

Original article

To Say or Not to Say: A Qualitative Study on the Disclosure of Their Condition by Human Immunodeficiency Virus–Positive Adolescents

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Abstract

Purpose: Human immunodeficiency virus (HIV)–positive adolescents face a number of challenges in dealing with their disease, treatment, and developmental tasks. This qualitative study describes some of the reasons why, and the extent to which, adolescents may or may not disclose their condition to others.

Methods: A semistructured interview lasting 40–110 minutes was conducted with each of 29 adolescents 12–20 years old, 22 female and seven male) living in Switzerland. Interviews were tape recorded and transcribed *verbatim*. The analysis of the content of interviews allowed us to identify salient topics (e.g., disclosure), which were then explored in detail.

Results: Of 29 participants, eight had not disclosed their condition to anyone outside the family, 19 had disclosed it to good friends, and 16 had disclosed it to some teachers. Four participants had engaged in public disclosure, and six of 10 sexually active teenagers disclosed their status to their partners. The attitudes toward disclosure among younger adolescents were mostly related to those of the parents, particularly the mother. Older adolescents, engaged in their search for autonomy, tended to decide independently what to say and to whom. Although foster/adoptive parents would often encourage disclosure, biological parents, especially HIV-positive mothers, insisted on not disclosing the adolescent's status for fear of stigma.

Conclusion: The health care team should systematically address the issue of disclosure with the adolescent and his family (or foster parents), the aim being to balance the right of the adolescent and that adolescent's family to maintain privacy against the concerns of sexual partners, as well as the adolescent's interest in divulging HIV status to relatives, school staff, and friends. © 2009 Society for Adolescent Medicine. All rights reserved.

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There are at least two reasons why human immunodeficiency virus (HIV)–positive adolescents may have difficulties disclosing their status. First, even in countries such as

Switzerland, which has campaigned against the stigma associated with acquired immune deficiency syndrome (AIDS) and HIV infection, a significant percentage of the population remains suspicious of infected individuals [1,2]. Thus, young people may hesitate to reveal their situation because they fear the reactions of their friends, their friends' parents, or other adults such as teachers. Second, they may also be indecisive because of the difficulty they have accepting their infection and because they do not feel like other, "normal" adolescents [3]. One can hypothesize that as their

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emotional and cognitive skills improve during development, older adolescents become increasingly likely to decide whether, and to whom, to disclose their condition.

Although a fair amount of literature addresses how and when to disclose to children and adolescents that they are HIV positive [4–7], little is known about HIV-positive adolescents actively disclosing their status or about the psychological correlates of such a disclosure [5,8] and its potential effect on therapeutic adherence. Also, although the disclosure of an HIV infection represents serious psychological and ethical problems for young people engaging in penetrative sexual intercourse, very little is known about how they manage these problems. The main objectives of this article are to describe the level of disclosure of status among adolescents who have acquired a vertically transmitted HIV infection, and the reasons given for choosing to disclose or not to disclose their HIV-positive status.

Methods

In Switzerland, most HIV-infected children and adolescents are treated by senior pediatricians specializing in infectious diseases and working in one of the seven university or large pediatric hospitals that participate in the Swiss Mother and Child HIV Cohort Study (MoCHiV cohort). Six of the seven centers agreed to cooperate in this study. In addition to the presence of an HIV infection, criteria for subject eligibility were age (12–20 years), no developmental disability, fluency in either French or Swiss German, and an awareness by adolescents of their diagnosis. The Ethics Committee of each participating hospital reviewed and accepted the study protocol. Subjects signed an informed consent form before the interview. All parents (including adoptive/foster parents) of adolescents less than age 18 years were informed of the study, and parents of adolescents less than age 16 years were requested to give their formal approval, in accordance with the ethical and legal guidelines that exist in Switzerland. Of 55 potentially eligible adolescents (40 girls), 42 were contacted to participate. Of the 13 individuals who were not, seven had left Switzerland, one had run away, and two had left the pediatric follow-up; in addition, it was determined that three were unable to give valid answers because of central nervous system (CNS) infection. Of the 42 patients contacted, 10 refused to participate and three did not turn up to the interview, leaving 29 adolescents to be interviewed (22 girls). The distribution of age, gender, and severity of the infection observed among those who dropped out was similar to that of the final sample.

