

Coping with an HIV infection

A multicenter qualitative survey on HIV positive adolescents' perceptions of their disease, therapeutic adherence and treatment

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Summary

HIV-positive adolescents face a number of challenges in dealing with their disease and its treatment. In this qualitative study, twenty-nine HIV-positive adolescents aged 13 to 20 years (22 girls), who live in Switzerland, were asked, in a semi-structured interview (duration of 40–110 minutes), to describe their perceptions and experiences with the disease itself and with therapeutic adherence. While younger adolescents most often thought of their disease as fate, older adolescents usually knew that they had received it through vertical transmission, although the topic appeared to be particularly difficult to discuss for those living with their HIV-positive mothers. Based on their attending physician's assessment, 18 subjects

were judged highly adherent, 4 fairly and 7 poorly adherent. High adherence appeared linked with adequate psychological adjustment and effective coping mechanisms, as well as with the discussion and adoption of explicit medication-taking strategies. The setting and organisation of health care teams should allow for ongoing discussions with HIV-positive adolescents that focus on their perceptions of their disease, how they cope with it and with the treatment, and how they could improve their adherence.

Keywords: HIV; AIDS; adolescent; development; coping strategies; treatment; therapeutic adherence

Introduction

Adolescence is a complex developmental process that includes the progressive adoption of autonomy and identity [1, 2]. Like other individuals suffering from chronic conditions, HIV-positive adolescents undergoing highly active antiretroviral treatment (HAART) face a number of challenges related to these two developmental tasks [3–5]. On one hand, HIV-positive adolescents have to develop their identity, a sense of personal sameness and continuity paired with some belief in the meaning of their life and their role in the community [1]. HIV-positive adolescents have to integrate the fact that they are not as “normal” as their peers, that they have to take medication, and they have to accept life in a context of uncertainty about whether they will survive and for how long [6, 7]. Thus, beyond providing the medical follow-up for the HIV infection, health professionals caring for these young people must assist them in developing their autonomy as well as a stable identity by discussing the impact of the disease and its treatment on their everyday lives [8, 9].

On the other hand, as they progressively strive to gain their autonomy, which can be reflected in their capacity to manage their treatment without parental/other caring adults' support, it is inevitable at times that their adherence to treatment weakens [10–14]. The risk of low adherence is increased by the fact that an HIV infection is often “silent” meaning that, contrary to asthma or rheumatic disease, not taking medication is not immediately followed by observable consequences [15, 16].

To shed further light on the situation of these adolescents, a qualitative study was designed focusing on their health, lifestyle, treatment adherence and psychosocial characteristics. The objective of this paper is to describe the adolescents' perceptions of their illness, of their therapeutic adherence and of their participation in decisions regarding their treatment, with the idea that a better understanding by health professionals of these perceptions will assist them in improving the outcomes, both in terms of the adolescents' coping capacities and how to improve adherence to treatment.

Methods

In Switzerland, most adolescents suffering from HIV infections have acquired it vertically. They are treated by paediatricians specialized in infectious diseases – usually in university-based hospitals – who regularly meet to discuss treatment issues and to participate in research within the Swiss Mother and Child HIV cohort study, the Mo-CHiV [17]. Criteria for eligibility for this study were age (12 to 20 years), any type of HIV infection, no severe mental retardation, fluency in either French or Swiss German and knowledge of one's diagnosis. The target number of participants was set at around 30 because it was felt that the most common representations and issues could be covered with this number. Of the seven identified treatment centers, six agreed to participate: the team from the Inselspital (Bern) said they had no time to be involved. Among 55 (40 girls) eligible adolescents, three did not know their diagnosis, three were considered unable to give valid answers due to mental retardation and the others could not be reached and were thus excluded from the selection. Among the 42 potential participants, 29 adolescents were randomly selected and interviewed (22 females). The Ethics Committee of each participating hospital reviewed and accepted the study protocol. Subjects signed an informed consent form before the interview. All parents or adoption/foster parents of under-age adolescents (<18 years) were informed about the study and for those under the age of 16 years, the parents' formal written approval was obtained, in accordance with the ethical and legal framework in Switzerland.

