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**Experiences of young adults growing up with innate or early acquired HIV infection – a qualitative study**

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**Conflict of interest**

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## **Abstract**

**Aim.** To explore the experience of young adults growing up and living with HIV in urban Sweden.

**Background.** HIV has become a widespread pandemic. Effective antiretroviral treatment has dramatically increased the survival rate of infected individuals such that HIV-infection is currently considered a chronic disease where treatment is available. Data concerning the experience of living with HIV since early childhood is scarce and more empirical knowledge is needed in order to direct the development of adequate care and interventions for this growing demographic.

**Design.** Exploratory qualitative study.

**Method.** Semi-structured interviews were conducted with ten HIV-infected young adults over the period from January to August 2008. Transcripts of the interviews were analysed using qualitative content analysis.

**Findings.** The analysis revealed five categories illustrating the experiences of growing up and living with HIV in Sweden: *1) to protect oneself from the risk of being stigmatised, 2) to be in control, 3) losses in life but HIV is not a big deal, 4) health care/health care providers, and 5) belief in the future.*

**Conclusion.** It is essential to offer a safe, trustworthy and professional health-care environment during the upbringing of HIV-infected children. Evidence-based interventions are needed to improve care and support, particularly regarding the handling of stigma and discrimination.

## SUMMARY STATEMENT

What is already known about this topic?

- The number of children with an early-acquired HIV-infection reaching young adulthood is increasing due to the growing access to and good adherence to antiretroviral treatment.
- Stigma is a major issue for all people living with HIV, regardless of ethnic background.
- Various losses and threats regarding health and welfare, social life and productivity face young persons infected with HIV.

What this paper adds

- Stigma and discrimination may affect the life decisions of HIV-infected young adults, including their willingness to disclose their HIV status.
- HIV-infected young adults only feel open and free to discuss their HIV-status with health care professionals. These professionals symbolise trust and play a significant role in the lives of many HIV-infected young adults; in fact, some health professionals act as a substitute for friends and family. Therefore, both continuity among the involved health care professionals and a high quality of care are important.
- Although facing many negative aspects in life, HIV-infected young adults may have positive outlooks on their future.

Implications for practice/policy

- Health care professionals caring for HIV-infected young adults should be especially attentive to their patients' need for support in their daily lives, including how to safely and responsibly deal with sexuality.
- Evidence-based interventions are needed to improve care and support for HIV-infected children and their families, particularly in matters concerning stigma, discrimination and disclosure.
- Efforts to decrease stigma and discrimination of young people living with HIV are warranted on the societal and community levels as well as on a family level.

**Keywords:** Quality of life, young adult, adolescents, human immunodeficiency virus, stigma, loss in life, nursing.



## INTRODUCTION

Over the past 30 years, human immunodeficiency virus (HIV) has changed from being the unknown cause of a rare but serious disease to being one of the biggest social, economic and health challenges worldwide. By the end of 2009, an estimated 2.5 million children under 15 years of age were living with HIV worldwide (UNAIDS 2009) and in Sweden alone approximately 140 children under 18 years of age were living with HIV (L. Navér, personal communication, December 14, 2011).

Since 1994, a high acceptance rate for pregnancy-screening programs, combined with access to appropriate measures for preventing mother-to-child transmission, have resulted in a significant decrease of HIV infection in new-born babies in Sweden and other high income countries (Naver *et al.* 2006, Townsend *et al.* 2008). The number of children living with HIV in Sweden is nonetheless increasing due to the prolonged survival of infected children as well as immigration from countries with high HIV prevalence (Naver *et al.* 2006).

In countries with good access to treatment with combined antiretroviral treatment, HIV-infected children are considered to be living with a chronic disease and have a long life expectancy (Lee & Rotheram-Borus 2002, Wiener *et al.* 2007). In these countries a new generation of HIV-infected children, previously not expected to survive early childhood, is now reaching adulthood and having to adapt to living with a life-long and potentially life-threatening sexually transmissible infection. Providing care for this diverse group of HIV-infected children and young adults is complex and associated with challenges.

