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Full Title

Sexual health of young adults living with perinatally-acquired HIV in Paris, France: a qualitative study.

Short running title

Sexual health of young adults growing up with HIV

Authors' name

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List of abbreviations

AIDS	Acquired Immunodeficiency Syndrome
HIV	Human Immunodeficiency Virus
PHIV	Perinatally acquired HIV
STDs	Sexually transmitted Diseases

Abstract

We aimed to explore the sexual health of young adults with perinatally acquired HIV (PHIV). 18 to 25 years old PHIV participants were recruited in two tertiary care units in Paris. Sexually transmitted HIV was an exclusion criterion. Individual interviews were conducted. Transcripts were analysed using a semio-pragmatic phenomenological method. Twenty-five participants were interviewed from March 2022 to September 2022. Some of them renounced being in any romantic relationship. Those who disclosed their HIV status to their romantic partner reported that dating was more complex and those who didn't disclose reported that keeping HIV a secret was a significant mental burden. Young men tended to disclose their HIV status to their romantic partner whereas young women did not consider doing so before marriage. Many participants had to educate themselves about sexuality, through school or websites. Identified interlocutors for sexuality varied across participants. All participants were aware of U=U (Undetectable = Untransmittable) slogan. Despite that, participants remained worried about transmitting HIV to their sexual partners. That hindered their sexual satisfaction. In addition, they neglected the risk of unwanted pregnancies or STDs. In our study, knowing the U=U slogan did not provide reassurance to PHIV participants regarding the risk of onward HIV transmission. Furthermore, they showed very little concern for protecting themselves from their partner's STDs.

Introduction

According to the United Nations programme on HIV/AIDS, in 2021, 1.7 million children (aged under 14 years) and 36.7 million adults (aged 15 or over) worldwide were HIV-positive ¹. In France, around 1500 children and adolescents with perinatal HIV infection (PHIV) were accounted for in 2012 ². From 2010 to 2021, 581 children under 15 were diagnosed with HIV in France, most of whom were born in Sub-Saharan Africa ³. Just as their peers, young PHIV individuals explore their sexuality during adolescence ^{4,5}. However, they encounter specific challenges such as the fact that they are carriers of a sexually transmitted disease ⁶. Furthermore, as most PHIV youngsters living in France belong to communities from Sub-Saharan Africa, they grow in a cultural and familial context where HIV is associated with sexual intercourse outside marriage ^{7,8}. Furthermore, their family history is often marred by the illness and the death of one or both of their parents from AIDS ^{8,9}.

Comparative qualitative studies have demonstrated that these young people do not engage in more risky sexual behaviour than their non-infected peers ¹⁰ as the similar sexual health outcomes are similar regardless of HIV status: rates of sexual intercourse ¹⁰, mean age at first intercourse ¹¹⁻¹⁴, number of partners ¹², frequency of pregnancies ¹⁴ and frequency of unprotected intercourse ^{11,14}. Qualitative studies have explored their experiences of romantic and sexual life. HIV disclosure was among the most reported difficulty, whether it was to their entourage ^{7,9,15,16} or to their sexual partners ^{16,17}. Silence seemed to surround HIV and sexuality ^{8,18,19}, leading in some families to a postponement of romantic and sexual relationships ^{4,16,20}. Literature is scarce about the way these youngsters acquire education about sexuality and the consequences of HIV on their sexuality. Documented sources of information about sexuality include healthcare providers, peers and school, although their roles have not been specifically described ^{4,19,21}. Among the described repercussions on sexuality, authors have reported the intentional postponement of sexual activities and abstinence ^{4,19,22,23}, due to their fear of transmitting HIV to their sexual partners ^{19,23}, a worry that appears “to become relative with time” ²²). Condoms have been described as “reminders of the infection” ²² and some youngsters seem to have developed strategies to justify their use ^{16,19,24} (16, 19, 24). The advent of the U=U (Undetectable = Untransmittable) slogan in 2016, i.e. the fact that HIV cannot be sexually transmitted when viral load is undetectable ^{25,26} may have an impact on sexual health of PHIV adolescents. To the best of our knowledge, no qualitative study has explored this population’s sexual health since the advent of the U=U slogan. Furthermore, most studies have interviewed

adolescents of 19 years of age or under ^{16,20,22,23}, while young adults aged 18 years or over are more likely to provide a substantial narrative. Indeed, a larger proportion of young adults aged 18 years or older is likely to have had sexual experiences and to have hindsight on their own experiences.