A single bilingual interviewer (RT), a psychologist with experience in the field of aids/HIV, performed all interviews. He was not part of the health care team and was unknown to the subjects until the day of the interview. The encounter, which was totally confidential, lasted an average of one hour (40 to 110 minutes) in French or Swiss-German depending on the patient. The interview was based on a guided semi-structured schedule and covered several broad issues. These topics were first discussed with some of the physicians in charge of the patients and then with two HIV positive adolescents with whom the interview was pre-tested. All interviews were tape recorded and anonymously transcribed verbatim. The interviews in Swiss-German were translated into French by the interviewer to facilitate analysis by the largely French-speaking study team. Using the principles of grounded theory [18], the main investigators (JCS, JJC, RT & PAM) had several encounters to identify and discuss the central themes and issues emerging from the content of the interviews, which were reviewed several times without the assistance of specialized software. Content analysis identified several categories of answers related to the selected topics of this article. Also, at the time the interviews took place, physicians were asked to rate the therapeutic adherence of their young patients on a ten points scale from poor (one) to excellent [10], based on the clinical course and the lab tests. A coding system permitted the authors to match each interview with this rating.

Results

Description of the sample

Table 1 provides some background characteristics of the sample. A third of the subjects (N = 10) came from Africa or South America, some of them having been adopted by Swiss parents or living with foster parents. While the majority of subjects suffered from a proven vertically acquired infection, the information was missing for four subjects adopted during infancy. None of the participants had been infected during adolescence as a result of

unsafe sex or injecting drugs. As shown on table 2, the vast majority of subjects were under medication, although the treatment for one boy and two girls had been discontinued because of poor adherence or refusal. Eleven adolescents had never had any complications of their infection (clinical stages 1) while 18 had experienced at least one symptom, either earlier or at the time of the interview (clinical stages 2–4)².

Perceptions of the disease: a developmental perspective

Younger adolescents (<16 years) had a concrete vision of their disease. They knew that it was a transmissible infection; they mentioned the risk of a drop of blood or they had heard of a virus. However, no one could give an explanation of what this illness was, giving such explanations as, "Maybe I once heard about CD4 or viremia, but it doesn't mean anything to me.... I come here every month. They take blood... There are drugs that enter through a tube" (girl, 13 years). "My parents call them little soldiers, the CD4, but frankly, when they say that everything is fine, I don't really understand what it means" (girl, 14 years). Most older adolescents gave the impression of having been able to integrate what their disease was and what it meant to them: A 15-year-old girl who had researched the web by herself said: "Wow, you ask me what I know... HIV is the virus and if it increases in the blood,

2 World Health Organization, WHO Case Definitions of HIV for Surveillance and Revised Clinical Staging and Immunological Classification of HIV-related disease in Adults and Children, August 7, 2006. Available at <http://www.womenchildrenhiv.org/wchiv?page=charts-00-02>

Table 1

Selected background characteristics of the sample.

	Girls N = 22	Boys N = 7	Total N = 29
Vertical transmission	18	7	25
No information on transmission	4	0	4
12–15 years of age	10	2	12
16–20 years of age	12	5	17
In school	17	3	20
Apprenticeship	3	2	5
Unemployed/untrained	1	2	3
Employed	1	0	1
Live with two biological parents	1	0	1
Live with one biological parent	10	3	13
Live with adoptive family	5	1	6
Live in foster home/foster family	3	2	5
Live alone or with roommates	3	1	4

Table 2

Selected clinical characteristics of the sample, including the assessment of therapeutic adherence by the physician.

