figured, well, before he just innocently blurts this out like at show-and-tell or something with his hospital band on or something, that we better at least let the school know.

Once children know about their diagnosis, the decision to disclose belongs partly to them. The words "HIV/AIDS" can be frightening for children. They may wish to share this fear with friends: "So he was feeling better and he one day said, 'I want to tell my friend.'"

However, when some children learn of their diagnosis, they also chose not to disclose to others. School, especially high school, can be a stressful time for young people without any added complications. With HIV the stress is magnified. One caregiver described how her child did not want to share the information with others while in school:

This is her decision as well. We originally made the decision but since she's old enough to make her own decisions now, she's decided that she will not pass on the information at all until she graduates and then if her friends choose to remain her friends, then they definitely are friends. And if they don't, well, then they weren't friends in the first place.

Disclosure is a complex issue. Telling a child may leave caregivers feeling pressured to tell the school, and telling the school may leave caregivers feeling compelled

to tell the child. The following quote illustrates this point: “When we actually told our son, you see, then I felt that we should tell the school and I didn't want the school to know until my son knew.”

Choosing to disclose to others was connected with disclosure to the child, but it was also connected to the level of disease progression. When children are diagnosed with AIDS, keeping their illness a secret may become more difficult. Moreover, at this point families may need the support of those around them. One family described how they came to the point when disclosure to others was more necessary:

So anyway, he did get shingles. And so we decided to tell [grandma] so that we could have some real – so she could – it would be fair for her to know before things got even rougher. And so then at that time, then our whole family knew, period.

Another caregiver said that she and her husband believed that the decision to disclose was a family and not a school decision. However, with her child becoming progressively more ill, she felt more comfortable informing the school so they would be better prepared for the consequences of her child's illness:

It's our decision who to tell and who not to, but if something happened, like she got sick a lot and she throws up a lot and if something like that were to happen at the school. At least now they're aware and they know, you know, that she gets sick.

Caregivers wanted their disclosure experiences to be controlled. They did not want the information to slip out at show-and-tell, nor did they want the school to be careless about the management of this information. One caregiver described how she wanted to tell

others in a responsible manner: “We know that this could really [get out of hand], you know, you have to arrange it properly to be telling people properly.”

Another caregiver, a teacher herself, had chosen not to disclose the information because she did not feel confident about the school's ability to maintain confidentiality. She was afraid of the information being shared in an irresponsible manner. She described how difficult it was to keep a secret in a school environment: “People try to be discreet at school, we really do as teachers, but you say things to each other and there's too many people listening. It's just very easy for things to slip in a school.”

Some caregivers outlined benefits of disclosing. Although sharing the information may be stressful, keeping the information a secret can be burdensome for parents. One caregiver described how she felt badly about not sharing the information with the school:

I felt a little bit uncomfortable at times I think mostly because of the secrecy around it. I'm not very good about hiding things and I – because I like these people [at the school]. I find it very hard to look them in the eye and not tell them the whole truth and not level with them.

Another caregiver described feeling awkward about not disclosing. She found that keeping the information a secret was difficult and provoked feelings of guilt:

It's difficult at times – presented with different situations; especially if you get into discussions about HIV and AIDS or anything else infectious and you cannot actually talk about it because you are not going to talk about it. You're not disclosing so you have to keep it to yourself. And I think there is a certain amount of guilt there that you just can't rid yourself no matter what kind of individual you are.

Some caregivers felt that sharing the information with the school was beneficial because it helped the teachers do a better job. They believe that teachers require all relevant information about their children so they can better understand the needs of their students.

I felt that the teacher should know because I think it's a big part of who [our child] is and any problems that he will have in school are probably going to be a result of this [HIV]. You know, falling behind because he misses days or he's sick or he's too tired or there's a lot of different issues. Vision, if his vision becomes affected by – there's a virus that affects your eyes and you can go blind, if his vision is affected by that, well, I can't just say, oh, well, he caught a bug. They're not going to fall for that, he lost his eyesight because he caught a bug. So it's very – it's very important that the school know what – I meant the school has every single letter and document and test – they need that in order to help him the best that they can. You can't serve the child with all of the best efforts if you don't know everything.

Some caregivers believed that schools were unprepared for the arrival of children with HIV. School administrators may not appreciate the need for educative programmes because they do not believe that schools are affected by the illness. If schools were more aware of the number of children with HIV, perhaps they would devote the resources needed for preparation. Some caregivers who have chosen to disclose have done so in order to make the schools aware, and perhaps more prepared. They feared if they did not share the information, schools would remain ignorant of the need for preparation:

And it's true, they [schools] should mobilize. And what it is, is that you, as professionals, and we as parents, have to make them realize; now the fact

that we opened the door a couple of times and made them realize, but maybe we're a hindrance because we're not allowing them to.

One caregiver wondered if remaining silent about HIV diagnoses inadvertently strengthened the stigma surrounding the disease. For many years this caregiver did not tell others about her son's health status. She felt as though she was hiding a dark secret. One day, however, she wondered if she had internalized the stigma she had most feared. At the time of the interview, she wondered if more openness about the disease would have lessened the stigma. "I haven't decided how – why are we saying we want to be so private? What are we afraid of? And wouldn't it help if this was not so?"

In sum, for caregivers of children with HIV/AIDS disclosure is a very complicated issue and one which often causes stress. Some caregivers choose to disclose in order to protect their children whereas others believed their children were best protected by remaining silent. When caregivers decided to disclose, this decision was sometimes connected with disclosure to the child, and sometimes connected with the level of disease progression. Whatever the reason, most caregivers preferred to share the information in a controlled and responsible manner, and some caregivers acknowledged that there were benefits to sharing the diagnosis with others. All in all, disclosure was one of the most salient themes discovered during the process of this research.

Cluster: Perceptions of Child Empowerment

Children with HIV are one of the most vulnerable population groups in society. By the nature of their infection, significant aspects of their lives may already be decided for

them. I found caregivers to be very sensitive to their children's level of empowerment. They clearly understood the challenges associated with HIV infection, and many sought to protect their children by increasing their "power." In consequence, caregivers actively encouraged their children to make choices and act responsibly. Often, this involved teaching children ways of handling their own blood. When attending school, most caregivers perceived their children's level of power to be equal to same age peers.

Caregivers carefully discussed their children's level of power. Some caregivers described how difficult it is for children to advocate for themselves. Children may not have the opportunity, or the capability, to assert their rights. One caregiver described how she worried for children and how she believed that it is the responsibility of adults to ensure that children have a say in how they are treated: "Children don't have voices, you know, we have to give them that."

Caregivers described how their children want and need an opportunity to make their own choices and assert their own power. Many caregivers detailed how they were careful about respecting their children's rights and how they encouraged them to exercise choice:

He's old – getting old enough now that he should have a right and some kind of control over his personal life.

You're not going to get everyone treating him the same. He has to become an advocate for himself; and this is what we always say to him; through the years we've taught him to be able to speak up.

Caregivers were especially cognizant of their children's choices regarding disclosure. Telling or not telling others about HIV infection has significant consequences for each child. Caregivers felt their children needed to have a say in these kinds of situations and they described how they actively involved their children in disclosure decisions:

[Our son is] at the age that he needs to have a say in how he wants – if he wants people to know or not to know, and [my husband] and I are quite careful about respecting that.

This [disclosure] is her decision as well.

And I told him, you know, he can choose to tell people when he feels it is right.

Decisions about school were also shared with children. Caregivers were careful to allow children an opportunity to discuss their needs when it came to school. One caregiver described how she listened to her child's desire to return to school full-time after a period of illness: "He is the one that approached me and says, 'Mom, I really want to go back all day.' So, because he's the one that asked me that's why I put him back all day."

Caregivers noticed that their children were not able to make all the choices, but they did make the same kinds of choices as their friends. One caregiver described her child's ability to make decisions and exercise empowerment to be "just as any other student."

Sometimes, however, children with HIV are not just like any other student. This is especially true when it comes to aspects of self-care. Almost all of the caregivers described how they instructed their children to properly manage open cuts. Even very young

children were expected to demonstrate a high level of responsibility when it came to taking care of their blood:

We do reminding of this on occasion, but [our son] has been taught if he has a cut someplace that's bleeding and he needs to have a band-aid put on or he needs to wash up, that he is to do that himself and that he is to – for instance when his teeth were coming in and occasionally they would bleed, I'd send him off with a plastic bag and kleenex. And if [he] had a tooth that was starting to bleed because it was coming in, then he'd look after it, and the tissue with the blood would go into the bag and go back into his backpack and come home and we would dispose of it properly here. So he's been taught how to properly take care of blood product.

Children with HIV/AIDS were encouraged to exercise choice, invited to contribute opinions, and expected to demonstrate responsibility. Caregivers were aware that their children may be vulnerable to the marginalizing forces of stigma and discrimination. In consequence, they were careful about ensuring opportunities for their children to exercise empowerment.

Cluster: Empowerment of Caregiver

Caregivers described their children's level of empowerment as they discussed their own. They were quick to acknowledge that with power comes responsibility, and they described in detail how they exercise this duty. Many caregivers felt that their empowerment was increased with additional school involvement and with additional information about school policies and developments in HIV research. However, it was difficult for some caregivers to access information, or to advocate for the rights of people

with HIV, without disclosing their own family's HIV status. In consequence, some caregivers felt voiceless. Nevertheless, families endeavoured to find ways of exercising choice and empowerment.

Often, caregivers demonstrated responsibility by ensuring that their children would not be a threat to others. Caregivers carefully instructed children on how to use proper precautions when dealing with their blood, and they carefully monitored their children's actions in order to ensure that these precautions were followed. Children were expected to demonstrate considerable responsibility, but caregivers demonstrated an even greater responsibility, a "meta-responsibility." One caregiver described how she needed to know that her child uses proper precautions for dealing with his blood. She felt a duty toward others: "I have to know that. I have to know that because there are moral issues for me too, that because I'm not telling anybody, I have to protect the people who don't know."

Caregivers described feeling empowered when they were "in the know." Gaining information about school policies or new developments in HIV/AIDS research helped them to feel in charge of the situation. Sometimes, caregivers felt skeptical about the school's desire to provide the best for their children. Knowing about their school's policies helped one family feel empowered:

Well, when we had [our identification, placement, and review committee meeting], they knew what we wanted. So they know what we want and we went in. But if you didn't know the regulations, what they must give you, they play games.

Many caregivers actively sought out this kind of information about their children's school. They educated themselves about policies and teacher training. One caregiver

described how she was planning to educate herself about her son's new high school: "I want to know – actually I want to know before my child goes to school next year, I want to go and see the principal."

Another caregiver discussed how she sought new HIV related information as a way of remaining "in the know." Oftentimes, she did not feel as though she had adequate access to this kind of information. She described how she would appreciate an information letter from the medical and scientific community:

One thing that I would like. I wish that there was some sort of a newsletter that updates families on progress that's being made and things that are being worked on. We hear very little, just through the newspapers is what we hear and from the news. So, we're not very informed about what's being done.