All interviews were conducted in strict confidentiality by a perfectly bilingual interviewer (R.T.), a psychologist with experience in the field of AIDS/HIV and qualitative research but who was not involved in the clinical care of the adolescents. The encounters lasted 40–110 minutes in either French or Swiss-German, depending on the patient. The semistructured discussions included such issues as the participants' health status, feelings about the disease and treatment,

therapeutic adherence, social life, and the issue of disclosure. All interviews were recorded and anonymously transcribed verbatim. The interviewer provided a French translation of the Swiss-German cases to facilitate analysis by the largely French-speaking investigation team. Using the principles of grounded theory [9], the four main investigators (J.C.S., J.J.C., R.T., P.A.M.) had several encounters to identify and discuss the central themes and issues related to the process of disclosure. Content analysis identified several categories of answers related to the selected topics. A large table was constructed, listing the salient citations relevant to these topics (by participant). Using a coding system, we were able to match each interview with some of the participant's clinical status and laboratory results.

Results

Study sample

The median age of the subjects was 16 years. Twenty participants were Swiss, whereas the other nine, all girls, were mostly from Africa. The majority did not belong to an intact family, generally as a result of the loss of one or two HIV-positive parents (Table 1). Twenty subjects were still at school, six had a job, and three were unemployed. Eighteen subjects currently had at least one clinical manifestation of their disease or had had symptoms in the past. Four participants had been adopted at a young age without their adoptive parents receiving any information about the route of transmission of their infections (mother–child prenatal contamination). Table 2 summarizes the extent of disclosure by type of people targeted.

Table 1
Sociodemographic and clinical characteristics of study sample

Characteristic	Girls (n = 22)	Boys (n = 7)	Total (N = 29)
Swiss nationality	15	7	22
Foreign nationality	7	0	7
Lives with two biological parents	1	0	1
Lives with one biological parent	10	3	13
Lives with adoptive family	5	1	6
Lives in foster home / foster family	3	2	5
Lives alone or with roommates	3	1	4
Age 12–15 years	10	2	12
Age 16–20 years	12	5	17
In school	16	4	20
Working	4	2	6
Unemployed	1	2	3
Sexually active (penetrative intercourse)	8	2	10
Vertical transmission of infection	18	7	25
No information on transmission	4	0	4
No symptoms (category A ¹)	10	1	11
At least one clinical symptom (categories B and C) ^a	12	6	18

^a Categories B and C indicate the stage of HIV infection, according to the international grading system that applies to children and adolescents [23].

¹ Letters indicate the stage of HIV infection, according to the International grading system which applies to children & adolescents (23).

Table 2
Disclosure status of the participants

Disclosure status	Girls (n = 22)	Boys (n = 7)	Total (N = 29)
Disclosure within nuclear family only (parents/brothers/sisters)	5	0	5
Disclosure to family only (not any other person, friends or adult)	6	2	8
Disclosure to teachers	12	4	16
Disclosure to good friends	14	5	19
“Public” disclosure	3	1	4
No disclosure to sexual partners (among 10 sexually active adolescents)	4	0	4

The analysis led us to distinguish between passive and active disclosure. By passive disclosure, common among younger adolescents, one means that the decision to disclose was most often taken by the parents/foster parents who would frequently make the disclosure themselves or advise their children how to do so (e.g., to school staff). Active disclosure refers to the adolescent’s decision to reveal his or her condition directly (e.g., to friends, or sexual partner). For example, a 16-year-old boy said, “Earlier, my mother managed everything, but I’m in charge at school now.” Although it was not always clear from the transcripts who among the adolescent, the family, and the doctor would be involved in the decision-making process, the actual decision appeared to be more and more in the hands of the adolescents as they grew older and more autonomous. However, we found no systematic variation between younger and older adolescents in regard to the extent and the target of disclosure, although a difference was observed between those teenagers living with foster/adoptive parents and those living with an HIV-positive mother. In the latter instances, parents, most often the mothers, were more insistent on not disclosing even if the adolescent wanted to. As a 13-year-old girl explained, “My mother always says that not many people have to know. I would like to tell it, but I don’t dare” [tears]. A 15-year-old boy commented, “My mother told me that I shouldn’t tell anyone.... In fact, I’ve told three people, and I don’t want my mom to know.” The status of eight subjects was not known to anyone except their family. An 18-year-old girl said that even her brothers did not know about her HIV status.