To improve and update knowledge about young PHIV individuals' sexual health and their needs regarding sexual health, the objective of our study was to explore the sexuality of young PHIV individuals aged 18 to 25, using a qualitative approach. How do they manage their romantic relationships? How do they obtain information about sexuality? Does their HIV-status influence their sexuality? How do they protect themselves from their partners' STDs? What would be their recommendations for the promotion of sexual health among PHIV individuals?

Methods

Recruitment

The participants were recruited in two specialised units in the care of adolescents and young adults infected by HIV in Paris: the Immuno-Infectious Unit and the Espace Santé Jeunes – Guy Môquet Unit, both in Hôtel Dieu university hospital in Paris. The inclusion criteria were: to have had a diagnosis of HIV infection before the age of 13, and to be aged from 18 to 25 at the time of the interview. The exclusion criteria were: having been infected sexually by HIV and/or having an illness or a disability making participation in an interview difficult. The sampling was directed to obtain a balanced gender ratio. Each eligible participant known to the recruiting unit healthcare team was contacted by a member of the team, who invited him/her to take part in the study. If they agreed, they were put in contact with the first author (NI), a female postgraduate paediatrician (MD) with no clinical experience in HIV infection and not involved in the participants' medical care, but with expertise in adolescent medicine and trained in qualitative research. She did not know the participants before the study. She was introduced herself as a researcher interested in the experiences of the illness, and in romantic relationships in a broad sense (whether or not there was sexual intercourse), among adolescents and young adults living with HIV since childhood. Participants did not receive compensation or incentives for this study.

Ethics approval was obtained from the national ethics committee for the protection of individuals (examination committee Île-de-France IV) (N° 2021/111). The study was registered on clinicaltrials.gov (NCT05206123).

Data collection

Semi-directive, audio-recorded, individual, face-to-face interviews were conducted by the first author in their unit in hospital. Each participant was seen only once and no one else was present at the interview. At the start of the interview, the aim of the research and the mutual principles of benevolence, absence of judgement and authenticity were recalled. Once consent was obtained, an evolving interview guide (supplementary table n°1), not tested prior to the interview, took place in three stages: growing up with HIV since childhood; experiences linked

to intimate/romantic and sexual relationships; and opinions on the way professionals should support young PHIV individuals regarding their sexual health. At the end of each face-to-face interview, socio-demographic data and data related to the illness were collected. The audio files and socio-demographic data were made anonymous with a single reference number immediately following the interviews. Each participant was given a fictitious first name. Notes were taken after each interview by the researcher.

Supplementary table n°1. Semi-structured individual interview guide aiming to explore how PHIV participants experience their sexuality.

Growing up with HIV	Tell me what is it like to live with HIV. <i>Cues: in your relationships with your friends and your family? How was the diagnosis announced? By whom?</i> What do you know about the origin of the virus in your case? How does your family talk about the virus?
Romantic and/or sexual experiences	I am now going to ask you questions about your sexual and love life. How were your first romantic relationships / the first attractions you experienced? <i>Cues: Can you tell me about your first relationships with girls and/or boys? How did it manage to say or not to say about your HIV status?</i> How do you protect yourself against STDs or the risk of an unwanted pregnancy? <i>Cue: In what way has the virus changed things in your sexuality?</i> How were you informed about sexuality? How does your family talk about sexuality?
Their suggestions	In your opinion, how can we help and empower young people growing up with HIV to feel fulfilled in their love and/or sexual relationships? <i>Cues: If you were to summarise what we have said today, what is the most important aspect for you? Would you like to add anything else? If you had a magic wand, what would you have changed?</i>

