Issues of sexuality and prevention among adolescents living with HIV/AIDS since birth

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Abstract: There have been few studies on sexuality, relationships, and HIV prevention issues among HIV+ adolescents and fewer still that have dealt with youth living with HIV/AIDS since birth. In the present qualitative study, we conducted individual, semi-structured, taped interviews on these topics with 29 youth perinatally infected with HIV. The 15 girls and 14 boys, 10-18 years of age, have been followed at the Centre Maternel et Infantile sur le SIDA (CMIS), Centre Hospitalier Universitaire Sainte-Justine in Montreal. Content analysis of the interview transcripts revealed two dimensions related to HIV prevention. From a rational perspective, the youth were generally knowledgeable about modes of HIV transmission and modes of prevention, including consistent condom use. From an affective perspective, they were clear about their responsibility to protect their current or future partners but fearful that efforts to do so might disclose their HIV status with subsequent threat of rejection, stigmatization and compromised relationships. The concealment strategies they adopted to address the tensions inherent in this situation are discussed in terms of their own psychosexual development and of interventions by parents, caregivers and professionals to foster healthy and satisfying sexuality for HIV+ youth and their partners.

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Introduction

For most youth, puberty and adolescence bring new experiences including increased interest in romantic relationships and sexual exploration (Millstein & Igra, 1995). The Canadian Youth Sexual Health and HIV/AIDS Study showed that the onset of sexual activities such as deep kissing, genital touching, oral sex, and sexual intercourse varied progressively by grade level and to some extent by gender (e.g., 40% of grade 11 males and 46% of grade 11 females had ever had intercourse (Boyce et al., 2006). This finding fits with Matica-Tyndale’s (2001) observation that first intercourse in Canada generally takes place between 16 and 18 years of age. The timing of the onset of such sexual activities can be influenced by gender, ethno-cultural origins, degree of acculturation, and other socio-cultural factors (American Association of World Health, 2006; Entwisle, 2002). Adolescence is characterized by risk-taking (Sturdevant et al., 2001) and also decision-making as sexual relationships emerge. Youth face decisions about engaging in different sexual behaviours, safer sex practices, and the risk of sexually transmitted infections (STI) including HIV/AIDS. These concerns take on added complexity when the adolescents involved are already living with HIV/AIDS. The present study therefore addresses these sexual adjustment issues through individual interviews with a specific and understudied
population of HIV+ youth, those who have been living with HIV/AIDS since birth.

The literature on HIV with paediatric populations indicates that few studies have dealt with the sexual behaviour of adolescents living with HIV/AIDS (Brown, Lourie, & Pao, 2000) and fewer still have done so specifically with youth infected with HIV perinatally (Ezeanolue, Wodi, Patel, Dieudonne, & Oleske, 2006; Fielden et al., 2006). These youth collectively represent a unique group in that they have to manage the issues associated with adolescence (bodily changes, behavioural changes, the damping of sexuality, etc.) while also coming to terms with the difficult reality of living with HIV, an illness that is chronic and sexually transmitted.

**HIV+ adolescents infected mainly by sexual transmission**

The available information on this topic has come mainly from studies of adolescents infected with HIV through sexual transmission. The samples studied were principally composed of gay youth (Anyia, Swendeman, & Rotheram-Borus, 2005; Levin et al., 2001; Murphy et al., 2001; Naar-King et al., 2006; Rotheram-Borus et al., 2001; Vermund et al., 2001). Two of these studies of HIV+ adolescents specifically addressed age of first sexual activity, at-risk behaviour, and condom use (Rotheram-Borus et al., 2001; Vermund, Wilson, Smith Rogers, Partlow, & Moscicki, 2001). The results revealed that the first sexual activity occurred at age 14 on average and that almost 75% of the youth had engaged in anal practices (Rotheram-Borus et al., 2001). Between 42% and 66% of youth infected with HIV claimed to use condoms most of the time (Rotheram-Borus et al., 2001; Vermund et al., 2001), though only 8% reported using them consistently (Rotheram-Borus et al., 2001). Female HIV+ youth appeared to choose condoms principally as a method of contraception although their use was inconsistent; the size of their age difference from their partner was strongly correlated with lowered condom use (Vermund et al., 2001).