Some caregivers found that being involved with the school was a good way of staying informed. Positive school involvement facilitated communication and left families feeling like "partners" with the school system. One caregiver described how he has gone to great lengths in order to be available to the school:

Because I explain to her if any problem. Because I work in the evening time, I drop to school, then I bring in the lunchtime and evening I take from the school and drop at home, then I go to work. I start my work at 4 o'clock. That's reason I work in the evening time. I stay in the morning time at home because any problem, I go there and I know very well what you do.

Another caregiver described her intense involvement with her child's elementary school. She spent a considerable amount of time at the school and this frequent

involvement helped her feel like a partner with the school: "I was married to the elementary school."

Some families, who have chosen not to disclose their children's HIV status, have felt disempowered by their silence. They do not feel as though they can freely ask about HIV policies or training without giving away the reasons for their curiosity. One caregiver described how a family member felt a need to remain silent: "Some of the information that they passed on to her, she was aware was incorrect, but she was afraid of speaking up because it would show she was too knowledgeable about it."

Another caregiver described how she was afraid to be active in HIV/AIDS demonstrations because of the possibility of being found out. It was difficult for her to feel like an advocate for her son: "I still don't want to participate in walks for AIDS because I feel like people would recognize me."

Whether families disclosed or not, many found ways to exercise choice and empowerment. Sometimes this involved seeking assistance from others, including support groups, family members, medical professionals, and legal counsel:

I have another example for you. We've always sort of hidden behind [our support group] to find out what's actually going on in the schools or to address an issue that we, you know, for the media. It's very good and it does give you that empowerment in a form because you are speaking up as parents and you are doing it. You are getting results.

So most of the time his grandmother will go to the [school] meetings – she's my voice.

I was just blessed with a very good doctor, you know, who has stood by me.

After, we said we were going to talk to a lawyer.

And, sometimes families sought empowerment by fighting for their children's needs. In order to gain access to resources, as well as access to well-trained professionals, many families had to advocate for their children. Here are their words:

Well, in elementary school anything we wanted we really had to really push for.

So I said [to the principal] make sure that he gets a teacher who would be understanding and knowledgeable.

We had fought for so many years to keep the teacher's aide.

Caregivers discussed their own level of empowerment. This included demonstrating responsibility, seeking information, and maintaining active involvement with the school. Sometimes, families felt disempowered by not disclosing their children's HIV status. However, families were able to gain empowerment by seeking support from others and by fighting for their rights and the needs of their children.

Cluster: Protection

Protection was an important issue for caregivers. They described how they endeavoured to keep their family and others safe from harm. This need to protect was present in many different situations. For example, caregivers felt a need to protect when

discussing issues of disclosure, self-care, and transmission to others. Most powerful of all, however, was the need to protect their children from any harm.

Many caregivers described feeling a sense of guilt about their children's infection. It was as though they failed in their ability to provide parental protection. Many caregivers described an intense need to protect their children from any further harm resulting from this sense of loss:

And I'm one of those mothers who's very much like the mother bear, you know, don't say anything about my kids or I'll rip your head off.

I have to protect my children.

I'm very cautious.

Caregivers also described a need to protect themselves and other members of the family. This protection often surfaced when discussing issues of disclosure: "She has to screen through me who she's allowed to tell and who she's not allowed to tell."

Protection was also discussed within the context of self-care. Families felt a need to keep themselves safe from overwhelming stress. This task was often accomplished by ensuring a sense of family normalcy: "It's not worth dealing with it. And I think it's better for her and us if – we really want to try and live a normal type life."

The protection of others was important to caregivers as well. As discussed above, caregivers tried to protect others by ensuring that their children and others used proper precautions for dealing with blood. However, caregivers also tried to protect others by shielding them from the pain in their lives:

And even when we moved here we thought we're not going to get anybody involved with our lives because it's just going to represent pain, from this time on things are going to progress.

Caregivers felt a great deal of pain because of their children's HIV status. Many reacted to this pain with intense endeavours to shield their children, themselves, and others from further harm. To them, protection was an extremely important issue.

Cluster: Research

A few families made a point of sharing with me how happy and willing they were to participate in research studies. It was as though they felt a higher sense of empowerment through this participation. They were able to express their feelings, ideas, and suggestions about pediatric HIV/AIDS infection in school systems to the greater public in a safe and confidential manner. Families who chose not to disclose their children's HIV/AIDS status found it difficult to advocate for change, or, conversely, to point out what the school systems are doing well. Participation in research studies allows families an opportunity to share their point of view. This point was beautifully expressed by caregivers:

This is our voice.

I think what I say is – I glad people is having this program, you know, this investigation.

You know, it's very important for [me] to share my feelings too.

We've [been involved in] various research projects. I think that it's so important to get the right information out there.

Caregivers also expressed a sense of hope when discussing HIV/AIDS research. From a biomedical perspective, they hope for advancements in treatments and, ultimately, for a cure. From a psychosocial perspective, caregivers hope for a more compassionate society where they can openly share their children's health concerns without fear of stigma. One caregiver described how she hoped that her participation in this study would facilitate positive change in the school community: "We were both quite willing [to be involved in research studies] because quite frankly we were hoping something more positive would come out of it."

Another caregiver shared this view. She chose to participate because she desperately wanted to see a positive change in society. She experienced various forms of stigma on a regular basis. In consequence, and although she hoped the study will be accepted positively, she was left with feelings of skepticism: "I worry. Will this study be listened to?"

Some caregivers expressed the importance of research. Participation allowed them to feel a sense of greater empowerment and they hoped that it would facilitate positive change within the greater school community. Although these caregivers face great challenges, they are searching for a greater purpose and a way to help others.

Category – Well-Being

How we feel about the quality of our lives often depends on how well we feel, and the issue of well-being is central to the quality of life model used in this study. Caregivers shared intimate aspects of their own and their children's well-being. This discussion covered emotional and physical aspects of the wellness of families touched by HIV/AIDS. For example, caregivers shared the pain and anguish they experienced, and how the virus affects so many aspects of their children's lives. They detailed how medications and treatments affected their children's school performance. And perhaps most poignantly, they expressed over and over again their concern for others and the need to use universal precautions.

The well-being category includes four clusters entitled issues of caregiver wellness, issues of child wellness, medications and treatments, and issues of transmission. The four clusters are depicted in Table four below together with their related themes. They are then discussed and supported by quotations from the caregiver interviews.

Table 4

Category – Well-Being

Clusters			
Issues of caregiver wellness	Issues of child wellness	Medications and treatments	Issues of transmission
Themes within the cluster:	Themes within the cluster:	Themes within the cluster:	Themes within the cluster:
- anguish	- unpredictability of illness	- school absences	- universal precautions
- time of initial diagnosis	- pervasiveness of illness impact	- benefit of treatments	- worry regarding transmission to others
- hypervigilance and connection with child	- psychological and neurological fragility	- hope	- ignorance and stigma
- concern for non-infected siblings	- complexity of health (concomitant risk factors)	- need for sensitivity	
- effect of illness on physical integrity of caregiver			
- need for hope			

Cluster: Issues of Caregiver Wellness

When asked to describe their own sense of wellness when interacting with school systems, caregivers found it difficult to limit their descriptions to the school environment. They expressed a more holistic understanding of their well-being. Caring for a school aged child with HIV encompasses much more than simple interactions with the school. It is safe

to say, however, that the school climate greatly influences caregiver wellness. When caregivers experienced (or especially when they witnessed their children experiencing) stigma, discrimination, and threats to privacy in the school environment, they worried intensely and their well-being was negatively influenced. Conversely, when the school environment was warm, welcoming, and open to diversity, families with HIV experienced less anxiety. There is no doubt that caring for a child with HIV takes its toll on caregivers in other ways, ways that have less to do with school. Caregivers wanted to discuss these other areas of their lives. They wanted me to develop a more complete understanding of their experience, and so, they told of how they experience moments of intense anguish, how they watch their infected children with vigilance, and how they worry about the effects of HIV on non-infected siblings. Many caregivers were also infected with HIV, and consequently they were required to closely monitor their own health as well. Moreover, caregivers described how hoping helped their sense of wellness on a day to day basis.

Caregivers described how much they hurt. Caring for and loving a child with HIV, a child with an uncertain future, created feelings of intense anguish in caregivers. These feelings were magnified when caregivers felt some sort of responsibility for their children's infection. They told of their tremendous pain:

I live in a nightmare. There are times when I just break out and cry, you know.

Hell has also fallen on my shoulders.

Big regrets. And that's why it is important for me to blame somebody and that's why it's important for me to blame myself.

The anguish caregivers experienced was especially great at the time of initial diagnosis. Caregivers discussed how this was a painful and confusing time. Those families who learned of this diagnosis in the early to mid 1980s, described utter ignorance about the consequences of this illness on children. One caregiver described in detail the agony she experienced when she first learned of her son's diagnosis:

When we first found out about [our son] six and a half years ago, I found that very painful. Well, I sat there and, you know, for the first three months it's like if somebody's – it's like somebody told you your child is going to get run over by a bus next year. I mean, you know, you have a big pain in your chest, it's like a physical loss. I mean more than when my mother or father died. I mean, there's a sadness when they died but they were old, but this physical pain you get in your chest and your throat. You're sitting there talking to people and you can feel this constriction, this nervous tension of some kind, I suppose. And trying to be pleasant all through Christmas and everything and all the time you're thinking, "Oh, God!" You know, "You don't know about this." You know, because they didn't know at the time.

Caregivers described how their own sense of wellness was connected to that of their children. When their children were well, they were well, and when their children suffered, they suffered severely. As a result, many caregivers discussed how they constantly worried about their children and how they needed to vigilantly monitor them:

I was a little concerned at the beginning of the year. Like what if she got sick or what if she – something happened? Because at the other school which is like two minutes away, if she got sick I'd just go get her. But this way she's a little bit farther and like she'd have to wait longer for me to pick her up and it really concerned me.

Caregivers worried about their infected children, but they also worried about their non-infected children. The disease has a profound impact on the wellness and functioning of the entire family. Non-infected siblings are at risk to be overlooked, however they too experience much pain. Caregivers with other children told of their concern for non-infected siblings:

My oldest son is most concerned. He just blocks it right out, you know, and it's a bit worrying.

Well, I'm waiting for her brother to say, "Why?" you know, "What's going on? Why is she doing that? Why does she take all this medicine? Why is she?" I know the day will come when he's going to start asking a lot of questions.

Some caregivers shared how they too were infected with HIV/AIDS. They needed to closely monitor their own health because they had to be well enough to care for their children. There were three caregivers, however, who were experiencing advanced disease progression. In fact, one interview for this study was carried out in an AIDS hospice. One mother described her fragile health: "I was sick last year and almost die because I was in a coma for a few days."

Hoping helped caregivers survive. Many expressed a need to hope that their children would remain well. Some caregivers described how they tried to force the negative images of the disease out of their minds and focus only on their children's good health. This was how they survived from day to day:

And his general attitude was, well, it's like having a child who has terminal cancer or something, right, which I didn't quite like to think quite that way because you still want to have some hope, you know.