	Girls N = 22	Boys N = 7	Total N = 29
No clinical manifestation (stage 1)*	8	3	11
At least one clinical manifestation (stages 2-4)*	14	4	18
Currently on HAART	20	6	26
No current treatment	2	1	3
1-2 consultations a year	0	1	1
2-3 consultations a year	1	0	1
3-4 consultations a year	13	2	15
>4 consultations a year	8	4	12
Excellent/good adherence (perfectly/well compliant)*	14	4	18
Intermediate adherence ("fairly" compliant)	3	1	4
Poor adherence ("poorly" compliant)§	5	2	7

* World Health Organization, WHO Case Definitions of HIV for Surveillance and Revised Clinical Staging and Immunological Classification of HIV-related disease in Adults and Children, August 7, 2006. Available at

<http://www.womenchildrenhiv.org/wchiv?page=charts-00-02>

* as graded from very poor to excellent by the physician in charge of the patient, using both clinical and lab information

§ including one boy and two girls for which treatment has been discontinued (poor adherence/refusal)

then you get AIDS, your immune system fails and you can get all kinds of infections". An 18-year-old girl reported, *"I've known about my disease since I was six, but somewhere around age thirteen or fourteen I realized its importance and impact on my life.... You know, that's the age one falls in love.... well, actually that's adolescence".* An 18-year-old boy disclosed, *"It's important to think about my disease when planning my future... but I don't know how long I will live".* Some participants seemed to have an attitude of denial or rebellion. For instance, when asked about the importance of her infection in her life, a 19-year-old girl responded *"No importance at all... it's as if I hadn't anything wrong.... Well, I really have nothing".*

Exchanging questions, ideas and feelings about one's disease: a difficult task

The majority of subjects indicated that they had not discussed much how they had been infected, neither with their physician nor with their parents. That seemed to be the case particularly for youngsters living with an HIV-positive mother. A young girl stated, *"I am HIV-positive since my birth.... My mother... got the infection... when she was young [but] we have never discussed this together".* A 15-year-old girl living with her HIV-positive mother commented, *"One day, maybe when I was twelve, my mother said to me, 'Look you have to listen to me...' and she explained what I had.... She was afraid how I would react..., that I would probably hate her.... I don't want to discuss this with her because I see it can hurt her; in fact... she has burst into tears so often, asking, 'Why did I give you this illness?'"* An 18-year-old girl with several HIV-positive persons in her family, in addition to her mother, didn't even seem to

know exactly the origin of her infection: *"When I was 12 years old, I asked my mother why I had to take that [medication].... Then she told me... that she also had it... maybe before she got married, but she didn't know.... I don't know how I was infected".*

Medication taking: from parent's control to autonomous choice of strategies

The younger patients depended on the parents to take the role of reminders. For several young subjects, the only reason for not taking medication was because of forgetting, usually under special circumstances: *"Last time I missed... we were with friends away from home"* (13-year-old girl). Older adolescents (>15 years) described more personal strategies: *"I have a little box with my medication in it, that I keep with me.... It is a routine I don't forget"* (17-year-old boy); *"It's the first thing I do when I wake up..."* (19-year-old boy). Some mentioned the use of cell phones or alarm-clocks: *"I put reminders on my cell-phone... since I use it twice a minute, I simply can't forget, it's clear"* (16-year-old girl). Some put post-it notes on mirrors and others put their pills in the chocolate box they use for their breakfast.

Developing specific strategies becomes increasingly important as the adolescent grows older and goes away from home more often, participating in parties or camps or being invited to stay overnight elsewhere. The majority of the subjects report that they don't reveal their condition to their friends and consequently take their medication secretly. Thus, a 15-year-girl reported, *"At school, I used to go to the toilets.... Swallowing the tablets doesn't take much time".* Other older adolescents had developed more automatic strategies and taking the medication outside one's home seemed to have become a routine: *"I always have pills with me... I have tablets in my pocket... I ask for a drink, even at a bar and I quickly swallow the pill"* (18-year-old girl). A few adherent subjects seem to have overcome the difficulty of swallowing medication in the presence of friends. For example, a 15-year-old boy reported, *"When I was younger, my father used to advise the parents when I would sleepover at a friend's home.... Later, I used to go to the toilet, but now if I stay with friends I know, I don't do it secretly".*