Naar-King et al. (2006) studied factors associated with sexual risk in 60 HIV+ youth of whom 91% were infected by sexual transmission, 58% defined themselves as predominantly heterosexual, and 65% had been sexually active (had intercourse) within the last three months. Seventy-one percent of the latter group mentioned having unprotected intercourse during this time period. Analysis using the Transtheoretical Model (TTM) indicated that self-efficacy completely mediated the relationship between stage of change and acts of unprotected intercourse. Social support specific to reducing risk was associated with increased self-efficacy. On the other hand, emotional distress and low general social support were not associated with decreased condom use.

The low rates of condom use among HIV+ adolescents infected by sexual transmission appear to have an important impact on their sexual health particularly in relation to STI (Levin et al., 2001; Vermund et al., 2001). Vermund et al. (2001) screened their sample of HIV+ youth for other STI acquired via blood or sexual activity and found many infected with gonorrhoea, Chlamydia, Human Papillomavirus and/or Hepatitis B.

**HIV+ adolescents infected mainly at birth**

Although the literature on this population is limited, clinical observations suggest that HIV+ adolescents infected at birth become sexually active later than their non-infected peers (Wiener & Lyon, 2006). One explanation for this is that HIV appears to slow down their pubertal development (Buchacz et al., 2003). This delay in pubertal development could delay psychosocial development and thus compound the social stigmatization associated with living with HIV, thus causing psychological distress (Wiener & Lyon, 2006). Frederick et al. (2000) studied the medical files of 131 HIV+ youth aged 12-20 years among whom 52% were infected perinatally and the remainder by blood transfusion including transfusions to treat hemophilia. Based on analysis of 47% of the sample, 60% had not had intercourse. Among those who had intercourse, 63% reported having done so during the past year; of these 80% said they used a condom. One-third of condom users did so each time they had intercourse.

We have found few prior studies on sexuality in HIV+ youth that focused exclusively on youth who had been living with HIV/AIDS since birth (Ezeanolue et al., 2006; Fielden et al., 2006). The Ezeanolue et al. (2006) survey study of 57 adolescents and young
adults aged 13-24 years with perinatally acquired HIV provided information on their knowledge about HIV transmission and prevention, their sexual experiences (79% had ever had a boyfriend or girlfriend and a third of the sample had ever had intercourse), and their intentions for procreation (65% intended to have a child sometime). This investigation did not include interviews or questions on feelings and relationship issues associated with being HIV+. The Fielden et al. (2006) interview study included family members and service providers and five male and five female HIV+ youth aged 9-16 years who had been infected perinatally. Qualitative analysis of findings from a semi-structured focus group with eight of these youth and individual interviews with the other two, yielded three categories of concern: social stigma, mental health, and sexual health. Many of these youth were curious about sexual relationships and some of the older respondents had sexual experience and/or romantic relationships. Although their parents, family members (most of the youth had been orphaned) and health professionals had encouraged them to disclose their HIV status, they expressed anxieties about the impact this would have on maintaining romantic relationships with their partners. Their worries and anxieties went beyond those experienced by others their age and raise concerns about depression and self-esteem. The adults in the study focused on providing sexual education to foster healthy sexual development and creating supportive polices and services to address disclosure and associated sexual health issues.

The present study further explored the psychosocial issues related to sexuality and prevention in perinatally infected youth. The goal was to identify their knowledge about modes of sexual transmission, their insights into issues related to protection, the prevention strategies they had thought about or adopted, and their feelings about the impact that disclosure might have for these strategies and on their relationships. To our knowledge, this is one of the few studies to address these issues through semi-structured individual interviews with a large sample of adolescents living with HIV/AIDS since birth.