The only person who upset me a little bit, and she didn't mean to, she just sort of thoughtlessly said, "Oh, I didn't realize [your son] had AIDS." And I'm not ready yet to accept that he has AIDS. Do you know what I mean? He's HIV positive and I know that it's a continual – I mean, AIDS is when you get to a certain point in your blood count or whatever, but I wasn't – I'm not willing yet to accept that he's at that stage yet, although I know it's a continual process. That's my defense, that's how you carry on from day to day. You take things as they come.

He is sick, I know that. I don't think of him as sick because he has this disease he's coping with, with the help of the doctors but – so I don't like to say sick at the moment because he's still all right, you know.

Caregivers expressed their sense of wellness when interacting with the school environment. However, their experience of wellness transcended that environment, and they chose to describe their well-being in a more holistic manner. This included discussing moments of anguish to moments of hope.

Cluster: Issues of Child Wellness

Caregivers described issues of their children's wellness when at school, as well as aspects of their children's overall health which would influence their school behavior. As with themselves, caregivers noticed how their children were adversely affected by a negative school environment and positively affected by a warm and caring school climate. School experiences are central to the lives of children and it is therefore especially important that the school environment is as nurturing as possible, especially for children who are sick.

Many families discussed the fragility of their children's health. Often, children with HIV appear to be healthy, normal children. However, as a result of their weakened immune system, they can very quickly become seriously ill. Caregivers wanted school staff to realize the unpredictability of the AIDS virus:

She was ill for the whole month of July. You have to be prepared, you know, there are things that – like anything comes up very very suddenly, totally unexpected illnesses that they pick up. It's unbelievable, because of the vulnerability.

Well, he had been so sick. He was good one day and then flat on his feet.

HIV infection also brings a multitude of health concerns. Children experience many different health concerns and these concerns influenced their overall well-being.

Caregivers wondered if school personnel fully realized the pervasiveness of the disease's impact on their children's health. Caregivers described how the disease (and also the HIV medications) affected their children's physical and neurological well-being, and consequently their children's school performance and social relations. Here are their words:

[My son] lost his sense of balance, [he] has a ten-speed bike at home that [he] can't remember how to ride.

And he was showing early signs of HIV-related dementia with memory, new memory problems.

Changes in personality – virus related.

Having felt well for a short time on 3TC [an HIV medication] where he became manic, but it took us about two weeks to realize that he was flying

high, sort of thing. You know, could not keep a conversation, his ideas were going from one to the next, he couldn't even say a sentence. So he was manic and we came off the drug and waited a while and went back on a half dose.

He was having seizures – it ended up being night paralysis or whatever. And then he lost the function of his bladder and his bowels.

We had a tutor come in. His energy level so low that he couldn't even lift a fork to eat and he wasn't coming off the couch and getting out of bed. So we had a tutor come for those physical fatigue reasons.

He has a lot of difficulty with school, academically – everything has been modified for him.

It's such a struggle. The language arts and math, but particularly the language arts, just putting that down into, you know, on paper is so difficult for him.

She does have a G-tube that she gets feeds overnight so she – so from a long time, especially in elementary school I was really concerned about this G-tube because it sticks out a little bit and I didn't want kids to say, "Oh, what's that and why do you have that?" So I was really careful about the clothes she wore. And she does have a bloated stomach so it would show sometimes and it was like very hard to dress her but it was okay.

Many caregivers described the fragility of their children's health. However, some caregivers also described the emotional impact of the disease. As children grow older they are more able to understand the consequences of HIV infection. Caregivers described their concerns about the psychological well-being of older children with HIV/AIDS. When

children reach adolescence, they may experience feelings of loss because of their inability to enjoy normal sexual relations with others:

No hope of getting married or having children or having sex. The everyday things with your body and everything, they're there all the time. You can't put them away. You can't shelve them, can you? It's hard to shelve them. Especially, when you take a crush on someone, you have a – what is it called? You know, puppy love.

The AIDS virus creates a myriad of health concerns for children and these concerns will influence their school performance. Many children with HIV/AIDS, however, also experience other health concerns ranging from hemophilia to cardiac problems, and the sheer complexity of their health needs must be fully understood in order for school personnel to be able to meet their learning and psychosocial needs. Some caregivers described how their children's other health concerns often took priority over HIV infection:

With [my child], I don't think of the HIV as much as I think of, you know, she has Down's Syndrome. She – a lot of things she can not do by herself and she needs help with a lot, that's what I'm looking at more than the HIV. The HIV I don't worry as much about at the school or her with other kids, as much as the Down's Syndrome part.

Caregivers who have chosen not to disclose their children's HIV status to schools expressed relief at openly discussing other health concerns which carried less stigma. These other health concerns allowed them an opportunity to engage in discussions with school staff about their children's well-being:

They know that he's – has special needs, so we've sort of been able to use that as our camouflage.

And you know, we could always say hemophilia, we could always say hepatitis, and we never had to say HIV.

It is clear that the overall well-being of children with HIV/AIDS is fragile. Not only does the virus itself influence overall health and wellness, but children with HIV often experience other health and developmental concerns. For children born to mothers with HIV, there are often concomitant risk factors (i.e., poverty), and for children who contracted the virus from a blood or blood product transfusion, there would likely remain the primary health concern which first required the blood transfusion (i.e., hemophilia). Caregivers discussed how schools will need to fully understand the range of health concerns their children are likely to experience.

Cluster: Medications and Treatments

When discussing issues of wellness, caregivers brought up the medications their children took and the medical procedures they underwent. Oftentimes, these treatments had a direct impact on their children's school performance. For example, caregivers described how their children were often absent from school in order to visit the hospital. Caregivers who have chosen to disclose their children's HIV status generally find the schools supportive of their need to be absent from classes. However, some caregivers who have not disclosed have experienced difficulty with the school over this issue.

Caregivers discussed the need for schools to communicate with them about possible contagious childhood illnesses in the classroom. Children with weakened immune systems can receive special immuno-enhancing treatments in order to help ward off these illnesses. Schools who do not warn families about chickenpox, measles, and the like, are placing children with HIV/AIDS at risk. One caregiver, who has shared her child's health concerns with the school, expressed anger about the lack of this type of communication: "There was an outbreak of chickenpox. I didn't find out about it until like three days later when a parent told me!"

Caregivers discussed the great benefits of their children's treatments and how this gives them much hope. Children with HIV/AIDS are healthier and living longer. As is indicated in other parts of this chapter, caregivers are faced with new concerns, concerns which center around the adolescent experience. Three caregivers in this situation described a pleasant surprise that their children were living so long after the initial diagnosis. As the majority of children with HIV/AIDS have contracted this virus from their mothers at or around the time of birth, this trend means that a large proportion will live well into their school years. Caregivers expressed a need for schools to be aware of the increasing presence of HIV/AIDS in their classrooms, whether parents have chosen to disclose or not. Schools must be prepared.

Caregivers described the benefits of HIV/AIDS treatments, but they also expressed concern over the lack of sensitivity of pharmaceutical companies. As discussed elsewhere in this chapter, some HIV medications "label themselves." Some tablets are engraved with the letters "HIV." For families who have chosen not to disclose their children's health

status with the school, this lack of discretion on the part of pharmaceutical companies required families to be ultra-sensitive about their children's medical routine. For example, some children may not be able to participate in overnight school outings without risk of missing a dose or the risk of school staff guessing the nature of their health concern, because of the writing on the tablets.

Cluster: Issues of Transmission

When discussing issues of wellness, caregivers felt a need to express their concern for the wellness of those around them. As is described in other areas of this chapter, caregivers went to great lengths to ensure that their family took proper precautions for handling HIV infected blood. This included teaching children how to care for themselves in case of injury. Often, it also included parental endeavours to ensure that their children followed through on these precautions. For example, caregivers described how they packed plastic zip-lock bags in their children's knapsacks and instructed their children to bring home any bloodied tissue. The concern of these families was so great that they often overlooked their own pain when injured in order to protect others. One caregiver described an incident when his child in grade two warned others to not touch her blood when she was accidentally injured at school. The teacher on duty told the caregiver how his young child was less concerned for her own injury than for others. She yelled: "Don't touch the blood!"

Caregivers explained how they taught their children to use proper precautions for dealing with their blood, but they also expressed concern for the limited use of universal

precautions at school. Caregivers described how they expected school staff to use universal precautions in order to protect themselves as well as to protect other children. Many caregivers used the expression "it's a two-way street" to indicate that when dealing with open cuts children could potentially be a risk to school staff, but that school staff could also be a threat to children. Caregivers discussed the need for additional training in schools around the use of universal precautions. One caregiver, who had openly shared his child's HIV status with the school, illustrates this need for additional training when relating a school story:

She had a nose bleed. Well, she had a nose bleed, I forget what she said. She fell off the slide or fell off the swing. Yeah, at the school. And they were right there. They had – like they had no gloves or nothing – they were unconcerned.

It is commendable that the school staff in this incident were more concerned with the injured child than with their own safety. However, it is vitally important that schools ensure a safe school environment by following proper procedures for handling HIV infected blood.

Some caregivers, however, described the opposite reaction from schools. Some staff members expressed utter ignorance about modes of transmission. As discussed elsewhere in this chapter, they worried about contracting HIV from mosquitoes or from picking at the same food as someone with HIV. In many cases, this ignorance has led to increased stigma. Some people are afraid of being around a person with HIV, and hence the story of one caregiver being denied the opportunity to volunteer as a driver for field

trips at the school. It is evident that school staff require additional training, of both a precautionary and calming nature, for modes of HIV infection.

Category – Satisfaction

In many ways "satisfaction" is a difficult concept to operationalize. Trying to do so is like trying to define happiness. Yet, however subtle and intangible the concept may be, being satisfied is a corner stone of quality of life. It is possible to be in power or in control, feel well, have many friends, and still not be truly happy. Although satisfaction is influenced by these external circumstances, as a state of mind it often stands alone. Consequently, and unique in comparison with the other tenets of Keith and Schalock's quality of life model, satisfaction cannot be as easily manipulated by external circumstances or medical interventions.

Caregivers described moments of their family's satisfaction and dissatisfaction. For example, they were satisfied when they were listened to, and when school staff went the extra mile to accommodate their needs. They were happy when they had hope for the future, when they witnessed their own inner growth, and when they noticed their children's happiness. However, at times, their happiness was tempered by mistrust and intimidation by school staff. Oftentimes, a whirlpool of emotions were expressed.

The satisfaction category is described in five clusters entitled perceptions of child's experience, experience of caregiver, connective experiences, human touch, and inner growth. Those clusters and their related themes are depicted in Table five below and are then discussed and supported by relevant quotations drawn from the caregiver interviews.