Method of analysis

The audio-recorded interviews were transcribed in full and coded using the software programme Nvivo 11. The interview transcriptions were not returned to the participants. The analysis of the verbatim for the first ten interviews was conducted by NI and CH, an IT coder experienced in qualitative data analysis. Regular meetings took place to discuss the categories emerging from the data, first to reach a consensus on coding, and then to discuss mutual interpretations (data triangulation). The coding tree is presented in supplementary table n°2. A semio-pragmatic method was used for this analysis: this is a descriptive method categorising life experiences using the principle of data ordering, whereby the categories are linked on the basis of their hierarchical, logical and semiotic relationships ²⁷. This phenomenological approach is based on Peirce's theory of categories ²⁸ limiting bias arising from the researcher's interpretation, and thus reinforcing the validity of the results ²⁹. The emerging categories were

set out in the form of phenomenological categories, including sub-categories, each piloting the meaning of one aspect of the phenomenon under study. The analytical steps were as follows: word-for-word transcription; detection of contextual aspects; cursory then focused reading of the verbatim; description of textual and contextual signifiers so as to identify units of meaning; linking these units of meaning to elaborate homogenous ensembles, from which categories emerge; characterisation of the categories obtained according to Peirce's theory of signs; hierarchical ordering of the categories according to the logical relationships that are established between them; rendition of the meaning via a main, synthetic and integrative category. The participants were not asked for their feedback on the results. The COREQ directives were used for this article ³⁰.

Supplementary table n°2. Coding tree used to analyse the interviews on romantic relationships and sexual health of PHIV participants.

Names of the encoding nodes	Description
Culture	How people talk about HIV and sexuality within the family and the community: their knowledge and their representations.
Life trajectories	The impact of HIV on life trajectories: migration, injunction to get treatment, to give life, etc.
Living with the virus	
Living well with the virus	Strategies developed to better live or better cope with the virus, to be in good health, etc.
Difficulties living with the virus	Stigmatization related to the virus, perceived difference, feelings of injustice, poor health, etc.
Code of silence	Strategies for controlling information
Anti-viral treatments	Mental load linked to the need to take medication (taking it in secret), inadequate compliance with treatment, etc.
Stigma	Stigmatization, ignorance within the general population, reactions of pity, discrimination in healthcare, etc.
Empowerment	Responsibility, activism, maturity, etc.
Participants' knowledge and representations of HIV	Diagnosis announcement, knowledge about the origins of the virus, representations of the virus, desire to be cured, feelings of incurability, etc.
Family	Resource person, injunctions from family members, presence/support or not, etc.
Mental health	Mental distress, depression, suicidal ideation, suicide attempts, etc.
Sexual education	School, peer groups, family, Internet, caregivers, associations, etc.
Relationship with partner	
Divuligation	Ways of sharing information on HIV status, required conditions for disclosure, etc.
Procreation	Desire to know/ask questions about reproductive health, etc.
Romantic relationship	First love experiences, current romantic experiences, living as a couple, etc.
Sexual relationships	Fear of transmitting the virus to the partner, effect of the virus on sexual practices, other STDs, etc.
Helping young people	The young people's recommendations.

Results

Participant characteristics

Socio-demographic data

Thirty participants were contacted from March 2022 to September 2022. Two refused and three could not be reached despite their initial consent. Mean interview duration was 50 minutes (28 to 100 minutes). All interview took place face-to-face except for one (over the phone) as the participant was positive for COVID-19. Participants' characteristics are presented in table 1. Half of the participants were women (n = 13; 52 %) and median age was 21. Most participants had completed-high-school (n = 21; 82%). Most had at least one parent born in Sub-Saharan Africa (n = 22; 88%). For participants born abroad (n = 17; 64%), median age on arrival in France was 10 years. Among the 16 participants for whom one parent was deceased, cause of death was AIDS for 8. All participants knew they were HIV-positive at the time of the interview, with a median age when they learned their diagnosis of 12 years (8-17 years)³¹. However, five participants did not know the origin of their HIV transmission at the time of the interview. Fifteen participants stated they had already had sexual intercourse during the interview (n = 15; 60%). Data saturation was reached at the end of the 25 interviews.