Interestingly, those participants who were less explicit about their strategies appeared to have a lower adherence rate. For instance, a 13-year-old girl with intermediate adherence said, *"I don't have any real strategy, it's just my mother who reminds me";* another non-adherent 17-year-old girl reported, *"No, it comes naturally; I just tell myself that I shouldn't miss it".* Some younger adolescents didn't seem able to anticipate how to deal with the issue of medication taking when left alone with this responsibility: two 14-year-old girls questioned about any kind of strategy they could imagine to remember to take their pills answered that they had never thought about it.

Therapeutic adherence: linked with attitudes towards the disease

Table 2 displays the therapeutic adherence rating according to the doctors. Most subjects were rated as very adherent with their treatment (>7 on the scale), while 4 out of 29 were rated as intermediate (5–7 on the scale) and 7 as poorly adherent (<5 on the scale). Although medication taking among adherent subjects seemed to have become a part of their existence, it was still not perceived as a real routine. For instance, a 16-year-old girl reported, *"I am happy to have medications; thanks to them, my viremia is low... but on the other hand, when you feel so well, then you don't always want to bother about taking them regularly.... I admit that taking my medication has never been an automatism; I have to force myself, even now"*. An 18-year-old female subject also said, *"Taking medication is just... it's just shit"*. Some mature respondents brought more abstract reasons for being adherent. For instance, a 16-year-old girl reported: *"I am, however, very careful because the medication is very expensive.... The price keeps me from forgetting; at least as far as I am concerned... not taking them is like throwing money out the window"*.

In general, the adherence rate reported by the physician appeared to be lower among older adolescents (>15 years) in comparison with younger subjects: while the mean rating among 12 to 15 year old was 8.3, it was only 6.2 among those 16 years and older. Additionally, it appeared that those with a low adherence rate had developed an attitude of rebellion or denial towards their disease. A 17-year-old girl reported, *"Having medication taking as the center of one's life is just a pity"* and another 18-year-old girl disclosed, *"I was in charge of my medication... and shit... I wanted to be normal;*

I wanted not to have to think about it all the time". The presence of side effects was never mentioned as a cause of poor adherence.

The role of doctor-patient relationship in the treatment

With some nuances, all our respondents except one expressed how good their relationship with their doctor was. However, although the overall feeling about the quality of the relationship with the physician was good, the nature of this relationship and how the issue of treatment was tackled (doses, frequency, type and number of medications) seemed to vary from one situation to another, from a fairly paternalistic type to a more collaborative one. This was independent of the age of the respondent, but was probably more as a result of the pattern of communication used by the physicians. Several – mostly adherent – adolescents reported being involved in the discussion about their treatment. For instance, a 17-year-old girl stated, *"I do make suggestions... everything I want to say, I say... and then my doctor says yes.... I once proposed to take my pills differently and he agreed"*. Nevertheless, several patients said that they did not really have something to say about the nature of their treatment, and some would even hide the problem they faced, in terms of therapeutic adherence, from their doctors. For instance, a poorly compliant 14-year-old girl said, *"Once I was vomiting every time and my mother suggested I should stop taking my pills.... Of course, we didn't say anything to the doctor"*. A non-adherent 16-year-old boy declared *"Tssss.. they have always chosen my medication for me.... I just had to follow orders"*.

Discussion

The results reported in this paper were drawn from a study of twenty-nine HIV positive adolescents who all knew their diagnoses and had undergone or were currently undergoing HAART. To our knowledge, our research is one of the first in-depth qualitative studies conducted in Europe on a substantial clinical sample of HIV-infected adolescents. Our careful assurance of confidentiality and respect of ethical guidelines allowed these adolescents to express themselves quite openly and sincerely, lending insight to their individual perceptions, attitudes and behaviours regarding their conditions.