Table 5

Category – Satisfaction

Clusters				
Perceptions of child's experience	Experience of caregiver	Connective experiences	Human touch	Inner growth
Themes within the cluster:	Themes within the cluster:	Themes within the cluster:	Themes within the cluster:	Themes within the cluster:
-satisfaction	-satisfaction	-compassionate connection between child and caregiver	-human connections	-courage, strength, & spirituality
-dissatisfaction	-dissatisfaction	-need to spend time together	-empathy from others	-maximizing life/choosing to live
	-tentative satisfaction	-need to communicate	-need for compassion	-hope

Cluster: Perceptions of Child's Experience

Many caregivers noticed how much their children enjoyed going to school. School was a place for their children to acquire new skills, meet new people, and learn more about themselves. Often, it was a fun and exciting place to be; an environment of wondrous opportunities. The following quotes from caregivers describe this aspect of their children's satisfaction:

Yeah, he loves high school. He comes home with a big smile on his face most days.

So he likes school. He likes getting together with friends and doing things.

For some families, school experiences of children were not always described favorably. As discussed in other sections of this chapter, children were dissatisfied with school when their illness prevented full participation in learning and recreational activities, when they experienced stigma, and when they had problems with friends. Most of all, children disliked school when they encountered negative teachers. One caregiver describes the negative impact a teacher had on her child and on her family:

I know that his science teacher last year – [our son] is not very good in math and his science teacher was really rude. It has nothing to do with the illness, but he really bombed on a test, really bombed. And when he handed it back, he said to him, "Obviously you're not good in math either." Well, that came home. And it also went back to the interview. And I said, you know, my son said something that you apparently said. He says, "Oh, I probably did – well, look at the test!" And I said, "Yes, but in our home we try to encourage with positive words." He said, "Well, what would you find positive about that test?" I said, "How about, hey, you bombed, but don't worry about it, you know, you'll do better next time." Or, if you can't find anything nice to say, you don't say anything at all, you know. But I said, "We really try and encourage our children with positive words. We use nice words." And I said, "What you've done is tear down something that we've taken years to build up and we don't appreciate it."

Although some children experienced negative moments at school, like the incident mentioned above, the overwhelming sense from these families was that their children were happy most of the time. Often, caregivers went to great lengths to ensure their children's

happiness. The illness was a factor in children's general sense of satisfaction, but as these children faced life, they faced moments of challenge and of joy.

Cluster: Experience of Caregiver

Much thought was given to issues of personal satisfaction and dissatisfaction on the part of caregivers. They described their delight when schools were supportive and accommodating. Some participants, however, were hesitant to express full satisfaction and others described great unhappiness.

Support was especially important to caregivers. If schools demonstrated flexibility and accommodation, many caregivers were satisfied. One caregiver described her happiness regarding the support she has received from her child's school:

I'm really, really excited about the public school that he goes to. I think we get a lot of support there; and the principal has really made an effort to find out as much as she can about HIV. And when we disclosed to her and told her that we were really public about it, she said that's fine, I'm prepared to deal with the parents or the media, no problem. So I'm really excited about that.

So, I feel very good about it. I mean, yeah, I mean they've been wonderful.

Caregivers also described satisfaction when they were able to communicate freely with the school. At times, teachers went out of their way to allow for this communication. Caregivers felt supported when this happened:

Yes, they really are [supportive] – like I've spoken – the teacher's aide has called a couple of times, the principal has called, the special ed. coordinator

she's called to see if everything is fine. And they have been very supportive and very nice.

Sometimes, school staff went out of their way to ensure that children with HIV were well taken care of. These endeavours on the part of school staff were important and remembered. Caregivers appreciated the extra little things staff members did for their children:

So she spent a little extra time with him and gave him a little extra special chore in the morning to help her, the principal did, and took him to his class and really took special care. And then she went back and checked on him again later to make sure he was okay and she phoned me and she talked to me for almost an hour.

Special attention showed that school staff cared, and this compassion left families with a sense of connection, satisfaction, and support. When asked to describe what support meant for her family, one caregiver offered this simple description: "Just, I guess, from the start, the warm feeling that you get from somebody's eyes."

It is important that schools show support, but too much support may leave caregivers feeling uneasy. At times, an abundance of attention created feelings of awkwardness and conspicuousness. One caregiver described feeling funny when school did too much for her child: "When people make such a big deal about things that you often leave feeling kind of funny about things."

Not all families were completely happy with the schools. Some caregivers described a tentative sense of satisfaction. It was as though they were going to reserve

their judgment in this regard. They were waiting to see what might happen: “The school so far is okay.”

Some caregivers described mixed levels of satisfaction. Oftentimes, they were satisfied with some, but not all, aspects of the school. One caregiver describes her sense of ambivalence. She is mostly satisfied with the school, but she has difficult interactions with the school secretary:

The school, the one you going to I like it maybe 65 or 75 percent I do, but then I have my problems with certain individuals in the school. The individual is a secretary. I find her very ignorant and misunderstanding. I find she gets into your personal life and you're a secretary of a school, you're not a social worker in the school, you know.

Moreover, one caregiver described a complete sense of dissatisfaction. She was not happy with any aspect of the school. She found the school environment hostile, and consequently she was always on her guard when interacting with school staff. If given the chance, she would prefer to not interact with the school at all. When asked to elaborate, she candidly said: “I don't trust the schools.”

Cluster: Connective Experiences

Caregivers described moments of their children's satisfaction and dissatisfaction. However, satisfaction was often conceptualized and expressed more holistically. Mostly, families experienced satisfaction when individual members of the family were happy. Happiness in one often spread to others. Over and over again, I heard these simple words: “Well, I like it [the school] because they like it.”

Caregivers described an intimate and compassionate connection between themselves and their children. This connection was life giving; it gave them something to survive for. Being satisfied and happy often meant being with their children and having ample opportunity to share in their child's world.

One caregiver described the joy she experienced when coming home to her children. Her voice was full with emotion as she shared this feeling with me:

[My children] wait at the window watching for me and when I come you can hear the three of them yelling out the window, "Mom" "Mom." It's really – it's very nice. And in a way I think that's the way God makes foster children so that you do love them.

In other sections of this chapter, I described how families centered themselves, how they were drawn to be together. This need to be close affected families' level of external socialization, but it also affected their general level of satisfaction. Families were most happy when together, and they especially tried to maintain this closeness as the disease progressed in their children, and sometimes in themselves.

Cluster: Human Touch

Schools can reduce feelings of mistrust when staff interact with parents on a human level. Professionals can be intimidating, especially to caregivers who have not had an opportunity to reach their own educational potential. Families affected by HIV may feel particularly vulnerable. Teachers need to be aware of the impression that they make on families. If this impression is favorable, and if teachers are perceived as approachable, they have the potential to become very important people in the lives of these families. School

staff can create this human connection when they provide families with support and accommodation. They can also instill trust when they are willing to show love and empathy.

One caregiver illustrated the importance of a human connection with teachers. Her child was blessed with two especially compassionate and understanding educators. These educators made a significant difference in her child's school experience and the caregiver was grateful to them for being a part of her family's life:

In the classroom setting, he's had a couple of teachers lately, and especially two math teachers that have made a difference. During the withdrawal where she's working with students that are having problems, a lot of times [our child] tries his best; you can tell he does try his best and, you know, he has a lot of difficulty, and she's – they've modeled the other students as – or he may remind other students of what they have to do or the homework they have to bring and they always remark that he is trying his best, that there's not an attitude about it, you know, that – so they do give him a lot of positive reinforcement in the classroom as well. Particularly teachers who understand. This is what I find, there's two math teachers who have been particularly understanding.

Another caregiver described the compassion displayed by the teacher when his child's health worsened. This child, who has since passed away, was relocated to a large hospital facility in another city. This hospital was a two hour drive away from the school, yet the teacher found time to visit. Once she brought blessings from the entire class:

[When our child was in the hospital], one of the times the teacher came out, like she had a bunch of gifts for her both times, but this one time she

had a big card from all the kids in her classroom. It was at least the size of this table, a big card.

Many caregivers described moments of human connection. Sometimes, very small gestures left families feeling warm. Sometimes these gestures came from people completely unaware of the child's diagnosis. Caregivers described how wonderful it was to find people so generous with their compassion every minute of the day and without any reason or ulterior motive. Other caregivers noticed how those well informed about the disease showed more kindness. With education comes empathy: "So I think that people are thinking, this can actually happen to anybody, and if they're already thinking that, they're already more inclined to show more compassion."

Teachers are privileged professionals. Every day they have the opportunity to be a part of a child's life. This involvement can be extraordinarily rich and meaningful if teachers can create human connections with those children and families they serve.

Cluster: Inner Growth

One of the most amazing and meaningful aspects of this research was learning how families survive with such tremendous burdens. Many of the caregivers involved personified strength and courage. They approached each day with a positive spirit and without a trace of bitterness. Moments of spiritual and inner growth were described with tenderness and emotion, and caregivers carefully expressed the great hope with which they hold each day. One caregiver, in particular, spent several minutes sharing aspects of her

personal faith. Her trust in God was strong and abundant and this spiritual relationship helped her make sense of her child's illness:

If we don't go through trials and tribulations, how do we grow in God? Right? How do we understand things? How do we – how do we learn to love Him? You know, we have a personal relationship with God and it's like if everything was just handed to us on a silver platter, we would take Him for granted. And we just wouldn't know His love the way we know it now. And His faithfulness and He never fails us. Never fails.

Moments of growth, whether of a spiritual or emotional nature, were commonly described by caregivers. Somehow they were able to find positive aspects to their troubling situation. When I sat face to face with them, I felt my spirit weak in comparison. Perhaps the most fulfilling element of carrying out my doctoral studies was having the opportunity to learn from these people. What I learned seems far greater than what years of academic study offered. Selected quotes from caregivers illustrate their tremendous strength:

I sometimes feel I'm just in a muddle and I don't – I suppose my philosophy is as I go along at the moment – We're okay, we're handling this all right, we take it each event as it comes along. I mean when you start medication, when you hear the odd comment on the bus and you have to tell the teachers, and you feel – in a way those seem small things that you've done but they were big before you did them.

You live a very protected life until something touches you like [HIV] and all of a sudden you realize, you know, there's more out there than what you realize.

I thank God for this because if we didn't – and I want it gone, trust me, I want it gone, but if we weren't going through this, I wouldn't be the person I am today.

It was as though along this journey, caregivers came to a crossroad: Either they chose to live or waited to die. Simply put, they chose to live and maximize life. These are their words:

We really do not think that [our child] is a victim but we are not going to live with that. We are not going to let our lives be destroyed by that.

You can't go through life looking at him that he's going to die tomorrow.

If I want to spoil them, I'll spoil them. I spoil my kids, yes, I spoil because I know what tomorrow is going to bring.

When asked how they do it, how they approach life with such strength and courage, caregivers told me, candidly, that they hope. Every day they hope:

You want to hope and I think you do hope even though you try not to hope because you don't want to be disappointed. I mean, you hope because you have to as a person, as a human being.

I never thought he'd get through junior school let alone through senior public school. So now high school is coming up at the end of the year and, well, touch wood.

I can only hope that his life expectancy will continue to be pushed a little further and a little further.

I have no question because, you know, I all the time pray to the God, okay, make the – try to make the medicine for people, everybody happy.