Table 1. Detailed characteristics of the qualitative study participants.

First name ¹	Gender	Current Age	Birth region of the participant ²	Birth region of the participant's parent ²	Age at which they learned their diagnosis ³	Completed high school diploma
Patrice	M	24	SSA	SSA	> 12 years	Yes
Marcel	M	19	SSA	SSA	> 12 years	No
Julie	F	21	SSA	SSA	10 to 12 years	Yes
Eric	M	21	France	SSA and France	10 to 12 years	Yes
Alexandra	F	20	SSA	SSA	< 10 years	Yes
Tina	F	23	SSA	SSA	10 to 12 years	Yes
Fatima	F	22	France	SSA	> 12 years	Yes
Diane	F	20	France	France	10 to 12 years	Yes
Myriam	F	20	France	SSA	< 10 years	Yes
Lina	F	22	Asia	Asia et France	< 10 years	Yes
Matthieu	M	19	SSA	SSA	> 12 years	No
Emilie	F	18	SSA	SSA	> 12 years	Yes
Martine	F	23	SSA	SSA	< 10 years	Yes
Aurore	F	20	SSA	SSA	10 to 12 years	Yes
Sylvie	F	21	SSA	SSA	< 10 years	Yes
Salem	M	25	France	North Africa and France	> 12 years	No
Thomas	M	19	UK	SSA	> 12 years	Yes
Adrien	M	20	France	SSA	10 to 12 years	Yes
Marc	M	23	SSA	SSA	> 12 years	Yes
Ahmed	M	19	France	SSA and France	10 to 12 years	Yes
Laurent	M	23	SSA	SSA	> 12 years	Yes
Sarah	F	23	SSA	SSA	< 10 years	Yes
Romane	F	18	SSA	SSA	10 to 12 years	Yes
Thierry	M	18	SSA	SSA	> 12 years	No
Valentin	M	21	France	SSA	10 to 12 years	Yes

¹ First names were made anonymous.

² Birth regions are given, but not countries, to preserve participants' anonymity.

³ Participants' age at diagnosis is presented through categories to preserve anonymity. Current consensus in this area, validated by the WHO, recommends full information provided to the child around the age of 10-12 years (31).

SSA: Sub-Saharan Africa; M: male; F: female

Living environment of the participants

The participants were first of all invited to tell us about growing up with HIV, so as to provide contextual aspects to understand their experiences and their behaviour in their romantic and sexual relationships (supplementary table n°3). For several participants, living with HIV was difficult because it meant being different and dealing with the unfairness of a stigmatising illness shrouded in secrecy. However, in daily life, most participants were healthy, with participants living “just like anybody else” or “keeping their chin up”. This feeling of normality relied on being diligent regarding medication and keeping their HIV-status secret, which is possible given the invisible nature of seropositivity.

Supplementary table n°3. Categories linked to the PHIV participants' life setting.