### Background

Up to date studies on the life situation of HIV-infected young adults are scarce; in a recent search of the literature we found only one Swedish (Christianson *et al.* 2007), two African (Bakeera-Kitaka *et al.* 2008, Li *et al.* 2010) and one Canadian study (Fielden *et al.* 2006). The Swedish study discussed risky behaviour, and indicated the lack of adult supervision, naïve views, alcohol and drugs taking, cultures of silence surrounding sexuality and a lack of awareness concerning the risks of infection accounted for this behaviour (Christianson *et al.* 2007). The two African studies were mainly focused on sexuality and growing up as an HIV-infected subject (Li *et al.* 2010, Bakeera-Kitaka *et al.* 2008). The study by Li *et al.* (2010) showed that adolescents negatively viewed their illness and that other social issues such as violence and poverty compounded their complicated situations. However, despite these stressors, most informants remained positive about the future and expressed their need for

health care support. The second African study by Bakeera-Kitaka *et al.* (2008) revealed knowledge gaps linked to reproductive health, HIV transmission, and contraceptive methods and suggested that improving motivations and consulting can generate hope for the future. The Canadian study (Fielden *et al.* 2006) pointed out that the needs of HIV-infected young adults are diverse; the study stressed issues surrounding stigma, sexual health and mental health. It also reflected on the importance of support, education and future planning as HIV-infected children transition into adulthood.

HIV infection is still connected with stigma and shame for the family. Previous family studies from North America in which one or several family members were infected with HIV have shown that the corresponding stigma and shame were associated with ostracism and, consequently, an impaired sense of emotional well-being and reduced competence of the children (Brown & Lescano 2000, Spiegel & Futterman 2009). As knowledge about the life situation of young adults infected with HIV since early childhood is restricted, more empirical knowledge is needed to direct the development of adequate care and interventions for this growing group.

## THE STUDY

### Aim

The aim of the study was to explore the experience of young adults growing up and living with HIV in urban Sweden.

### Design

Exploratory qualitative study.

### Participants

A convenience sample of HIV-infected young adults was recruited in order to achieve maximum variation in sex, age and sociocultural background. Due to a small population size, the intention was to include our clinical site's complete sample of young adults that fulfilled the inclusion criteria. The inclusion criteria were that participants should: 1) have a perinatal or early acquired HIV infection, 2) have been treated at a paediatric clinic in Sweden for more than five years, 3) be aged between 15 and 21 years, 4) have been informed about his or her HIV infection, and 5) understand and speak Swedish fluently. The study was performed at a paediatric university hospital clinic that cares for a large number of HIV-infected children in



Sweden. The fourteen HIV-infected young adults that met the inclusion criteria received written and oral information about the study by the nurse responsible for their care. Of the fourteen patients, four declined to participate; three due to their parents' advice and one preferred not to think about his or her infection. The remaining ten accepted the invitation to participate in the study. This cohort consisted of five males and five females, with a mean age of 18 years (range from 15 to 21 years). Six were born in Sweden and four were immigrants, seven had an African background and three had at least one parent with a Swedish background (all three born in Sweden). Five of the ten participants lived with one or both biological parents and the remaining five lived either with other legal guardians or by themselves. Eight of the participants had a verified mother-to-child acquired HIV infection, while the remaining two were diagnosed at an early age with the route of transmission unknown. All participants had been informed about their infection between 10 and 14 years of age.

#### Data collection

Data were collected over eight months from January to August 2008. A senior paediatric nurse that was not involved in the regular care of the participants performed all the interviews. After receiving informed consent from the potential participants (and the legal guardians for those younger than 18 years old), the interviewer contacted the participants and arranged for the interviews to be performed at a location chosen by the participant (hospital clinic or café). A semi-structured interview guide was created based on the pre-understanding of the first author's extensive experience as a senior nurse in the field of focus (Kvale 1996) and two pilot interviews were conducted in order to test the usability of the interview guide. These pilot interviews indicated that the interview guide was adequate for use and the material from the two pilot interviews was included in the present analysis.

The main subjects of the interview guide included general questions about the origin, family and living conditions of the participants as well as more specific topics concerning their experiences from growing up as an HIV-infected child in Sweden, stigma and sexuality. The interviews were conducted in the form of an open conversation, with the interview guide used as a support for the interviewer; follow-up questions were asked concerning topics introduced by the participant. The participant had control over when to start, pause and discontinue the interview. Each interview, lasting between 45 and 90 minutes, was tape-recorded and the first author transcribed the recordings verbatim shortly after each interview.