Six years. It's just incredible. God is so good and He's so faithful. And we know that there is one day when [our son's] records are going to be – show that's – it's not there. We know it. I mean, he shouldn't be alive. He's breaking all the records. He had no platelets two years ago.

With strength, courage, and hope, caregivers were able to grow when faced with tremendous challenge. Their ability to take on the most immense of difficulties was awe inspiring and we can learn much from their words as they offer a richness and depth of experience. What they said most loudly is that they refuse to give in to the disease. Their families may be touched by HIV, but they will continue to survive and maximize the life with which they were blessed.

Caregiver Recommendations

A significant portion of each interview was spent questioning caregivers about their recommendations for school systems. A total of 28 recommendations were identified. Many families have experienced a positive relationship with the school. They wanted to share aspects of this partnership in the form of recommendations so that other families could benefit from their positive experience. Other families, however, lacked a positive relationship with the school. They offered suggestions which would have improved their association with the school system. Listed below are caregiver recommendations:

1. Encourage children of all abilities to develop more positive social skills;
2. Find a way of including children with diverse abilities in all school activities, and find alternative activities if children are too ill to participate in regular school events;

3. Focus on the child, not on the disease;
4. Treat families with HIV/AIDS in a normal manner and ensure that school staff do not treat families with HIV/AIDS in a discriminatory manner;
5. Be careful not to make careless comments about marginalized populations;
6. Understand that HIV is a multi-cultural epidemic and that it knows no social boundaries;
7. Do not focus on or ask about the way children or families with HIV/AIDS became infected and understand that this information is irrelevant;
8. Ensure that staff and students are trained in the use of universal precautions and that these precautions are used consistently;
9. Ensure that staff and students receive correct and up-to-date educational materials about HIV/AIDS, especially about the modes of HIV transmission;
10. When presenting information about HIV/AIDS, be careful to present the information in a sensitive manner realizing that some students may be infected and have chosen not to disclose their health status to school officials. Provide information about the materials to be covered in health education classes to all parents;
11. Ensure a high level of hygiene throughout schools;
12. Understand the prevalence of HIV/AIDS infection among school age populations;
13. Respect parental values, include parents in decision making activities, and encourage parental involvement in school activities;
14. Accommodate children's absences and medical routines;

15. **Respect the rights of foster parents and treat them in an equal manner to biological parents;**
16. **Encourage and facilitate school-based research endeavours;**
17. **Advocate for additional governmental funding and resources for children with special needs;**
18. **Encourage the creation of parental support networks;**
19. **Be sensitive to the cultural and linguistic diversity of families;**
20. **Ensure that proper HIV/AIDS policies are in place and make this information readily available to parents. Be flexible about modifying policies when needed;**
21. **Respect the privacy of families with HIV/AIDS and ensure that sensitive documents are handled in a confidential manner;**
22. **Reduce the amount of school bureaucracy around issues of assessment, school entry of a child with HIV/AIDS, and special student placements;**
23. **Create a warm and open environment in order to facilitate communication and so that families feel like partners in education;**
24. **Be sensitive to the diverse health needs of students;**
25. **Understand the importance of school in the lives of families and in the community;**
26. **Accept support from community and medical agencies and be willing to work with these agencies;**
27. **Ensure the competence of school leaders in all areas, but especially in areas relating to HIV/AIDS; and**
28. **Treat all families with compassion.**

CHAPTER FIVE: DISCUSSION

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. Given these changing demographics, the purpose of this study was two-fold. First, I wanted to better understand the quality of life school experiences of Canadian families with HIV/AIDS. Second, I wanted consider how schools might best prepare for, support, and accommodate the affected families. However, when reviewing the stories of the families involved in this study, as well as their recommendations for school systems, I see many 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 chapter, I describe some of the most salient psychosocial and educational implications regarding children with other chronic health concerns and by way of comparison show precisely how HIV/AIDS is different. This discussion will also provide a basis for future educational policy discussions. Throughout I emphasize my own recommendations for school systems and I then provide a concise listing of these. Issues of family adaptation, ethical implications for school psychologists, and comments relating to the utilized quality of life model are provided. Moreover, the limitations of this study as well as directions for future research are offered.

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, when 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.

When 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 children too sick to attend school, 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 children with illness 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 what is described in elements of the HIV/AIDS literature, and with what the families involved in the present study have stated. 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 et al., 1997; Reidy, Taggert, & Asselin, 1991). The results of this study 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 enjoy friendships and participate 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 et al., 1989, Pequegnat & Bray, 1997; Maj, 1998). Families involved in this 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. This is consistent with the psychosocial "need to communicate" identified by Reidy, Taggart, and Asselin (1991). 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 described the importance of spending time with their families and that this has become one of their most pressing priorities. Families with HIV/AIDS viewed their time together as precious and actively endeavoured to maximize these opportunities. It was as though families experienced a centering and turning inwards. One family even went to the length of moving to another city in order to avoid external social obligations and to create more opportunities for family activities. Caregivers described feeling most happy and experiencing a heightened sense of quality of life when the family was able to be together. The data collected from this study allows us a glimpse into the lived experiences of these families and as a result, our knowledge about their lives and experiences is enriched.

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 is 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. 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) discussed how families with HIV/AIDS experience social marginalization, and many families involved in this study described encountering moments of stigma. The literature details how HIV/AIDS infection is becoming more prevalent among minority and ethnic populations and how this segment of society may feel more and more set apart. The results of this study support these conclusions. Although the participants involved in this 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 I observed that those families who had told others about their health status shared with me more experiences of encountering stigma.

Lack of Education Regarding HIV/AIDS

Most of the families stated a belief that stigma is grounded in ignorance. The people they have encountered have little understanding of the modes of transmission of HIV/AIDS or that the 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 interviewed in the present study reflected upon and carefully described the challenges associated with disclosure, a discussion which contributes greatly

to our understanding of this issue. 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, from my own experience teaching, I believe that schools do not fully understand the need to devote attention to paediatric HIV/AIDS in the school setting. I have personally observed that 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 them ever knowing it.

The results of the study also indicate that many caregivers perceived that choosing not to disclose would result in giving up some of their rights. This information is a new and important contribution to our knowledge of this topic. 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. Families should not have to feel ignorant. School information can 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 school absences 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 and they are 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 were properly trained in universal precautions, or 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 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 the results of the present study 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 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 infected with, or affected by, HIV/AIDS in the audience. 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 teeming 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 can 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.

The available literature does detail the physical and neurological consequences of HIV/AIDS infection and the experiences of some of these families are consistent with the results of the studies reviewed. Some of the children involved in this study have experienced serious neurological problems and these difficulties have 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. Even if school staff are not familiar with these medications, the situation is further complicated when some of the tablets are engraved with the letters "HIV." There is a need for sensitivity on the part of pharmaceutical companies and for them to be aware of the social consequences of producing disease-labeling medications.

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. These reports are consistent with the available literature which outlines that HIV/AIDS is increasingly being

thought of as a chronic, rather than a terminal illness. With hope, families feel as though they are able to survive and dream about a future for their families.

Family Wellness

Intrafamilial infection is a defining feature of HIV/AIDS. As described by Belfer, Krener, and Miller (1989), multiple infections within a family are not uncommon and the consequences of this can be devastating for family adaptation. However, this does not seem to be the case with the families involved in this study. Although it was not considered appropriate in this context to question families about their modes of infection, some families chose to share this information with me. As a result, I can assume that approximately two-thirds of the families involved had children who contracted the virus from blood products. This is strikingly different from the literature where it is reported that the majority of infected children contract the virus from their mothers at or around the time of birth (Cooper, 1990; Reidy, Taggart & Asselin, 1991).

The fact that many of the involved caregivers were not themselves infected with HIV/AIDS does not mean that they were unaffected. Rather, many caregivers experienced extreme emotional pain. They spoke of their anguish and the emotional difficulties they encountered at the time of initial diagnosis. They experienced feelings of intense loss, and, in keeping with the notion of disenfranchised grief discussed by Siegel and Gorey (1994), many caregivers were not able to share this pain with others. As a result, many grieved alone. Caregivers also described how the HIV/AIDS diagnosis affected each and every member of their families. They worried about their infected children, but they also worried

about their non-infected children. These descriptions are congruent with the writings of Mangos et al. (1990). It is clear that when examining the psychosocial impact of paediatric HIV/AIDS, it is vital to examine the impact of the disease on the whole family. However, there is very little mention of the experiences of non-infected siblings and other family members in the available literature.

Family Adaptation

It is clear that the families involved in this study experienced great pain. However, few expressed intense anger and many described being able to find moments of satisfaction. This pattern of behaviour indicates a general sense of family adaptation.

Satisfaction remains one of the most elusive tenets of quality of life. It is intricately connected with the other cornerstones of quality of life (i.e., empowerment, socialization, and well-being), however as a state of mind it often stands alone. Feeling satisfied is akin to feeling happy and discussing the concept of happiness with caregivers of HIV/AIDS infected children was a delicate task, but an extraordinarily important one. Those who can find happiness in a situation filled with challenge are great people; they embody strength and courage. The ultimate goal of research is to learn, and we can learn a great deal from these people. However, there is very little mention of the positive aspects of the lives of people with HIV/AIDS in the available literature. Researchers have tended to focus on the pathology, both of a physical and an emotional nature. There are discussions of stigma and the ethics around exclusionary practices, but there is little talk about the way these people have grown. How have they found moments of happiness?

The caregivers interviewed in this study described their holistic conceptualization of happiness, describing moments of satisfaction and dissatisfaction which their families experienced. Oftentimes, these discussions transcended the school environment.

Caregivers described how satisfaction was at times viewed in a tentative, fragile way, but how happiness was most often felt when families spent time together. This theme of family connectedness resonated throughout the study. From the caregiver perspective, the lives of family members are intricately connected to one another. They face pain and challenge, but they face these hurdles together.

In fact, no matter the level of difficulty, families found ways to maximize their happiness and grow from their experience. They faced each day with strength, courage, and hope. Caregivers described making a decision between sitting back and allowing the disease to ravage their lives, or choosing to fight back and to live. In fact, Jevne (1994) describes “hope” as “the voice that yearns to say yes to life” (p. 8). Although in tremendous pain, some caregivers even told of an appreciation for the challenge as it had allowed them the opportunity to grow as a person.

Many caregivers had renewed and/or strengthened their faith in God and their spirituality allowed them to make sense of the pain they experienced. They have looked beyond their own lives and have tried to develop a greater awareness of life itself. Neufeldt and McGinley (1997) discussed the impact of spirituality on quality of life. In their work, they described how a person’s perspective toward life changes when facing the prospect of death. There is a shift in perspective toward a greater emphasis on spirituality.

As such, “the person’s ‘spiritual perspective’ [becomes] the shaper of the person’s quality of life” (p. 306).