Main categories	Sub-categories	Verbatim
Living with HIV was experienced as the injustice of having to live with a chronic, incurable disease, shrouded in secrecy.	HIV underscores the difference of the unfairness of having an incurable disease that requires lifelong medication.	<i>Thierry, 18 years old: Why do we get it? Why is there no cure?</i> <i>Sylvie, 21 years old: It's like a prison, because I am condemned to take medication all my life.</i>
	HIV is stigmatised for two main reasons: ignorance in the general population and, in African cultures, the association of the virus with immorality.	<i>Salem, 25 years old: Nobody is informed. I think that one person out of twenty outside [general population] knows.</i> <i>Tina, 23 years old: In Africa, when we know that a person is HIV-positive, we say it's an illness from the brothels.</i>
	Secrecy applied to the participants themselves, so that some of them did not know the origin of the virus at the time of the interview.	<i>Emilie, 18 years old: In my family, we don't really talk about it [the origin of the virus] so I don't know [how I was infected by the virus].</i>
However, for the best daily living with HIV, it	HIV infection is invisible.	<i>Eric, 21 years old: In fact, I live like anybody else; I consider that the illness is not visible.</i>

was necessary to conceal one's HIV status and to be diligent with medications.	There were two strategies to avoid being affected by HIV infection: concealing their HIV status and to be consistent with medication.	<i>Eric, 21 years old: In fact, it has almost no impact, given that nobody knows about it, except my family.</i> <i>Patrice, 24 years old: If you take your medication properly, you can do whatever you want.</i>
	Certain participants developed an ability to solve problems.	<i>Patrice, 24 years old: I manage to take a lot of things upon myself, I manage to cope without breaking down.</i>

Perinatal HIV has a negative impact on romantic life

Table 2 presents the four main categories relating to romantic life. At the onset of adolescence, most participants refrained from romantic and sexual relationships due to HIV status. Years after the onset of adolescence, at the time of the interview, several participants still refrained from romantic relationships while others dated. Participants who dated without disclosing their HIV-status reported a mental burden to keep it secret. Those who dated and disclosed their HIV status to their partner reported that dating was a complex and prolonged process.

Table 2. Categories related to the PHIV participants' romantic life.

Main categories	Sub-categories	Verbatim
At the onset of adolescence, most participants refrained from romantic and sexual relationships because they fear HIV onward transmitting, leaking out and rejection.	Intense fear of transmitting the virus emerged at their first experience of physical contact with a partner, secondary to a lack of knowledge about the routes of HIV transmission.	<i>Mathieu, 19 years old: At first I thought that the illness could also be spread by saliva. (...) I realised that in fact it is not spread by saliva, so... When I found out, I was angry with myself, of having messed up my relationships [...] I had deprived myself of what I wanted.</i>
	Fear of HIV transmission was coupled with a desperate need for reassurance by healthcare professionals.	<i>Patrice, 24 years old: It started with my doctor, my nurses, they gave me reassurance.</i>
	Fear of public disclosure was one of the worries.	<i>Mathieu, 19 years old: Well, imagine you break up and she lets it all out.</i>
At the time of the interview, some participants continued to postpone romantic relationships.	This led to the avoidance of any romantic relationship and/or to premature breakups.	<i>Laurent, 23 years old: I was content with just making friends and did not seek any romantic relationship.</i> <i>Tina, 23 years old: Well, my first love relationships they happened but didn't go well, because I avoided any attachment.</i>
	Some participants provided religious arguments or argued that they needed to focus on their personal development.	<i>Romane, 18 years old: I am in favour of after-marriage sexual relationships.</i> <i>Thomas, 19 years old: This was the first and the last time [relating to dating]. After that, I only thought of myself. Well, I didn't want a relationship any more.</i>