Regarding the sample, there were more girls than boys, as is the case within the entire Swiss MoCHiV cohort. We do not know to what extent this is due to chance or if it reflects a greater vulnerability of male children to the HIV infection, who may have died earlier from their disease, as suggested in other publications [19, 20]. Only one out of the 29 participants lived with both biological

parents, while a third of the subjects' mothers had died and one out of five patients was an adopted child. Such family patterns are closely linked to the fact that most of the HIV-positive children and adolescents in Switzerland have been infected vertically by an HIV-positive mother, in contrast with the situation in other countries where many adolescents contract their disease through sexual intercourse or intravenous drug use [21–23].

Contrary to the findings of a qualitative study of Canadian adolescents [24], the adolescents of this study appeared to be fairly well oriented about the nature of their disease and treatment. Several patients reported, however, that the specifics of their condition were not discussed with their parents much and some of them had actually resorted to the internet for information. Most of the subjects living with an infected mother expressed how difficult it was to raise this topic with her, given the guilt, torn loyalties and emotional dilemmas it

inevitably evoked [25–27]. Younger adolescents considered their condition as a kind of fate, apparently living with the disease without reflecting on its meaning to them or on how they had acquired it. This absence of in-depth reflection may be attributed to the pattern of concrete thinking that is characteristic of early adolescence or, as found in a qualitative study run in Africa, may be linked, for some orphan subjects, to a difficulty in overcoming the bereavement they face [27]. Older adolescents, who were developmentally more capable of abstract thinking, tended to see their condition less as fate and more as an infection they had received through the transmission of a virus from their mothers. Other insights gained from the interviews also underscored the importance of effective communication between health professionals and HIV infected adolescents. Given the apparent difficulties for these patients to talk openly about their disease and their condition, health professionals should be encouraged to undertake exploratory discussion with infected adolescents as well as with the families, in spite of the strong emotions of fear, sadness, or guilt which may ensue. This is particularly needed when a parent is also living with an HIV infection, as questions pertaining to the source of transmission of the disease appears to be highly emotional and difficult to approach [27, 28]. The phenomenon observed in this study in which some older adolescents progressively rejected their disease and treatment needs to be anticipated from the very beginning of adolescence, and those subjects (and their families) who have difficulties in accepting their condition should be offered early psychological support [29].

Three quarters of our subjects were considered by their physicians to be highly compliant with their treatment regime (table 2). The rating achieved in our sample, based on lab tests and the physicians appraisal, is somewhat higher than that self-reported in two USA-based studies of youths in the same age range [30, 31] and much higher still than another USA-based survey of 32 adolescents (13–21 years) of whom 78% were judged non-compliant [13], as assessed by a review of the patients' charts. However, in a recent quantitative study from Ethiopia, the non adherence rate over the last seven days, as reported by parents among a sample of 390 subjects (half children/half adolescents) was as low as 13% [32]. One has to recognize the difficulty linked with any comparison in this field, since both the size, age range and adherence measurement differ greatly from one study to another.

While the results suggest that most of our older subjects could integrate their disease with the development of self, a few exhibited an attitude of refusal or denial of their condition that appeared to result in low adherence. This finding is consistent with a study focusing on identity development among HIV positive teenagers [6]. A Belgian study of HIV positive children also linked adherence to personal psychological attributes and

coping strategies (e.g., denial versus acceptance) with the authors concluding that “coping with HIV and the process of establishing good adherence may be interrelated” [33].

Although a progressive assumption of responsibility for taking one's medication properly belongs to the process of increasing autonomy during late adolescence, the drop in adherence observed in some older adolescents may suggest they have not been prepared to take over this task adequately [12, 34]. The account of two 14 year-old girls who could not imagine coping with their treatment without the oversight of their parents underlines the importance that health providers also anticipate the younger adolescent's acquisition of autonomy and its impact on adherence [15], raising the discussions of self-management as it becomes developmentally appropriate. Actually, many of our participants offered creative ideas to ensure or improve their own adherence, a finding that could encourage health professionals to systematically ask these adolescents for their own views and solutions, thereby augmenting their patients' sense of autonomy and preparing them to manage medication on their own.