This search for meaning and infrequent expression of anger on the part of many caregivers may indicate a general sense of adaptation. When reviewing the work of Elizabeth Kubler-Ross (1969), we see that people go through several stages when they experience loss. These stages include: denial, anger, bargaining, depression, and acceptance. Other theorists, such as Goldmeier (1987) have used and/or adapted this theory for work with people with HIV/AIDS. It would seem that many of the families involved in the study are in, or are entering, the acceptance phase. It is not surprising that many of the families have progressed to this final stage of adaptation, considering that all of them have lived with HIV/AIDS for several years. Moreover, many of the families have chosen not to share their diagnosis with others. As a result, some have avoided being targets of stigma and harassment. The majority of the families became affected by HIV/AIDS through blood product transfusion. Intrafamilial infection and its consequences were not of concern to many of these participants. Their heightened level of adaptation may have been facilitated by avoiding many of the common psychosocial stressors associated with this illness.

With adaptation comes resiliency, and many theorists agree that a better understanding of resiliency will allow us to help children and families at risk (Werner, 1993; Kysela, McDonald, Drummond & Alexander, 1996). The results of this research, and especially discovering how families find moments of happiness, contribute to the study of resiliency. Through this in-depth understanding of the lived experiences of these

families we are now in a better position to engage in policy discussions in the field of paediatric HIV/AIDS in the school.

Summary of Recommendations for School Systems

As indicated above, one of the primary objective of this study was 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. A significant portion of each interview was spent questioning caregivers about their recommendations for school systems, and a listing of caregiver recommendations is offered at the end of chapter four. In this chapter, I have discussed the results of the study in light of the available literature. Throughout the discussion, I offered my own recommendations for school systems. A concise listing of those recommendations is summarized below:

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 right to disclose a child's health status must remain with caregivers.
8. Schools need to understand that there may be students in the audience who are infected with, or affected by, HIV/AIDS without their knowledge.
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.
13. Pharmaceutical companies should be more sensitive and become aware of the social consequences of producing disease labeling medications.

Ethical Implications for School Psychologists

When reviewing these recommendations, it is clear that school systems should consider developing their policies regarding paediatric HIV/AIDS in the classroom. School psychologists are in a particularly salient position to discuss and implement these kinds of paediatric HIV/AIDS policies. In many ways, they serve as a link between student, parent, teacher, and administrator. Moreover they would be involved in – or even solely responsible for – assessing cognitive and educational abilities of children with HIV/AIDS within school systems, and designing individual programmes for them. In fact, Peterson and Brofack (1997) described how school psychologists are potentially “important street-level bureaucrats” and how they are “uniquely qualified to ‘ride point’ in developing and implementing AIDS policy in public schools” (p. 81). These authors explain their position by pointing out the extensive training school psychologists receive and their subsequent skill in working with families, schools, and the larger community. They argued that it is important for school psychologists to be proactive when it comes to HIV/AIDS policy discussions, by viewing themselves as “change agents” and by advocating for these children.

When engaging in potentially controversial practice such as this, I believe that the Canadian Code of Ethics for Psychologists (Canadian Psychological Association, 1991) is an excellent reference for school psychologists. It serves as a “moral framework” which practitioners can refer to and rely upon when encountering difficult and challenging dilemmas. Of considerable importance and utility in the field of HIV/AIDS are the Guidelines for Non-Discriminatory Practice (Crozier, Harris, Larsen, Pettifor, & Sloane, 1996). In November 1996, the Canadian Psychological Association adopted these guidelines. According to the authors:

These guidelines were developed to encourage non-discriminatory practice among psychologists. The guidelines are based on the Canadian Code of Ethics for Psychologists (CPA, 1991) and are aspirational in intent. The goal is to promote non-discriminatory care in therapeutic work with clients, as well as to provide guidelines for evaluating the extent to which one's work falls within the parameters of non-discriminatory practice. As our society and culture become more diverse, and as we become more aware of specific diversities, it is important that psychologists gain an awareness of the need for non-discriminatory practice. (p. 1)

These guidelines can be applied to children and families with HIV/AIDS and can provide a foundation for policy development. Infected and affected individuals are vulnerable to various forms of discrimination. It is important that involved practitioners are aware of this discrimination and that they defend against it. By doing this they can adopt the identity of “change agent” which Peterson and Brofack (1997) encourage them to do.

When considering the Guidelines for Non-Discriminatory Practice (Crozier et al., 1996) I support their “aspirational nature.” This focus is in keeping with the four general principles of the Canadian Code of Ethics for Psychologists, (Canadian Psychological Association, 1991), being: I. Respect for the dignity of persons, II. Responsible caring, III. Integrity in relationships, and IV. Responsibility to society. Both the Guidelines of Non-Discriminatory Practice and the Canadian Code of Ethics for Psychologists encourage us to reach for a higher moral level, and they remind us that ethical practice is more than simply abiding by the letter of the law. These ideals are especially important within the evolving field of HIV/AIDS.

Another provision of the Canadian Code of Ethics for Psychologists (Canadian Psychological Association, 1991) which I believe to be of central importance to school psychologists working with infected children is the “ethical decision-making process.” This decision-making framework enables psychologists to systematically approach ethical dilemmas, and consequently make decisions, in the most ethically rigorous manner possible. The basic steps of this process include:

1. Identification of ethically relevant issues and practices;
2. Development of alternative courses of action;
3. Analysis of likely short-term on-going and long-term risks and benefits of each course of action on the individual(s)/group(s) involved or likely to be affected (e.g., client, client’s family or employees, employing institution, students, research participants, the discipline, society, self);

4. Choice of course of action after conscientious application of existing principles, values, and standards;
5. Action, with a commitment to assume responsibility for the consequences of the action;
6. Evaluation of the results of the course of action;
7. Assumption of responsibility for the consequences of action, including correction of negative consequences, if any, or re-engaging in the decision-making process if the ethical issue is not resolved. (Canadian Psychological Association, 1991, p. 85)

Throughout the ethical decision-making process, psychologists are expected to follow the four basic principles of the Canadian Code of Ethics for Psychologists (Canadian Psychological Association, 1991). When conflict amongst the principles arises, psychologists are to prioritize them in the order of presentation. For example, if Principle I (Respect for the dignity of persons) is in conflict with Principle II (Responsible caring), psychologists are to give Principle I more weight in the ethical decision making process (p. 84). Moreover, when deliberating over ethical dilemmas, psychologists are “encouraged and expected to consult with colleagues and/or advisory bodies when such persons can add knowledge and/or objectivity to the decision-making process” (p. 85).

The total of these steps in conjunction with the Canadian Code of Ethics for Psychologists (Canadian Psychological Association, 1991) and the Guidelines for Non-Discriminatory Practice (Crozier et al., 1996) will allow school psychologists who work with children with HIV/AIDS to feel confident in their ability to approach dilemmas ethically. In an area where ethical challenges are in abundance, such as this one, it is

important that practitioners have a moral framework which they can refer to and rely upon. School psychologists have a valuable tool which they can use to navigate through possibly contentious HIV/AIDS policy discussions.

Comments Regarding the Utilized Quality of Life Model

Before concluding the discussion section of this study, it is important to reflect on Keith and Schalock's (1992) quality of life theoretical model which served as an important research guide in this investigation. This model particularly appealed to me because of its face value. I could consider my own sense of quality of life within its framework. This is not a small accomplishment as quality of life is a difficult concept to clearly define. However, Keith and Schalock offer an approach to quality of life which is both simple and useful. The broad framework of satisfaction, well-being, empowerment, and socialization allow researchers the opportunity to operationalize the model in order to fit various contexts. When considering other quality of life models, such as the one offered by Felce and Perry (1997), I found it awkward to try and work within the framework provided. It would seem that other quality of life models are more devoted to comprehensiveness than to ease of operationalization.

However, Keith and Schalock's model can be operationalized – especially for use with children. Their efforts to construct a questionnaire based on this model in order to measure the quality of life of students would attest to this fact. Other quality of life discussions (i.e., Flannigan, 1982) focus more on adult than child realities. Elements

related to vocation or financial freedom are often included. Keith and Schalock's approach is more general, and as a result, can be more easily adapted to various age ranges.

The broad and general nature of this model makes it particularly appealing to qualitative researchers, since one of the goals of qualitative research is to allow participants an opportunity to share their own voices with as few external limitations as possible. However, at times it is helpful and appropriate to use a research interview guide in order to obtain the most comprehensive account of a particular phenomenon (Moustakas, 1994). Keith and Schalock's model provides researchers with a tool which enables a comprehensive exploration of experience while imposing relatively few external limitations.

Finally, the validity of this model is supported by the results of this study. As discussed in chapter three, the themes generated from this research could easily be grouped together under the categories of satisfaction, well-being, empowerment, and socialization. The data fit together naturally. For example, salient themes relating to normalcy and stigma emerged and these themes quite appropriately fit together under the socialization category. This is a logical organization given that both concepts are socially defined. Furthermore, when the data analysis was brought back to participants for confirmation, they acknowledged the validity of the groupings as a whole. Participants could also conceptualize their family's quality of life within this theoretical framework and their stories help us to better understand what quality of life means to them. These overall results support the general validity of Keith and Schalock's theoretical model. I believe that their model makes an important contribution to this field of study.

Limitations

As discussed in chapter three, there were a number of complications encountered concerning access to participants. Moreover, there were also financial restrictions. These complications posed limitations to this study.

Access to participants for the present study was facilitated through the HIV programme at the Hospital for Sick Children in Toronto. Many of the families involved in this study were also involved in a larger research agenda at the hospital and the hospital HIV team presented the concern that these families may be overburdened by research requests. It was suggested that access be limited to caregivers in one face to face interview, one telephone interview, and additional written correspondence when appropriate. Due to issues of confidentiality, a group interview or contact with school officials was not feasible. The results of this study would have been stronger if (a) more participants were interviewed, (b) additional face to face interviews and/or a final group interview were arranged, (c) school officials were contacted in order to provide their perspective, and (d) if the children themselves were interviewed to express their own viewpoint.

It would have been beneficial to interview families affected by HIV/AIDS located in different Canadian regions, and additional financial support would have facilitated this travel. The data collected from various provinces could be compared and contrasted. Regional specific recommendations could then have been developed. Moreover, interviewing additional participants, especially from various geographic locations across

the nation, would have allowed us to develop a more complete understanding of the school experiences of Canadian families affected by HIV/AIDS. Additional interviews and/or a final group interview would have facilitated a deeper exploration of the lived experiences of these participants. Schools also have an important perspective to share. Interviews with school staff would have enabled us to understand both sides of the issue. Finally, interviews with the children would have provided a more in-depth appreciation of this topic. Children may have had their own recommendations for school systems. By following the criteria above, the results of the study would have been stronger. However, given the complications concerning access to participants, it would have been impossible to meet these criteria.

The majority of the children involved in this study were infected with HIV/AIDS through blood product transfusion. As a result, the extent of intrafamilial infection is restricted. This pattern of infection is not representative of the general population in most American and European studies, where most children are infected at or around the time of birth by their mothers (Cooper, 1990; Reidy, Taggart, & Asselin, 1991). In consequence, the extent of psychosocial stressors for many of these families is reduced and therefore the applicability of these results to the general pool of families with HIV/AIDS is limited.