Methods

Population
The final study population was 29 pre-adolescents and adolescents who were infected with HIV at birth (27) or at a young age (2) and have been followed at the Centre Maternel et Infantile sur le SIDA (CMIS), Centre Hospitalier Universitaire Sainte-Justine in Montreal known for its work with HIV+ youth. For ethical reasons, all the adolescents solicited for this study had to have known of their HIV status for at least six months. Since this research involves minors (less than 18 years old), written consent from parents as well as written approval from the adolescents was required and obtained. The project received approval from the ethical board of the Centre Hospitalier Universitaire Sainte-Justine. The study focused on participants whose state of physical and mental health would not compromise their participation in a semi-structured interview. The final sample represents a participation rate of 88% of those approached. All participants understood that they were guaranteed anonymity. The names associated with each quote in the text are thus pseudonyms and were, in fact, chosen by the individual youth themselves.

Data collection and analysis
Each youth participated in an individual, semi-structured interview that ranged between one hour and one hour and thirty minutes in duration. The interviews were conducted in the language of choice of the participant, 27 in French and the other two in English, and took place either in the medical facility environment or at home, depending on the choice of the participant. The interview structure was adapted from the format developed by the Children’s & Women’s Health Centre of British Columbia (2000). The research team adapted the structure in several stages to take into account different cultural sensibilities, resistances, and other elements in order to facilitate discussion of subjects that participants would feel close to. These topics included their everyday experiences living with HIV/AIDS (state of health, secondary effects, medication), the ethnocultural dimensions of their lives (ethnic identity, spirituality and religion), their interactions within the family and with peers and health professionals. Sexuality was also addressed particularly in relation to HIV transmission, actual or anticipated safer sex.
practices (such as refraining from sexual intercourse or condom use), attitudes about sexuality and prevention, and the implication that disclosure might have on their relationships. The present analysis focuses on these latter sexuality-related topics.

The interviews were recorded on audiotape and then transcribed verbatim. Coding and analysis of the transcripts followed the mixed coding approach of Van der Maren (2004). Initially three of the authors identified “meaning units” in the text and these guided reconsideration of themes anticipated from the literature review and conceptual framework of the study. In this process, the most important aspects of the issues under investigation were further named and categorized in light of the groupings and information included in the initial coding. Themes agreed upon in this step were then organized to show links between the diverse conceptual categories identified. At this stage, other researchers reviewed the pre-established conceptual categories (Deslauriers, 1991; Laperrière, 1997) and suggested revision and reanalysis to ensure reliability and validation of the final result. To support the analysis process, the interviews were systematically treated using ATLAS/ti version 5 (PC) software.

Results

Sample characteristics

There were 29 participants, average age 14.24 years, 15 girls and 14 boys, of Haitian (10), African (6), Quebec (5), European (2), or mixed cultural origin (6) (i.e., their parents were from two different countries). More than half (17) were born in Quebec. Those born outside of Quebec had been resident in the province for 7.75 years on average. Eighteen participants lived with one of their two parents, among whom twelve were with their mother and six with their father. Two youths were in foster families, five lived with members of their extended family (aunt, uncle, grandmother) and four lived with both father and mother. All but one (28/29) attended school, five at the primary level, twenty at the secondary level, and three had completed a professional studies diploma.

HIV infection was by vertical transmission for 27 participants and unknown in two cases although assumed to also be by vertical transmission. Hence it is likely that all had been living with HIV/AIDS since birth. Participants had known their diagnosis for 3.4 years on average and had learned about it around 11 years of age on average. Almost all (26/29) had been following antiretroviral treatments starting at ages 1 to 16 years old (M = 9.7 years old). This difference reflects their varied migratory routes. One participant was under bi-therapy, twenty were under tri-therapy and four took more than three antiretroviral agents. Although the question about drug use was not asked systematically, it seemed clear that drug use was uncommon among our participants with only two reporting occasional marijuana use. In this respect, our sample may differ from some other studies of HIV+ youth in which drug use was more prevalent.