Disclosure within the school setting or at the work place

As shown in Table 2, the status of half of the adolescents was known by at least one adult in the school, the head teacher or the school nurse, or both. In most cases, and especially among younger adolescents, the decision to divulge was taken jointly by the doctor and the parents. The condition of a 14-year-old girl had to be disclosed in her school when she was nine because another student bit her and she bled. Apart from the initial anger of the perpetrator’s mother, the adolescent claimed that she had no further problems. Furthermore, the same girl stated that having already

disclosed her status had made the entire situation easier, saying “I think that if I had told them [my friends] later [that I am HIV-positive], it would have been worse because they would have said I should have told them earlier.” In some cases, the family and/or the adolescent decided not to continue to disclose after experiencing some problems. For example, a girl and her family stopped disclosing after a teacher told all other teachers without the girl’s consent. In fact, many families and adolescents, with the physician’s approval, recommended not disclosing the condition within the school setting.

Active vs passive disclosure

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condition within the school setting. Therapeutic adherence was rated by both the adolescents and their doctors (who had access to the laboratory tests). It did not seem to be related to the decision whether to divulge the adolescent's infection.

Adolescents already outside the school system and working ($n = 6$) faced the same challenge. A 16-year-old girl who had to reveal her condition to stop rumors after a leak of information at her workplace explained, "Many workmates know because I decided to talk about it. In fact, there was a leak and I had to clarify some stuff, so really I had to go public about my disease at work, but that's something that one shouldn't feel obliged to do unless he works with dangerous objects."

Disclosure to peers

Given the significance of socialization in the adolescent process, the issue of disclosing one's HIV status to peers has a particular importance. Although nine participants reported not having revealed the information to any peer or friend, 29 participants actively divulged their status to at least a few close friends, usually quite selectively. For instance, a 16-year-old boy and a 20-year-old girl reported that the circle of informed people was very restricted: "Mostly [I tell] people I've known for 10 years who were my friends in primary school... but let's say that, yeah, you can count them on the fingers of one hand, maybe a little more... not a lot of people" (20-year-old girl). The proportion of those sharing their condition with peers was the same among younger and older adolescents, irrespective of the severity of the disease.

When asked for reasons for not disclosing their status to their peers, participants most often mentioned the fear of rejection or discrimination: "I'm afraid nobody will want to be with me anymore" (13-year-old girl); "You never know how people react, if afterwards they move apart or something like that" (15-year-old girl). Some participants insisted that the lack of knowledge in the general population may lead to inappropriate reactions: "There are nevertheless a lot of people... who do not really know the disease... and who think we are highly contagious" (16-year-old boy). "I think that people are very badly informed and they still see it in a very primitive way and I think it's a pity, but... that's how it is" (18-year-old girl).

For some youth, their seropositivity was considered as something very personal and intimate and they just wanted to keep it to themselves: "I don't really feel the need to talk about it" (15-year-old girl). "In fact, I decided that it concerned nobody but me" (19-year-old boy). Some participants were adamant about not disclosing their infection to anyone: "In fact, I don't imagine myself ever telling someone in my life, ever" (18-year-old girl). Interestingly, some of those who did not disclose to other peers/friends seemed to realize that hiding the disease was perpetuating the stigmatization that makes their lives more difficult: "... by hiding it you're giving the idea that there is something to hide" (15-year-old

boy). The decision whether to share one's status with friends was not associated with the stage of infection [23] nor did it appear to be correlated with therapeutic adherence, as rated by both the adolescents and their doctors.

Public disclosure

Although four adolescents decided to go public about their HIV status, there had been a specific incidence in two already mentioned cases: a leak at the work place and an accident in school (bleeding injury): "As soon as a kid knows it, everyone knows.... I live in a small place, it's very small...." The two others reported having no problems in going public and having never had a bad experience from it: "My teachers..., my family, my classmates all know...; it's not a problem.... I feel like everybody else" (13 year-old girl).