## Ethical considerations

Etichal approval was granted by the Regional Ethical Review Bord in Stockholm. Informed consent was obtained from all participants and in addition from the legal guardians for those younger than 18 years. All participants were informed that participation was strictly voluntary and they could choose to terminate their participation at any stage without explanation or impact on their present or future care. Due to the risk that participation in the interviews may give rise to thoughts and feelings that the participant may need help processing, all participants were offered support from the interviewer and, if necessary, referral to a counsellor. Special efforts were made to ensure confidentiality when transcribing and presenting the material; participants' names were replaced with pseudonyms.

## Data analysis

The interview transcripts were analysed using qualitative content analysis, a systematic approach for describing a certain phenomenon by objective means (Downe-Wamboldt 1992, Elo & Kyngas 2008, Graneheim & Lundman 2004). The first and second authors read the texts repeatedly, both individually and together, and discussed their findings until consensus was reached. Meaning units were identified, condensed and coded. The condensed units were compared with one another for differences and similarities and then sorted into sub-categories, which were clustered into five categories. The results were discussed among all co-authors during the entire analysis and writing process. Quotations representing the results were selected and translated into English. All names in the quotes were replaced with pseudonyms in order to maintain confidentiality. In addition, some linguistic changes were made to increase the clarity of the quotations without changing the content (Sandelowski 1994).

## Rigour

In order to achieve trustworthiness, the method of Graneheim and Lundman (2004) was applied. Quotations were used to illustrate the results and facilitate the readers' judgment of credibility (Elo & Kyngas 2008). To increase trustworthiness in the material, we strived for obtaining a mixed sample as regards age, sex and background. Furthermore, the interviewer was a paediatric nurse with experience on data collection but with no clinical experience on working with HIV-infected children, thus decreasing the impact of pre-understanding. In addition, to avoid the risk of data deviation from the actual content of the interview material,

the research team included two authors with very limited or no clinical experience with HIV-infected children or youth.

## FINDINGS

The results presented below are based on the interviews with ten HIV-infected young adults. The analysis of the interviews resulted in five main categories; 1) to protect oneself from being stigmatised, 2) to be in control, 3) losses in life but HIV is not a big deal, 4) health care/health care providers, and 5) belief in the future.

### To protect oneself from the risk of being stigmatised

The participants described living with HIV as living with a dark secret. Issues surrounding secrecy were important to the participants, most of whom expressed the desire to live without secrets in their lives. Interestingly, the secrets connected to HIV were not always those with the greatest impact on their lives; rather, the participants alluded to other secrets of greater importance, though they did not reveal the nature of such secrets to the interviewer.

In order to protect themselves from the risk of being stigmatised, the participants hid their HIV status and only declared their status in health care situations. In school and among friends, the participants pretended to be as healthy as the others. Even within the family, the topic of HIV was often taboo and discussion with close family members was rare. In fact, negative attitudes towards people living with HIV were sometimes expressed within the family. The participants mentioned different reasons for not discussing their HIV infection with family members, including protecting their siblings from stigma.

Ignorance and prejudice in society were considered more harmful than the disease itself. The participants expressed the fear that demonstrating any knowledge about HIV would lead to embarrassing questions about the source of their knowledge. Consequently, they choose to conceal their knowledge, even when others communicated incorrect information related to HIV. The participants seemed to use this silence as a strategy to avoid further stigmatisation.

Although medical treatment has become more manageable and made it easier to live with HIV today than it was in the early combined antiretroviral treatment era, maintaining secrecy about taking medicine was a major issue for the participants. Despite the risk of future resistance problems, the participants sometimes chose to interrupt treatment when travelling or partying in order to avoid the risk of revealing their HIV status. Peter described one situation in which he interrupted therapy during travel:

When I was in Spain last summer with my friends... It was difficult to have privacy and take medicines... I remember I was a bit careless and I [later] thought that the virus might have become resistant. I was there one week and during that week, I might have taken the medicine [only] three times.