Regarding sexual education, the participants mentioned four principal sources: school (13), family (14), friends (6) and the health professionals of the medical facility (5). At home, sexuality was never mentioned for 15 of the youth; was mentioned for another 10 only in the context of preventing HIV transmission, and four youth reported a climate where sexuality was openly discussed. The medical facility did not offer a formal sexuality education program which may explain why so few youth identified it as a principal source. Health professionals did deal with this subject on a case-by-case basis depending on the patient’s situation and level of development. In this context, topics such as HIV prevention, condom use, feelings, desire, and similar affective topics were easily discussed. More intimate issues related to body and pleasure were more difficult because of moral or cultural sensitivities. With respect to romantic relationships, 18 participants had had at least one romantic partner so far in their lifetime (the average among them was five such relationships). All participants defined their sexual orientation as heterosexual. At the time of the study, six adolescents acknowledged being sexually active (which we define here as having ever had sexual intercourse). For those with sexual experience, first sexual intercourse had taken place, on average, at the age of 15 and these romantic relationships had lasted between 1 to 5 months. It should be noted that 11 of the 29 youths had never had either a romantic partner or a sexual partner.
**Thematic analysis**

Our analysis identified two main dimensions that appeared to modulate respondents’ perspectives on the strategies they would adopt to prevent HIV transmission in their current or anticipated relationships. The rational dimension includes knowledge about transmission of HIV and about modes of protection. The affective dimension includes a sense of responsibility toward an actual or future partner, coupled with the fear of being rejected as a result of the disclosure that may be required to negotiate a prevention strategy. The participants’ observations suggested three main and possibly overlapping, strategies: the use condoms; sharing his or her HIV status with a partner; and abstinence. The categorizations and associated quotes that follow reflect these on the themes that emerged from the analysis. As noted above, each name has been changed to a pseudonym chosen by the individual participant.

**HIV, a virus that is usually sexually transmitted**

All participants but one knew that HIV is transmitted sexually. One boy believed that the virus could not be passed on by sexual contact.

> HIV is caught from blood to blood and by sexual relations (Dany, 14 years old, sexually active).

Well it’s by sexual relations that it’s passed on (Sara, 13 years old, not sexually active).

However, the statements of some younger participants suggested that they did not understand how sexual activity transmitted the virus (e.g., that it could get into a partner’s body from semen when a man ejaculates or from a woman’s vaginal secretions). Although the details remain abstract for such youth, they try to explain it with the knowledge that they possess.

> Well, when we make love without a condom, I couldn’t really say in detail, I don’t understand (Katarina, 12 years old, not sexually active).

During sexual relations there can be blood transfers without us knowing because it’s fragile [...] the virus is in the blood but in the sperm I don’t really know (Albert, 16 years old, not sexually active).

Some youth added that boys are more likely to transmit HIV to girls than the reverse because of the fragility of vaginal mucus.

> It’s easier for a boy to transmit the virus to a girl because the girl, she doesn’t penetrate. The boy does. That’s it! (Dany, 14 years old, sexually active).

My mother she says that for a guy it was more difficult to catch it than for a girl. It sucks to not be sure if the person will have it or like they say on the tv, one time and it can be done (Cassandra, 15 years old, not sexually active).

**The condom, a means of effective protection**

A primary strategy for prevention identified by the sexually active youth consists of using condoms. All, including the youngest, recognize that the condom is an effective means of prevention against the transmission of HIV and indicate that it allows sexual relations without compromising the health of either partner.

> There’s this sort of thing that we put on when we make love. A condom. It will make it so that you’ll give your illness less (Simon, 11 years old, not sexually active).

> If the condom is reliable, the girl won’t catch it (Dany, 14 years old, sexually active).

However, among the youngest, some had only a vague idea of what a condom is and how to use it.

> The condom it’s like made of “rubber,” but I don’t know how to put it on (Mylène, 13 years old, not sexually active).

The youth, whether sexually active or not, indicated that they were worried by the potential to transmit
the virus and emphasized the importance of protecting their actual or future lover. The use of condoms thus seems motivated by a sense of interpersonal responsibility.

Well, me, I’m starting to get older, I understand what I have to do now! It’s my responsibility to control myself (James, 17 years old, sexually active).

This interpersonal responsibility extends to a legal level, in that some youth are aware that criminal charges are possible in some cases of transmission of the virus to a partner.

I know that if I have sexual relations with a certain guy, I’m sure that I’m going to think about my HIV, because I heard talking that, according to the government, if you have sexual relations with a guy but you don’t warn him that you have that you’ve got HIV and he catches it, that something [criminal accusations] could happen to you (Naika, 16 years old, not sexually active).