In a similar way, the results suggested that adherence was linked with the kind of relationship established with the health care provider. Some subjects vividly described how they were able to find new adherence strategies when openly discussing with their physicians about how to improve the situation. The reverse is true as well: the fact that some subjects would hide their episodes of non adherence from their doctors appeared related to the fact that these physicians offered a more paternalistic kind of relationship in which the adolescents felt they would be judged instead of being helped. Even some of those subjects who claimed to have good relationships with their doctors did not always admit to missing medication. Although this is probably inevitable to some degree, improved provider communication grounded in a non-judgemental, non-paternalistic attitude may positively affect therapy adherence.

Many of the limitations of this study may be attributed to its qualitative and cross sectional nature, which does not allow for firm causal relationship and inferences to be gained, regarding the link between various personal and environmental factors and the attitudes and behaviours of the participants. The comparisons of the compliance ratings observed in the current study with those of other studies are tempered by the fact that although our measure was based on laboratory tests and clinical characteristics, it was qualitative and does not perfectly reflect the amount of missed medication. There is also the possibility that the adolescents excluded from the target population ($N = 13$) may have a higher rate of poor adherence. Additionally, we cannot assume that the interviews reflect the whole range of attitudes and behaviours among HIV-positive adolescents, considering that about half of the adolescents living

with HIV in Switzerland were not included in the sample.

Based on our results, practical recommendations are suggested for professionals treating HIV-positive adolescents that could help improve the quality of life of these adolescents and their adherence to treatment. Firstly, they should foster an open discussion of the infection with patients and their families, while allowing for the exploration of the underlying emotional dimension, especially among those in which the mother is also infected. Secondly, in an attempt to improve adherence rate, they should inquire directly about it and encourage patients to propose their own solutions to improve it. Finally, they should anticipate the potential problems of denial and rebellion which can arise during the adolescent process, especially with those patients in the earlier stages of adolescence. Although this probably applies to any adolescent with a chronic condition, the fact that the HIV infection is often not symptomatic among these

young people makes it more difficult to take medication without being able to feel any positive effect on their health.

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Annex: Semi-structured questionnaire (main questions, not necessarily addressed in this order)

Your family: Who do you live with? How would you define your relationship with your parents/guardians? How would you define the relationship with your siblings? Are there conflicts in your family?

Your lifestyle: Overall, do you think that your health is good? During the last 30 days, have you used any of the following substances...? Do you have a boy/girl friend? Have you ever had sexual intercourse? How many partners have you had in the last year? What kind of contraception do you or your partner use? Does he/she know about your disease? Have there been times when you have not used a condom? If yes → how many times? What are the reasons for not saying about your disease?

The disease: Who knows about your disease? What do you know about your condition? When did you learn that you were positive? Can you explain what the terms "viremia", "CD4" or "viral load" mean?

The treatment: Please describe your treatment. When and where is it more difficult to take your medication? What are the strategies you use to take your medication when you are not at home? Are there any strategies you use to remind yourself that you need to take your medication?

Are there strategies that you think might help you in taking your medication (even if you have not tried them yet)? Are there pills/doses that you did not take yesterday? How many? What are the reasons for not taking the pills/doses? What would make it easier to take your medication? Apart from the medication prescribed by your doctor, are you taking any other medications/alternative therapies (in the broader sense)? Which ones? Why? Do they help?

Your life: Do you have a best friend? Does he/she know about your disease? Do you currently study, work or both? How is your schooling/work going? How is the relationship with your teachers/employers? Do they know about your disease? Do you have friends at school/work? Do they know about your disease? What do you usually do on week-end or during your leisure time?

The health system: How would you rate your relationship with your health care team? What would be the things in this relationship that you would like to change or improve? What are the things in this relationship that you really appreciate? What are the things (if any) that you do not discuss with your doctor but you would like to discuss? What are the issues (if any) that you do not bring up to your doctor/team? Why?