The participants also expressed their worry that if their HIV status was discovered they could be accused of unaccepted behaviour within society, as if they were somehow personally responsible for their situation. The end result of such perceptions would be stigmatisation and discrimination in society, as demonstrated by Felicia:

I had a discussion with some people who said it could be acceptable if the virus was transmitted from parent to the child. But if you got infected through sex, people think you're the one to blame. I don't think that it is true, or it is never so that you want to become infected.

To be in control

The participants declared the wish to be independent in life and to have full control over who had knowledge of their HIV status. Participants related disclosure of their HIV status to fear and insecurity. The potential spread of rumours linked to HIV infection within the participants' small ethnic communities was one of their greatest concerns, as it could lead to isolation, powerlessness and alienation. Therefore, many participants struggled to maintain control over who received information and details about their life situation. Maria illustrated this fear of disclosure:

Yes, some I would tell. It feels good that they know. But some of them talked so much about me. I felt so sad. I would make a police report to those who talked shit about my name like that!

Alternatively, some participants believed they could maintain control and decrease prejudice and ignorance among their peers by being open about their HIV infection. Those participants who had told a friend about their HIV infection felt that life became easier when they had someone who was aware of their HIV status; the confidant often became an intimate friend. Participants also described their responsibility to provide information about HIV to their informed friend in order to support and help him/her in handling his/her reactions and feelings regarding HIV. Other participants had faith in a higher power; for instance, some of the participants with non-Swedish background believed that God had given them HIV as a

mean of testing their faith. They believed that God was in control over their lives and that if they lived faithfully according to their beliefs God would cure them of the disease.

Another aspect of control related to dealing with safe sex and the corresponding legal requirements. The participants in the study expressed the need for tools to facilitate an active, safe and responsible sex life. The participants were aware that under the Swedish Communicable Diseases Act (Smittskyddslagen 2005) they must inform their sexual partners about their HIV status before having any type of sex; failure to do so is to break the law. Despite the potential risk of penalty, participants sometimes found it preferable to break the law than to risk losing their partner as a consequence of disclosure. The participants stated that a change of the Swedish Communicable Disease Act (Smittskyddslagen 2005) is necessary to keep up with modern day society. Some of the participants reported to follow the Danish law instead of the Swedish law, as the Danish law only requires disclosure of positive HIV status before unprotected sex. Furthermore, other participants chose to abstain completely from sexual relationships in order to maintain control and in this way minimise the risk of any accusations of unethical behaviour or transferring HIV to others.

#### Losses in life but HIV is not a big deal

The participants mentioned various losses in their lives, such as feeling disconnected from their origin as a result of emigration or the loss of parents or siblings as a consequence of HIV infection, accidents or drug abuse. Although many conveyed feelings of sadness related to their losses, some indicated improvements in their lives after receiving legal guardians other than their biological parents. Participants that had been assigned foster parents due to the psychological or social problems of their biological parents (e.g., drug abuse) described a sadness related to the loss of one or both of their parents as well as feeling calmer and more secure with legal guardians that provided a safe and stable environment.

Another kind of loss discussed by some participants was the limited freedom to travel due to regulations prohibiting HIV-infected persons from entering certain countries. The participants experienced this as a potential restriction that threatened to affect their lives. For instance, such restrictions could lead to alienation in the sense that they could be prevented from working or studying abroad, unlike their uninfected peers. One strategy for overcoming this hurdle, and thus be able to travel abroad, was to conceal their HIV status; for example, some participants intentionally excluded information about HIV infection when applying for visas. Other participants chose not to lie and thus could not to travel to countries where HIV-infected persons were prohibited. The effect of such prohibitions was discussed by Sara:

I had not thought about it until the singer [referring to a public person who was open about his HIV infection] was not welcome to sing in that country. Then I thought, 'But God, its 2008!' I was pretty sad.

Despite the losses in life, several of the participants mentioned that over time they had developed an acceptance of their condition and did not feel that HIV was a big issue in their lives. In fact, some had discovered good consequences that emerged from their situations and many described feeling lucky to have a life and a future.