**Using condoms despite the fear of being rejected**

Questions about condom use inevitably evoked the potential for disclosure of their HIV status to a partner. Most of the youth interviewed feared that such disclosure would lead to negative reaction and rejection even from their closest peers.

Well, sometimes, it’s certain that I want to tell to the ones that I really trust, because they’ll come and tell me all that they feel, but, me, I won’t go and tell them because I’m just too scared that I’ll be rejected. That’s my problem (Cindy, 14 years old, not sexually active).

Well, that’s it. It’s like a secret that you have in you. Because we don’t know how people will react if they knew [...] [they will be] scared because they don’t know this (Bobby, 15 years old, not sexually active).

In the context of romantic and sexual relationships, this fear of their partner’s reaction or rejection is palpable. Whether they are sexually active or not, most indicated that they would keep the secret surrounding their HIV status and would consider making up arguments, e.g., fear of pregnancy or other such feelings, in order to achieve condom use without arousing doubt in their partner. In other words, they could reduce the risk of transmission without the possible risks of disclosure.

It’s for sure that we put on condoms, that’s for sure yeah, but not obliged to talk about HIV (Christopher, 17 years old, not sexually active).

Because he talked about unprotected sexual relations all the time, I wasn’t interested in one, I didn’t want to hurt him. But if I didn’t want to without protection, I had to have a reason (Pat, 18 years old, sexually active).

**Asserting contraceptive arguments ... and sometimes affective ones**

The potential threat of pregnancy was the main argument brought up by the girls to try to convince their partner of the necessity of using condoms. They appeared to feel it was he who would ultimately make the decision.

I would say no because I wouldn’t want to become pregnant (Marie, 16 years old, sexually active).

The excuse that I would give him would surely be that I’m not ready to have a kid (Cindy, 14 years old, not sexually active).

One boy mentioned that he used the excuse of not feeling ready to assume the responsibility of a child to justify the use of condoms with his partner.

There’s one, one time, that I had a sexual relation, but she didn’t want me to use a condom. I said, “No but it doesn’t tempt me becoming a father (James, 17 years old, sexually active).
From the same perspective, certain girls mention the possibility of having resorted to arguments of a more affective nature to get their partner to adopt condom use.

[...] and if you love me, you will use condoms, because me I will not do it (Marie, 16 years old, sexually active).

**Integrating condoms into erotic scenarios**

Some sexually active youth reported having learned to integrate condom use into their erotic scenarios by introducing it in the form of a game or play without having to necessarily approach the question of condom use directly with their partner.

My next door neighbour taught me how to put a condom on without letting the guy know. She did the demonstration for me with a pogo [laughs]. She had put the condom in her mouth, and then, after, let’s say that the guy he doesn’t want it, you give him little kisses and, at the same time, you put it on. It was really hot. I learned a lot. She shows me all sorts of strategies (Marie, age 16, sexually active).

The first time, we both had condoms. We used hers because she had flavoured ones and I only had coloured ones (Dany, 14 years old, sexually active).

**Sharing their reality with their partner**

Two of the girls said they had revealed their HIV status to their romantic partners to sensitize them to the necessity of protecting one another. This kind of disclosure, although difficult, may feel more possible in established relationships as is movingly described below.

Well, I was with him for a few months and I loved him very, very much, to the point of talking to him about my diagnosis. When I talked to him about it, he cried because he loved me too. After, I told him, “Me, I don’t want to cause you pain, so it’s for this reason that we’ve always protected each other” (Marie, 16 years old, sexually active).

**Abstaining from certain sexual practices or temporarily from sexual activities**

Other than the use of condoms, a second strategy of prevention identified by the sexually active youth involved abstaining from certain sexual activities such as oral-genital practices. Such self-limitation appeared to be associated with a strong feeling of fear of infecting their partner while at the same time proving a way to avoid the risk of disclosing their HIV status.

I was disappointed because there are things that we can’t do without a condom [...] if I didn’t get HIV, I would not have refrained from having fellatio (Dany, 14 years old, sexually active).

But you can’t do everything [oral sex], so you say to him, “No, I don’t like that” but it’s not true (Léa, 15 years old, sexually active).