	<p>Some participants felt stuck: although they wanted to date and to let their partner know about their HIV status, but they did not know how to do that leading to avoidance of any relationship.</p>	<p><i>Adrien, 20 years old: To have a healthy relationship, it's best not to tell any lies, not to keep any secrets. (...) I don't know how I'm going to make this announcement, or even if I'm going to do it. I'm prepared to live alone so I that don't have to tell.</i></p> <p><i>Julie, 21 years old: There's a man right now, I suppose I like him, but as soon as he takes a step, I back away, I run away from him.</i></p>
<p>Participants who were dating without disclosing their HIV status reported a mental burden to keep it secret. This mainly concerned young women.</p>	<p>Certain participants, mainly young women, could not conceive telling their partner about their HIV-status outside marriage.</p>	<p><i>Martine, 23 years old: As I said, I don't think I'll tell anyone, except if it is my husband.</i></p> <p><i>Romane, 18 years old: I think that, apart from the person I marry, there is no need for me to say anything to anyone.</i></p>
	<p>Keeping HIV secret was a mental burden: finding a way to hide medication intake and worrbersome of HIV transmission.</p>	<p><i>Lina, 22 years old: He has to be in the bathroom or somewhere to make sure that (...) I open a bag of crisps and at the same time take it [my pills], this is what happens, every day.</i></p> <p><i>Fatima, 22 years old: If we do it without a condom, I'm going to be thinking "I hope that after this, nothing will happen. »</i></p>
<p>Participants who dated and disclosed HIV reported that disclosure made dating more complex. This mainly concerned the young men.</p>	<p>Certain participants, mainly young men, thought that not talking about their HIV-status would hinder their ability to build a healthy and lasting relationship.</p>	<p><i>Laurent, 23 years old: I wanted to tell her to make sure that we were starting a healthy relationship.</i></p> <p><i>Thierry, 18 years old: If I don't tell her, I cannot go forward.</i></p>
	<p>Telling about HIV meant forming a relationship within a more complex and longer process.</p>	<p><i>Mathieu, 19 years old: Each time you have a new girlfriend, you have to start from scratch, it's always the same process: thinking about it, how to say it, in what situation, is she going to accept it, is she going to tell everyone? It's really hard.</i></p>
	<p>The decision to disclose their HIV-status to their partner was made despite their entourage's advice not to do so.</p>	<p><i>Julie, 21 years old: She [her mum] made the decision not to say anything [to her husband], but I don't have to do the same.</i></p>

How to disclose HIV to a partner: an essential skill to navigate one’s romantic life

As experiences accumulated, participants developed a specific skill: being able to tell their partner about their HIV. Three conditions were outlined from their discourse (table 3): choosing a partner who belonged to a different social environment, choosing a partner with some degree of maturity and being able to cope with the partner’s reaction.

Table 3. Categories related to the PHIV participants’ conditions before telling a partner about their HIV status.

Main categories	Sub-category	Verbatim
When telling their romantic partner about their HIV status, participants identified three conditions to decrease the risk of leaking out and rejection.	The partner's social environment should be different, to reduce leakage risk.	<i>Salem, 25 years old: I did everything I could to avoid getting into a relationship with someone from my neighbourhood or from my town, just because I didn't want the news to get out.</i>
	Partners needed to show a certain maturity and open-mindedness, for instance in their position regarding the LGBTQIA+ community.	<i>Aurore, 20 years old: I prefer to wait [until I can say] ok you're now ready to hear it, to understand it, I'm not forcing you to accept it, but at least you won't react badly, telling anyone I don't know what. Laurent, 23 years old: I think that it [their opinion regarding the LGBT cause] has an influence in the same way.</i>
	The day the news is shared, one had to be prepared to receive their partner's reaction of fear and to be able to provide convincing medical evidence in order to reassure them.	<i>Laurent, 23 years old: I want her to have as much information as possible so that she's not frightened. Lina, 22 years old: To reassure him, I'll [share the information] in presence of a professional.</i>

Sex education for PHIV participants: common challenges and individual paths.

Categories relating to sexual education are presented in table 4. All participants mentioned a dual taboo on the subjects of sexuality and HIV within their families. In this context, many participants had to self-educate themselves, through information gathered at school and on websites. All participants learned the U=U slogan through their healthcare providers in hospital. Interlocutors varied: although most of them had been informed about it by their doctor or a nurse, some identified their psychologist as a key provider of sexual education while others recalled healthcare professionals in therapeutic education programs.

Table 4. Categories related to the PHIV participants’ sexual education.