#### Health care/health care providers

The participants rated their paediatric care for HIV treatment as fairly good; they had been well treated at the hospital and had some influence over their long-term care, such as setting the time for regular consultations. Some of the young adults relied heavily on their health care providers, including social workers, physicians and nurses. They described the ease with which they could communicate with these professionals on any topic, including issues outside their medical problems, and indicated that they were “replacing” family. Maria summarised this phenomenon with the following:

If I'm sad or feel alone, I would call my social worker for an appointment... we can meet and talk not only about the test results.

In fact, all participants mentioned the importance and necessity of having someone with whom they could talk about their life situation. Although most seemed satisfied with talking to their health care providers, others expressed a desire to have a contact outside the health care system. As health care providers such as social workers are sometimes involved in the treatment of more than one family member, difficulties could arise when discussing sensitive topics. Some participants also felt that talking to a social worker was an indication that they had psychological problems, a point of view expressed by William:

No, I have not been feeling bad in that way. If you have to talk to the social worker, it feels as if you are a psycho.

Continuity in treatment and particularly in terms of the health care staff were important to the participants; knowing the staff members personally made it easier to address problems and issues. The need for health care professionals with appropriate knowledge concerning HIV

was also expressed, as health care staff lacking sufficient skills and knowledge about HIV induced frustration and anger among the participants.

The participants emphasised the importance of acquiring the necessary skills and support for living with HIV. Moreover, as young adults they felt ready to take on greater responsibility for their own treatment and thus transition from paediatric to adult care.

### Belief in the future

Despite the various problems the participants communicated, they also expressed a positive belief and attitude towards the future. Several of the participants with an African background declared that it was a wonderful relief to live in Sweden where they had access to excellent HIV-related treatment and support. Furthermore, they believed that they had many more opportunities for a successful future and a long life in comparison with young adults still living in their country of origin. The fear of developing a deficient immune function that might require the start (or alteration) of antiretroviral treatment was marginal and did not rob the participants of the courage to maintain a lifestyle similar their uninfected peers.

## DISCUSSION

### Discussion of findings

According to DeMatteo *et al.* (2002), stigma and discrimination can be a part of oneself, family and society. In the present study, stigma and discrimination was a major issue that governed the young adults in their decisions about how to live their lives. A recently published study focusing on adults infected with HIV found three different strategies for handling stigma and discrimination: to tell everybody, being partly open or disclosure to no one about the infection (Rodkjaer *et al.* 2011). In the present study we found that maintaining secrecy and being partly open about HIV infection were strategies employed by the participants to avoid and protect the family from prejudice and negative attitudes. Some of the participants simply avoided disclosure, while others consciously decided to lie.

The secrecy surrounding their HIV infection might be one of the factors contributing to the increased risk of behavioural and psychiatric problems among HIV-infected young adults found in previous studies (Bogart *et al.* 2008, Gaughan *et al.* 2004, Kemppainen *et al.* 2003, Howland *et al.* 2007, Spiegel & Futterman 2009). In this respect, parallels can be drawn between families living with HIV and families suffering from drug abuse or other factors that disrupt the family's social life. For example, when a drug addict becomes increasingly

isolated and self-centred, the family may try to protect both the addict and themselves from further embarrassment by withdrawing from others, a form of self-isolation and self-stigma that acts as an adaptive strategy for maintaining control of their life situation and avoiding stigma (Runquist 1998, Woodside 1988). Similar strategies seem to be used by families affected by HIV.

Control was another recurrent theme found in the present study; this theme has also been reported in studies focussing on HIV-infected adults (Carstensen 2008, Rodkjaer *et al.* 2011). In order to maintain control, the young adult needed to feel safe and confident, particularly in matters related to sexual relationships. Although the debut of sexual activity is a difficult phase for young adults in general, for those infected with HIV it is especially challenging. The fear of rejection, losing control over the situation or being stigmatised can inhibit participants from disclosing their HIV status to new sexual partners. This fear of losing control can also appear in platonic relationships; by telling a friend about their infection, they risk losing that friend's trust or respect. In order to be in control of their own lives and avoid jeopardising their relationships, most participants chose not to disclose their HIV status to anyone. This finding is consistent with studies involving HIV-infected young adults performed in African contexts (Li *et al.* 2010, Fielden *et al.* 2006, Bakeera-Kitaka *et al.* 2008).