Disclosure to sexual partners

Of the 10 participants who reported having had penetrative intercourse, two sexually active boys and four of the eight sexually active girls had systematically disclosed their status to their partners. Among those girls who had not systematically disclosed their status, two had never shared the information with any partner, whereas two others had eventually decided to do so with some of their partners. A 15-year-old girl said, "Well, sometimes we didn't have condoms...and we would have sex, but I felt guilty.... He'd say that he doesn't care if he becomes HIV positive...but that would have been a problem for me.... I feel he was a bit careless ... he didn't quite realize what it means." One 18-year-old girl reported a traumatic experience upon disclosing her status to a boyfriend: "I've had around six or seven partners... from time to time; let's say with four partners we did not use a condom, although I felt guilty they didn't know about my HIV status [very moved].... My current boyfriend, knows...and now that I've told him, I regret it...it's just terrible for me... [tears] he left me.... I will never disclose my status again." Another 18-year-old girl said, "I always used a condom, but they don't know.... I am 18 years old and they are not people I will spend my life with.... I will not disclose my status now" In some cases, a participant would say that disclosure had become necessary because the condom had leaked or broken. One 18-year-old girl explained, "I had had unprotected intercourse with him... and my conscience wouldn't allow me not to tell...; he reacted well..., he wasn't angry.... You know, at that time I already took the pill so he felt he didn't need to use a condom ... I was so afraid to lose him.... The most difficult time was after that intercourse and the moment I finally disclosed... it took me a week...; during that week I wouldn't go out, I was in my room ... alone."

Discussion

This study offers a multifaceted description of the way adolescents in Switzerland cope with the issue of disclosure,

and explores why a few of them feel comfortable about it while most of them face serious emotional problems in dealing with the issue. After a quarter of a century of the acquired immunodeficiency disease (AIDS) epidemic and of Swiss public campaigns that fight stigmatization [1,2] being HIV positive is still a condition raising anxiety in, or rejection from, part of the population. Accordingly, most adolescents and families in our study restricted the disclosure of their infection to a small number of selected adults and peers of fear of reactions. Moreover, eight subjects and families did not share the information regarding their HIV status with anyone outside the family. The overall impression gained from the interviews was that our subjects had few people with whom they could openly discuss and share what it meant for them to be HIV positive. In fact, the interviewees sometimes became quite emotional when dealing with the issue of disclosure in detail. These results are similar to a recent exploratory study published in this journal [8].

Of 29 participants, 19 disclosed their serologic status to a best friend. However, other studies have found that, compared with adults, HIV-positive adolescents are less likely to divulge their status to a friend [8]. Also, some studies suggest that teenagers with nonvisible chronic conditions such as HIV infection have more difficulty in revealing their condition to their peers [10,11]. Many of these teenage individuals want to preserve the view that other people have of them and want to be as “normal” as possible. They believe that by not telling, they will be seen and treated like everybody else, although some admit that this secrecy makes their lives more difficult.

Currently, in Switzerland, there is no official reason for these youngsters to be identified as HIV positive within the school system. However, when children and young adolescents begin to attend camps or to be away from home for several days, parents raise the issue of medication adherence, and it often becomes necessary to share the situation with a teacher or with the school nurse. This is probably the reason why, in 16 cases of 29 in this study, the doctors, the parents, and sometimes the adolescents themselves decided to disclose the infection to some teachers despite the risk of informational leaks or indiscretions.

Disclosing one's HIV status to people that one dates and with whom one has sexual intercourse is obviously a major concern. Some of our participants chose not to disclose their situation at all to their boyfriends or girlfriends, and in some cases did not even dare to discuss condom use. As also reported by others [12], some of those who had revealed their status had had bad experiences such as having the partner break off the relationship.