Directions for Future Research

The results of this research will help us to understand what school is like for children and families with HIV/AIDS. Caregivers have 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 data 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 are 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. They also

would 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 working with school-age children infected with HIV/AIDS. They are in a 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. The knowledge I gained as a result of my interaction with staff at the Hospital for Sick Children was profound. Moreover, without the support of these staff members this study would not have been possible. There are three large paediatric HIV medical networks in Canada located in Vancouver, Toronto, and Montreal. The professionals working in each of these locations would have a unique perspective to offer the greater scientific community. 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, 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 six 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 would enable us to develop this holistic awareness.

There are many more avenues of inquiry which need to be explored in order for us to feel confident about our knowledge and understanding of paediatric HIV/AIDS. The caregivers involved in the present study suggested that they would welcome additional studies and described how participation in research helps them experience a greater feeling of empowerment. Human and financial resources are required in order to facilitate additional studies in this area.

Conclusion

In chapter one, I introduced the need to study paediatric HIV/AIDS in the school environment. I discussed the pathology of the virus and modes of transmission, showing that children infected at or around the time of birth are living longer, are healthier, and that they pose no significant risk to other children in the school environment.

Chapter two reviewed Canadian demographics and epidemiological statistics in order to emphasize the growing number of infected women of a child bearing age and the subsequent need to be prepared to manage paediatric HIV/AIDS infection in the future. Research studies which outlined the cognitive abnormalities and psychosocial difficulties of infected children were discussed in order to shed light on how the illness might affect school children's behavior and performance. Lastly, the ethical and school implications of paediatric HIV/AIDS were detailed in order to show that infected children have every right to attend school and have their privacy respected.

In chapter three, I emphasized that the goals of the current study were to identify perceptions of primary caregivers regarding quality of life experiences of HIV/AIDS infected children and their families in Canadian public and separate schools. The purpose was to clarify how schools can prepare to meet the needs of these children and their families, and to be able to accommodate and provide support for them. I further described the current school situation as well as the complications associated with this type of investigation. I explained why I chose to ground this study in a quality of life model as well as use a qualitative mode of inquiry, guided by phenomenological methodology. The exact procedures for data collection and analysis were outlined and the ethical considerations described.

Chapter four offered the results of the data using a variety of tables to organize the information and I provided quotes from the interviewed caregivers in order to bring this information to life. To conclude this chapter, a listing of caregiver recommendations directed at school systems was offered.

In the current chapter, I discussed the caregiver's perceptions with reference to the available literature, showing how paediatric HIV/AIDS is both similar and unique in comparison with other chronic childhood illnesses. I provided my own recommendations for educational policy development and discussed how schools can prepare to meet the needs of these children and their families, and to accommodate and provide support for them. Issues of family adaptation, ethical implications for school psychologists, and comments relating to the utilized quality of life model were also offered. In addition, I outlined the limitations encountered with this particular study and suggested directions for future research endeavours.

Final Comments

This has been a tremendous journey and a wonderful way to conclude years of academic study. I have learned a great deal about the families interviewed and about myself. I feel thankful for having had the opportunity to experience this. When I think of these families and the time and intimacies they have shared with me, I am filled with wonder, awe, and gratitude. However, when I think of the children with HIV/AIDS, I am left with one thought, a prayer:

The Playground of God

If I could share my treasures with you
I would constantly send you blessings
from the depths and beauty of each day,

I would seal your smile with sunshine
I would leaf your walk of life
with the tenderest of greens
and the deepest of autumns,

I would catch at least three rainbows,
and set a seagull on each one
to sail you constant hellos
from the heart of the Transcendent,

I would whisper wonderings
from silent nooks of mountain tops
and the humming heart of the sea,

I would call forth the deer
and all tender animals
to run with you in happiness,

I would ask each tree
in her most majestic mood
to cover you with constant care,

I would breeze in billowy clouds
to share their rainy wanderings
when you need to feel washed anew,

I would take you by the hand
and hold your heart near mine,
to let you hear the constant love
bounding forth from me,

and most of all,

I would join my heart with yours
and have you share the path of love
that God has caused and carved
in the shadows of my soul.

(Rupp, 1992, pp. 93-94)

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Appendix A

Interview Guide

I invite you to share with me your family's school experience. Hopefully, through better understanding what school is like for you, we will be able to offer schools some guidance on how to better accommodate, prepare and support families with HIV/AIDS. I will invite you to share with me any other thing that comes to mind, and then follow up with questions specific to quality of life issues. Please let me know if my questions don't make sense. I will be happy to reword them. (*The interviewer will simplify questions as needed and as appropriate.)

What is school like for you and your family?

***Satisfaction**

- 1) How satisfied in your child with his/her current school?
- 2) How satisfied are you (and your spouse) with the school?

Simplified Language:

- 1) How much does your child like school?
- 2) How much do you (and other members of your family) like the school?

***Well-Being:**

- 1) How would you judge your child's well-being at school?
- 2) How would you judge your (and your spouse's) well being when interacting with the school?

Simplified Language:

- 1) Is your child Okay when at school? (yes/no) Please tell me more.
- 2) How about you? Are you (and other members of your family) Okay when at the school? (yes/no) Please tell me more.

***Social Belonging:**

- 1) How would you evaluate your child's social belonging at school?
- 2) How would you evaluate your family's social belonging when interacting with the school?

Simplified Language:

- 1) Does your child have friends? Is he/she invited to birthday parties? Do other children tease your child? (yes/no) Please tell me more.
- 2) How about you? Do you (and other members of your family) feel accepted at the school? (yes/no) Please tell me more.

***Empowerment/Control:**

- 1) How much control does your child have over school-related issues?
- 2) How much control does your family have over school-related issues?

Simplified Language:

- 1) How much "say" does your child have at school? Is your child able to choose or decide school things on his/her own? (yes/no) Please tell me more.
- 2) How about you? How much say do you (and other members of your family) have over school issues? Does your say count? Does the school respect your decisions? (yes/no) Please tell me more.

Open question:

Please share with me any other comments, suggestions, or concerns you may have regarding your child's school situation.

- **what has the school done that is the most helpful?**
- **what has the school done that has been the least helpful?**
- **what could the school do differently which would have a positive impact on your family?**

Appendix B

Letter of Introduction from The University of Calgary

Educational Psychology

September 17, 1997

Dear Mr./Ms. Participant:

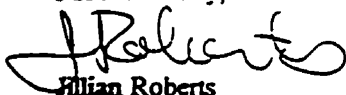
My name is Jillian Roberts. I am a graduate student in the Department of Educational Psychology at the University of Calgary, conducting a research project under the supervision of Dr. Kathleen Cairns, as part of the requirements towards of Ph.D. degree. I am writing to provide information regarding my research project entitled "Identification of the Perceptions of Primary Caregivers Regarding the Quality of Life Experiences of HIV Infected Children and Their Families in Canadian Public Schools".

The purpose of the study is to 1) to identify the perceptions and experiences of the primary caregivers regarding interaction with the schools which impact both the child and family's quality of life; and, 2) to clarify how schools can best support, accommodate, and prepare for these children and families. As part of the study you will be asked to discuss school experiences which have an impact on your family's quality of life. This discussion will be audio-taped, transcribed, and searched for patterns of themes. At a later date, you will be asked to evaluate and/or validate the themes derived from your interview. Once collected, this data will be kept in strictest confidence. The only individuals having access to the data will be myself and my supervisory committee. Your identity will never be revealed, and at all times, the data will be kept in a locked file cabinet. The raw data will be destroyed two years after completion of the study.

If you have any questions, please feel free to contact me at (403) 270-3778, my supervisor Dr. Kathleen Cairns at (403) 220-5980, the Office of the Chair, Faculty of Education Joint Ethics Review Committee at (403) 220-5626, or the Office of the Vice-President (Research) at (403) 220-3381. Two copies of the consent form are provided. Please return one signed copy to me and retain the other copy for your records.

Thank you for your cooperation.

Most sincerely,



Jillian Roberts

Enclosures

Appendix C

Guidelines for Informing Patients About Study (from the Hospital for Sick Children)

Guidelines for Informing Parents about Study

Background:

"I'd like to tell you about our research study on children with HIV/AIDS in school and ask if you would be interested in taking part. You and (your spouse/partner and children) are in the group of families who have children who attend Canadian public schools. We would like to learn from your experience so we can help schools better prepare, support, and accommodate children with HIV/AIDS. Hearing your thoughts and experiences would be valuable for this study and having a chance to educate others may be of interest to your family. We hope that the results, in conjunction with results of others studies, will be used to develop a booklet for school personnel. Taking part in this study would involve an interview with you, as well as a follow up phone conversation."

Interviewer and respect for privacy:

"The person doing the interview would be Jillian Roberts. She is a graduate student in school psychology at the University of Calgary, and this research project will help her earn a Ph.D. Your names will never be published, and your confidentiality will be protected. The interviews would be arranged at a time convenient for both family and interviewer. Interviews could take place at the hospital or another place where privacy and quiet can be insured."

Interview and Follow-up:

"If you decide to participate, you would be asked questions, and engage in informal discussion with the interviewer. There are no right or wrong answers, we want to learn about your family's school experiences. Each interview takes about 1 to 2 hours. The conversation will be tape recorded, and later transcribed. These transcriptions will not include an identifiable information about yourself or your family. The researchers will use these transcriptions to search for themes of experiences. These themes will be brought back to you at a later time (by phone) for your review."

Appendix D

Letter Requesting Final Participant Feedback

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

January 2, 1998

Dear Participant:

Please find enclosed a summary of my data analysis. I send this to you for final confirmation as your perspective is of utmost importance. I ask that you read the information and let me know if any aspect of it seems incorrect to you. I have included a self-addressed stamped envelope and there is space available on the bottom of this page for your comments. Please reply by the 30th of January. I hope that this mode of communication is the least intrusive for you and your family. Please note that you may also call me collect at (403) 270-3778 if you wish to discuss this further. I will always be happy to hear from you!

Please know that I have greatly appreciated your time. This experience has been a valuable one for me.

Sincerely,



Jillian Roberts
Researcher

COMMENTS:

Appendix E

Ethics Approval from The University of Calgary

1997-06-10

Jillian Roberts
1805 Bowness Road NW
Calgary, AB. T2N 3K5

Dear Ms. Roberts

Subject: Ethics Approval of Your Proposal

Please be advised that your proposal "Identification of the Perceptions of Primary Caregiver Regarding the Quality of Life Experiences of HIV Infected Children and Their Families in Canadian Public Schools" has been given the Ethics approval by the Faculty of Education Joint Research Ethics Committee. Your approval is enclosed. **Please note that you are responsible for obtaining approval from all participants as well as from any other institutions or agencies from which you are drawing participants (e.g. Mount Royal College, VRR, nursing homes etc.).** If your proposal is under review by another research ethics committee (e.g., Joint Research Ethics Committee or the Conjoint Medical Ethics Committee), you cannot proceed with your research until this committee has also granted its approvals.

Good luck with your research.

Sincerely,

A handwritten signature in cursive script that reads 'Michael Pryt'.