Our participants expressed the need for increased skills for handling the legal requirements related to carrying a communicable disease, a finding in agreement with a previous study involving young adults with HIV in Sweden (Christianson *et al.* 2007). The participants mentioned that having sex without disclosing their HIV status might lead to feelings of anxiety concerning the potential for their partners to become infected with HIV and guilt over breaking the law. This indicates the need for better support for improving the ability of HIV-infected young adults to disclose their HIV status to potential sexual partners, as explicitly demanded by the Swedish Disease Act (Smittskyddslagen 2005). It would be interesting to contrast the disclosure concerns of the participants with those of young adults living in contexts with less strict legal demands on disclosure.

Experiences from loss of parents have been shown to be complex and related to concerns regarding social support, financial stability, security and health in a Ugandan context (Satzinger *et al.* 2012). However, the orphaned participants of the present study, living in a high-income context, did not raise such concerns and instead even expressed relief of benefitting from a more stable situation with new foster parents.

The young adults in our study emphasised the importance of continuity in their health care, as it facilitated problem solving and assisted with various issues. Continuity became



especially evident when the health care staff was used as substitutes for friends and family. Unfortunately, not all HIV-infected children in Sweden (and other countries) have access to specialised paediatric care (Socialstyrelsen 2009). The fact that shortcomings in treatment and care of chronically ill context-specific children and adolescents have been shown to increase risk behaviour when the patient reaches adolescence (Rydström 2007, Wiener *et al.* 2007) underpins the importance of care based on knowledge and skills. Previous studies have shown that it is important for all chronically ill children to have contact with health care professionals knowledgeable in the management of paediatric chronic diseases ( Lightwood *et al.* 1959, Spicer & Arul 1998); this finding is also applicable to children growing up with HIV. Furthermore, several studies have demonstrated that a good psychosocial and supportive environment throughout childhood and puberty is essential for HIV-infected children to cope with their infection, handle combined antiretroviral treatment (Hazra *et al.* 2010) and avoid unsafe behaviour when entering adulthood (Storm *et al.* 2005, Spiegel & Futterman 2009).

The young adults participating in the present study showed a positive view of their future and neither their historic nor present life situations seem to have much impact on this outlook. Their need for support similarly seemed to be independent of their individual backgrounds. Although the situation for young adults living with HIV infection differs around the world, a positive life view have also been reported in other contexts, including among HIV-infected young adults living in South Africa (Li *et al.* 2010).

Multiple factors impact HIV-infected young adults and their view of life, such as society's view on HIV, stigma and the family's health (Elkington *et al.* 2011). This indicates the importance of developing context-specific support mechanisms for providing optimal care, assisting HIV-infected young adults in their life struggles and reducing the fear of stigma and discrimination. As the lack of HIV-related knowledge in the general public was reported to be problematic by the participants in the present study, one strategy to ease their burden is to implement interventions aimed to increase the general public's knowledge about HIV. Finally, as the socio-cultural background of the population of HIV-infected children and young adults has common features in many high income countries, at least in Western Europe, the findings of the present study ought to be of relevance for nurses working with the target population in similar settings internationally.

## Limitations

The sample included a great majority of the young adults registered in paediatric HIV care in the region in which the research was performed; therefore, the results ought to represent the

experiences of young adults living with HIV in urban Sweden. In contrast, the experiences might differ for young adults living in smaller communities lacking specialist care.

## CONCLUSION

The findings of the present study support the current knowledge gathered from different contexts: despite a positive outlook on the future, growing up with and living with HIV as a young adult are related with issues surrounding secrecy and the struggle to avoid or cope with stigma and discrimination. For many of the participants, health care professionals were viewed as a significant aid in coping with HIV-infection and its consequences. Therefore, health care professionals caring for this group of patients should be especially attentive of their needs for support in handling their daily lives, not least how to deal with sexuality in a safe and responsible manner. Evidence-based interventions are needed to improve care and support for HIV-infected children and their families in how to handle stigma, discrimination and disclosure matters. Finally, efforts to decrease the stigma and discrimination experienced by young people living with HIV are warranted on the societal and community levels as well as on a family level.

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