There were no associations found between the participants' gender, age, nationality, and family composition and the extent and target of disclosure. One would have expected some degree of correlation between the adolescent's capacity to share his or her condition and his adherence to treatment on the assumption that those who are able to speak about their disease overtly would have less difficulty in taking their

medication (especially outside home). In fact, neither the adolescent's nor his family's decision to disclose the infection was associated with the rate of adherence with medication nor with the presence/severity of symptoms. One possible reason for this unexpected finding is that other factors more related to the psychological and social functioning of the adolescent and his family may play a role.

The study identified some factors which were correlated with the disclosing of one's status. Among younger adolescents, the decision to divulge one's status was linked with that of the parents (particularly the mother), while older adolescents tended to decide independently what to say and to whom. Older adolescents were also able to be more specific in discussing the potential positive and negative effects of such decisions on their friends and colleagues. The difference in terms of cognitive and reflective skills between younger and older adolescents was also well reflected in the statements by older subjects concerning the long-term potential negative impact of not disclosing one's status on the society's acceptance of HIV-positive individuals. However, although the process of disclosure differed between younger and older adolescents, its extent did not; in other words, there were equal numbers of individuals among younger and older adolescents who did or did not disclose their situation to others. The decision to divulge or not divulge their situation seemed not to be linked so much with their level of maturation but more to their own representation and family situation. Indeed, we found a difference between adolescents living with foster/adoptive parents and those who stayed with an HIV-positive mother. Although the former would often encourage disclosure and be open to discussion, the latter, especially HIV-positive mothers, seemed to advise the adolescent not to reveal his or her condition. In one of the few similar studies of young people with a vertically acquired HIV infection, Wiener et al [13] indicated that one reason that families avoid disclosure is their fear of the negative impact that the stigma can have not only on the child but also on the family itself. Adolescents may thus have decided not to reveal their condition as a way of protecting and being loyal to their families [14].

A few comments must be made regarding our sample. First, it contains more girls than boys, a characteristic that also applies to the entire sample of adolescents within the Swiss MoCHiV cohort. We do not know to what extent this may be due to a higher chance that girls contract HIV infection through vertical transmission, as suggested in a few publications [15,16]. Another characteristic of this sample is that only one of the 29 subjects lived with two biological parents. Moreover, one-third of the subjects' mothers had died, and one of five patients was an adopted child. These circumstances are closely linked to the fact that most HIV-positive children and adolescents in Switzerland have been infected vertically by an HIV-positive mother, in contrast with the situation prevailing in other countries in which many adolescents contract their disease through sexual intercourse or intravenous drug use [17–21]. This qualitative

study was strengthened by our access to a goodly number of HIV-positive adolescents who, under the assurance of confidentiality and ethical guidelines, expressed themselves openly and sincerely, which allowed a broad exploration of factors linked to their decisions to disclose the infection to others. However, we cannot assume the findings from these interviews reflect the whole range of attitudes, experiences, and behaviors among HIV-positive adolescents in Switzerland or elsewhere. In addition, we cannot assume that the profile of the nonparticipants is the same as the sample. Finally, the validity of some of the relations observed is limited by the small sample size. Thus, our results may not be generalized to all adolescents living with an HIV infection, especially those who have acquired their infection during adolescence as a result of unprotected intercourse, a group not represented among our subjects.

Despite these limitations, this study illustrates the importance and the impact of the issue of disclosure on these adolescents' everyday life and call for more research in this field. The interviews gave the impression that, for many participants, there is some benefit to not disclosing their situation, although a lot of energy is spent in keeping it secret. Also, as one young person rightly pointed out, by maintaining silence around this issue, one encourages to some extent the persistence of suspicion or rejection toward HIV-positive individuals in the society.

In conclusion, as recently stated by Johnson et al [22], these adolescents and their parents or foster parents would benefit from a systematic and ongoing discussion of all the issues linked with disclosure. It is part of the job of the physician in charge to ensure that such an exchange takes place on a regular basis, whether it be conducted by himself or by a mental health professional or a clinical nurse. The exchanges between the health care team, the adolescent, and the family have to take into account many factors, including the parents' opinions and HIV status, the adolescent's competence and own attitude, and to balance the right of the adolescent and that adolescent's family to maintain privacy against the concerns of sexual partners as well as the adolescent's interest in divulging HIV status to relatives, school staff, and friends.

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