Sexually experienced participants also chose to abstain temporarily from sexual activities, in one case because it felt easier to not have sexual relations at present than to disclose their HIV status, and in another because of parental insistence based on the risk of passing HIV to a partner.

I was scared to involve myself in a romantic relationship; to hurt the person and to hurt myself as well. Because in telling him it hurts me [...] This has a great impact because the HIV affects sexuality as well. I don’t want to know anything about revealing my secret at the moment for a romantic relation. It hurts me, but I tell myself that it’s pain for another. It’s not as bad as being forced to tell my secret and after not being accepted with it and to risk the end of the relationship (Pat, 18 years old, sexually active).

Yeah, before I saw girls but not anymore. But it’s because my dad said to me, “Don’t go out with those girls!” So that I won’t give them my illness [his father forbids him to see girls] (Alain, 17 years old, sexually active).
Discussion

It should be noted at the outset that the present study differs in a number of ways from most of the investigations into sexuality and HIV+ youth. First, our study dealt exclusively with adolescents who had been living with HIV/AIDS since birth. Most of the other studies involved youth who became infected later in life through sexual transmission (Anya, Swendeman, & Rotheram-Borus, 2005; Levin et al., 2001; Murphy et al., 2001; Naar-King et al., 2006; Rotheram-Borus et al., 2001; Vermund et al., 2001). Second, a majority of youth in the latter studies self-identified with a homosexual orientation whereas all in the current sample self-identified as heterosexual. Third, our study differed from others that have also looked at adolescents infected at birth (Fielden et al., 2006; Frederick et al., 2000). Frederick et al. (2000) used quantitative chart data to report intercourse experience and related medical and social information, whereas our study used semi-structured individual interviews to explore knowledge and affective issues associated sexual behaviour and HIV prevention. Fielden et al. (2006) used a semi-structured format to guide a focus group interview with eight youth HIV+ since birth and individual interviews with two other such youth. Using an adaptation of the Fielden et al. (2006) format, we did exclusive individual interviews with all 29 participants. This methodology provided considerable depth and a unique level of personal insight among the few such investigations that have been done to date.

Our findings do not permit conclusions about differences in the emotional and sexual lives of the youth living with HIV/AIDS since birth from youth infected through sexual transmission later in life. This is perhaps not surprising given the relatively few studies available for comparison and the differences in methodology, sample, and emphasis described above. However, our findings have distinct similarities with those of Fielden et al. (2006) in that youth living with HIV since birth showed emerging interest in sexuality, some were sexually active, and most, whether sexually active or not, were conscious of the need to prevent HIV transmission, aware of the interpersonal responsibility involved in doing so, and concerned about the rejection that might come if they were to disclose their HIV status to a partner. Similar insights can be drawn from the findings on youth who contracted HIV by sexual transmission later in life (Murphy et al., 2001; Rotheram-Borus et al., 2001; Vermund et al., 2001; Wiener & Lyon, 2006).

Condom use, avoidance of disclosure, and psychosexual development

Youth in the present study appeared to understand modes of HIV transmission and means of protection and to have positive attitudes toward condom use. However, the question of the condom use was closely linked in the minds of some youth with the risk of exposing their HIV status to a partner. They were not personally prepared to make this disclosure for fear of rejection. Fielden et al. (2006) also identified social stigma, along with mental and sexual health, as a dominant theme in their study. Our youth thus face the challenge of dealing with the feelings involved in negotiating condom use while at the same time trying to avoid a disclosure that they felt would jeopardize their relationships. Their strategies for doing so included: saying they were concerned about pregnancy to justify condoms use, integrating condoms into erotic scenarios, using excuses to abstain from sexual activity (parental disapproval, saying incorrectly that they did not like an activity in order to avoid it), and in a rare case disclosing to a close partner in order to share reasons for protection. Since the youth in this qualitative study were relatively young (average age 14) and at various early stages in their sexual lives, we can only speculate on the psychosocial and developmental implications attached to such issues. It is possible that their HIV status will lead them to delay the timing and extent of their sexual exploration. Although Ezeanu et al. (2006) did report that one third of their sample of 13- to 24-year-old perinatally-infected youth had ever had intercourse, the nature of the sampling does not permit comparison with expectations for youth who are not HIV+.