Michael Pryt, Ph.D.
Chair, Faculty of Education Joint Research Ethics Committee

Appendix F

The University of Calgary Education Joint Research Ethics Committee Certification of
Institutional Ethics Review



EDUCATION JOINT RESEARCH ETHICS COMMITTEE
 CERTIFICATION OF INSTITUTIONAL ETHICS REVIEW

This is to certify that the Education Joint Research Ethics Committee at The University of Calgary has examined and approved the research proposal by:

APPLICANT: Jillian Roberts

OF THE DEPARTMENT OF: Educational Psychology

ENTITLED: "Identification of the Perceptions of
Primary Caregivers Regarding the Quality of
Life Experiences of HIV Infected Children and
Their Families in Canadian Public Schools"

(the above information to be completed by the applicant)

97-06-10
 DATE

Michael C. Bryant
 CHAIR, EDUCATION JOINT RESEARCH ETHICS
 COMMITTEE

Appendix G

Ethics Approval from the Hospital for Sick Children**THE HOSPITAL FOR SICK CHILDREN****RESEARCH ETHICS BOARD**Approval & Terms of Agreement

APPLICANTS: Ms.J. Roberts & D. De Matteo

PROJECT TITLE: Children with HIV/AIDS in Canadian Public Schools

FILE NUMBER: 97/085

MEMBERS OF THE BOARD*:

Dr.A. Moore, Chair
 Dr. B. Stevens
 Rev. Dr. T. Trothen
 Dr. P. Joshi
 Dr. D. Bagli
 Dr. B. McCrindle
 Dr. M. Crawford
 Ms. S. Doyle

Dr. M. Dennis
 Ms. L. Macleod
 Mrs. B. Benoliel
 Ms. M. Rowell
 Ms. C. Cirilli
 Dr. S. Baruchel
 Dr. A. Feigenbaum

*Meeting may not have been attended by all members.

I agree to carry out the proposed research involving human subjects in accordance with the protocol approved by the Research Ethics Board using the approved consent forms. I shall notify the department/division chief and the Research Ethics Board prior to implementing any modifications in the protocol and of any adverse or unexpected events as soon as possible.

SIGNATURE (INVESTIGATOR)

[Signature] DATE Aug 1/97

I agree to monitor the protocol on an ongoing basis, and to notify the Research Ethics Board as appropriate.

SIGNATURE

(DEPARTMENT/DIVISION HEAD)

[Signature] DATE August 12/97

The Research Ethics Board of the Hospital for Sick Children has reviewed and approved the above-named project.

Chair, Research Ethics Board

[Signature] DATE Aug 15/97

DATE OF APPROVAL AUG 15 1997EXPIRY DATE AUG - 1998

Appendix H

Information Form for Adult Primary Caregivers

1

INFORMATION FORM FOR ADULT PRIMARY CAREGIVERS

Title of Study: Identification of the Perceptions of Primary Caregivers Regarding the Quality of Life Experiences of HIV Infected Children and Their Families in Canadian Public Schools

Short Title: Children with HIV/AIDS in Canadian Public Schools

Investigators: Jillian Roberts, University of Calgary
Dale DeMatteo, HIV Program

Purpose of Research

The purpose of this study is to identify the perceptions of primary caregivers regarding the quality of life experiences of HIV infected children and their families in Canadian public schools.

Procedure

I will interview these self-declared primary caregivers in order to identify issues related to the appropriate management of these children and families in public school settings; and to clarify how schools can best support, accommodate, and prepare for them. This research is grounded in a quality of life theoretical framework which focuses on affected families' general feelings of satisfaction, well-being, social belonging, and empowerment or control over their lives (Keith & Schalock, 1992).

Benefits

The principal benefit to you will be to have an opportunity to anonymously educate and provide guidance and practical help to schools faced with the challenge of meeting the needs of children with HIV/AIDS in their care.

Discomforts

A potential discomfort for you may be upset or sad feelings that come from talking about difficult issues and events in your life. You may refuse to answer any questions, and/or to stop the interview or withdraw from the study at any time. Your decision to participate, or not participate, will have no affect on the care you or any family member receives.

No names, only a code number, will be attached to questionnaires. Confidentiality will be respected and no information disclosing your, or your family's, identity will be released or published without consent unless required by law.

Appendix I

Consent Form for the Hospital for Sick Children

2

CONSENT

With regard to the study entitled "Identification of the Perceptions of Primary Caregivers Regarding the Quality of Life Experiences of HIV Infected Children and Their Families in Canadian Public Schools", I acknowledge that the research procedures described above have been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of the alternatives to participation in this study, including the right not to participate and the right to withdraw without compromising the quality of medical care at _____ for me and for other members of my family. As well, the potential harms and discomforts have been explained to me and I also understand the benefits (if any) of participating in the research study. I know that I may ask the researchers (Jillian Roberts and Dale DeMatteo) now, or in the future, any questions I have about the study or the research procedures. I understand that these researchers can be contacted at the numbers listed below. I have been assured that records relating to me and my care will be kept confidential and that no information will be released or printed that would disclose personal identity without my permission.

Signature

Persons who may be contacted about
the research are:

Jillian Roberts (403) 270-3778
Dale DeMatteo (416) 813-5017

Name of person who obtained
consent:

Signature

Date

Appendix J

Videos, Photographs, and Sound Recordings Consent Form

Name:

D.O.B.:

HSC#:

VIDEOS, PHOTOGRAPHS, AND SOUND RECORDINGS CONSENT FORM

Title of Research Project: *Children with HIV/AIDS in Canadian Public School
(Short Title)

Investigators:

Jillian Roberts & Dale DeMatteo

I hereby consent to be taped/photographed during participation in this research project. I understand that I am free not to participate in this part of the study and that if I agree to participate I am free to withdraw from this part of the study at any time without compromising the quality of medical care at The Hospital for Sick Children for me and for other members of my family.

Name of PatientThe Person who may be contacted
about the research is:Dale DeMatteo_____
Signature (if 16 yrs.)

Who may be reached at telephone #:

(416) 813-5017_____
Name of person who obtained consent_____
Signature_____
Date

Appendix K

The University of Calgary Consent for Research Participation

CONSENT FOR RESEARCH PARTICIPATION

I, the undersigned, hereby give my consent to participate in a research project entitled "Identification of the Perceptions of Primary Caregivers Regarding the Quality of Life Experiences of HIV Infected Children and Their Families in Canadian Public Schools".

I understand that such consent means that I will take part in a discussion regarding my family's school experiences. This one to two hour initial discussion will be audio-taped, transcribed, and searched for patterns of themes. At a later date, I will be asked to evaluate and/or validate the themes derived from the initial interview. This second discussion will also take approximately one to two hours.

I understand that this study will not involve any greater risks than those ordinarily occurring in daily life.

I understand that the responses will be kept in strictest confidence.

I understand that I have the right to withdraw from research at any time without penalty as well as the corresponding right to the investigator to terminate my involvement.

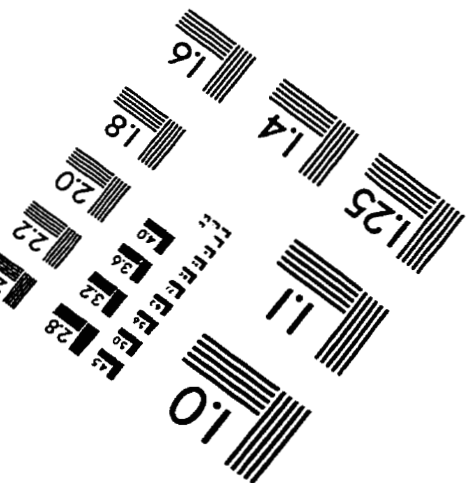
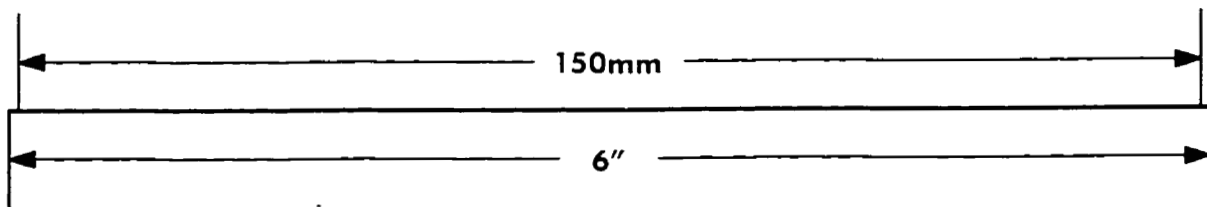
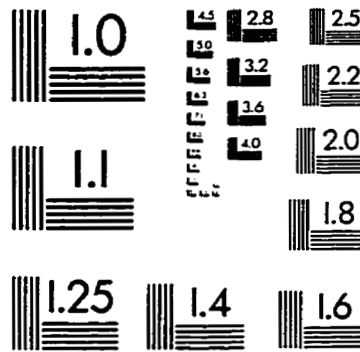
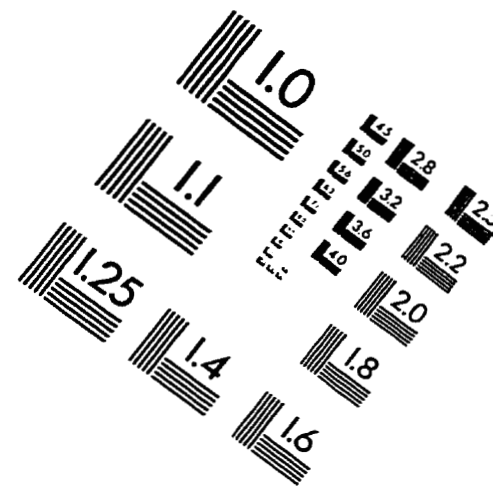
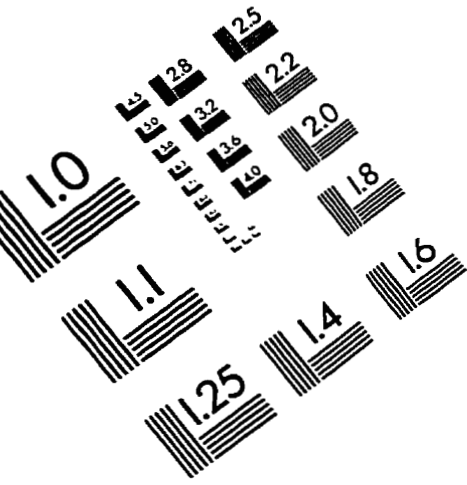
I will receive a copy of this consent form for my records. I understand that if I have any questions I can contact the researcher (Jillian Roberts) at (403) 270-3778, her supervisor Dr. Kathleen Cairns at (403) 220-5980, the Office of the Chair, Faculty of Education Joint Ethics Review Committee at (403) 220-5626, or the Office of the Vice-President (Research) at (403) 220-3381.

 Date

 (Signature)

 Participant's Printed Name

IMAGE EVALUATION TEST TARGET (QA-3)



APPLIED IMAGE, Inc.
1653 East Main Street
Rochester, NY 14609 USA
Phone: 716/482-0300
Fax: 716/288-5989

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