Pubertal delay has also been suggested as a possibility in early-infected HIV+ youth (Wiener & Lyon, 2006) and this would also have development implications. These and other such examples warrant further study to determine whether youth HIV+ since birth differ in some aspects of their psychosexual development from youth infected sexually later in life. Further
study of these issues is also needed in different sub-populations of adolescents living with HIV who differ not only in their mode of infection, but in gender, sexual orientation, socio-economic status, substance use and cultural background (Rotheram-Borus & Miller, 1998).

**Supportive sexuality education and related services**

Our findings reinforce the observation of Fielden et al. (2006) that youth living with HIV/AIDS since birth need sexuality education interventions designed to address their particular needs at different stages of development. Based on their results on sexual behaviour and procreational intentions of such youth, Ezraelone et al. (2006) recommended “…innovative intervention programs offering reproductive health education including procreational choices and considerations” (p. 719). Fear of disclosure or stigmatization may inhibit youth living with HIV from sharing their reality in the context of school-based sexual health education interventions or during exchanges with their peers (Battles & Wiener, 2002; Wiener & Lyon, 2006) and other sources of sexual education identified by the youth, such as the hospital milieu and the family, may take on greater importance. However, our participants indicated that sexuality was rarely approached at home and when it was condom use was the principle element and often the only one. Often missing from these exchanges, or from other sources, is discussion of the emotional issues surrounding experimentation in romantic and sexual relationships.

Our participants had varied family constellations, as do other HIV+ youth, shaped in part by the dynamic of an HIV history for mothers, perhaps for fathers, and indirectly for other family members. This unique dynamic may colour the perspective that parents and caregivers have toward sexuality. Family and social relations may also be organized and affected by who is and is not included in the “secret” about the youth’s HIV status (Champion, Lefebvre Des Noëttes, Taboulet, & Lemerle, 1999). This may contribute to keeping the secret within the heart of the family (Fielden, 2005). Interventions that support parents in discussing sexuality with their children are thus important both in general and for HIV+ youth in particular (DiIorio, Pluhar, & Belcher, 2003). This could include safer sexual behaviours (condom use and contraception) and avoidance of risk behaviours (postponing the age of first intercourse). However it is the emotional and affective dimensions of dealing with sexuality, and particularly so in the context of being HIV+, that appeared to pose the greatest challenge for our participants. Addressing these issues within the context of disclosure and HIV prevention may contribute to a satisfying and healthy sexuality for them and their partners.

One theme noted among our participants was an intention to use condoms motivated by a sense of interpersonal responsibility. Interventions that positively reinforce such intentions and values should be supported both for youth who are not yet sexually active and for those who are and need the motivation and skills to establish and/or maintain safer sexual behaviours. Rotheram-Borus & Miller (1998) discuss altruistic motivations for behaviour changes in the context of ethical dilemmas of which our participants’ joint concerns about condom use and costs of disclosure could be an example. Interventions that allow clarification of values in the context of different romantic and sexual relationships could help HIV+ youth to evaluate their options and decisions in relation to their current and desired self-image. Concurrent interventions that allow youth to develop or consolidate skills linked to the negotiation and regularization of condom use may well foster safer sex practices consistent with personal values among HIV+ youth (Rotheram-Borus & Miller, 1998). In this regard, Naar-King et al. (2006) have demonstrated that self-efficacy completely mediated the relationship between stage of change and acts of unprotected intercourse among youth living with HIV.

Lastly, it is important that educational interventions address the issues surrounding disclosure. Rotheram-Borus & Miller (1998) identified the question of disclosure as a central factor in the lives of youth living with HIV. The decision of when, how, with whom, and what to disclose - and for what goals – is difficult. No firm guidelines exist on how to disclose, and particularly so when disclosure could compromise an existing or intended relationship. We hope that further interventions in this area will foster an environment that gives these youth less reason to fear disclosure of their HIV status and more freedom.
to be themselves in relationships and to find the intimacy in which disclosure means the revelation of oneself.

References