Main categories	Sub-categories	Verbatim
There was a dual taboo concerning sexuality and HIV within families, with an injunction to abstain from sexual intercourse.	Participants reported a dual taboo in their families on sexuality and HIV.	<i>Thierry, 18 years old: In my family, we don't talk about the virus, the illness or sexuality.</i> <i>Julie, 21 years old: I grew up with the idea that " No, we don't talk about it in the family".</i>
	There was an injunction to abstain before marriage for young women, on the basis of religious arguments.	<i>Romane, 18 years old: My mother does not condone sexual or romantic relationships before a certain age, before marriage; it's obvious that she's not going to talk about it for the moment.</i>
	There was also an injunction to abstain for young men, but with the argument that romantic relationships would threaten their professional future.	<i>Mathieu, 19 years old: He [the father] is convinced that I don't need a girlfriend for the moment and that I should concentrate on my studies.</i>
In this context, many participants reported a need for self-reliance, even for sexual education, and mentioned that school and websites played an important role.	Several participants said that they were not given any information and that they had to rely on themselves to obtain information about sexuality.	<i>Ahmed, 19 years old: I relied on myself to get help, and I did some research.</i> <i>Alexandra: For everything about sexual education, I did it all by myself.</i>
	School was the first source of information for many participants. Nevertheless, the teaching content was often criticised because it was deemed too stigmatising.	<i>Marcel, 18 years old: Well, in reality, it's [source of information] school, because in my family, we don't talk about it.</i> <i>Sarah, 23 years old: When they talk about (...) sexuality at school, they do it to scare the children.</i>
	Many participants found answers to their questions by consulting more or less reliable websites.	<i>Valentin, 21 years old: If it wasn't for Internet, I don't know what I would have done.</i> <i>Mathieu, 19 years old: When I had my first telephone, [...] I used to get on porn websites.</i> <i>Tina, 23 years old: I once went on an AIDS-info website. I sent them an e-mail.</i>
	Participants had heard about the U=U slogan most of the time through their doctor or their nurse.	<i>Patrice, 24 years old: [the doctor] explained to me that I could do whatever I liked, like everyone else, as long as I took my medication.</i>
All participants had heard about the U=U slogan at hospital, with different providers being identified.	Some participants reported that psychologist were the best interlocutors as they had more time to provide further explanations and reassure them, contrary to doctors.	<i>Sarah, 23 years old: With doctors, when I am in private consultation, I don't ask questions. (...) During the therapeutic session [with the psychologist] that we had (...) that's when I understood.</i> <i>Fatima, 22 years old: In a medical consultation, I don't talk much. So as long as the doctor says everything is fine, it's all OK », that's enough for me, everything is OK, we don't talk about it too much. With the psychologist, we had time (...) I had lots of questions (...) I had never spoken about it before. As a result, I felt liberated. (...) This is when I asked if we needed to use a condom and I realised that in my case, there was no need, given that all is well and that it wasn't possible to pass on the virus.</i>
	Some participants thought that it was not appropriate to talk about sexuality with a doctor and seemed almost unable to receive any of their doctor's suggestions.	<i>Martine, 23 years old: Personally, I am Congolese, there are cultures in Africa where we don't dare talk about this kind of thing, even to the doctors themselves, it's quite taboo.</i>

Perinatal HIV has a negative impact on sexual health.

Table 5 presents the main categories relating to sexuality. Among sexually-active participants, fear of transmitting HIV to their sexual partners persisted even if they were aware of the U=U slogan and if they knew they had an undetectable viral load. This preoccupation had a negative effect on their sexual satisfaction. Seldom was mentioned the risk of contracting any STD from their sexual partner.

Table 5. Categories relating to sexual health among PHIV participants.

Main categories	Sub-categories	Verbatim
HIV transmission to their sexual partner was a central preoccupation, ranging from a feeling of guilt to an omnipresent fear.	The participants who had transitioned towards a sexually active life were very careful regarding medication intake.	<i>Martine, 23 years old: Concerning sexual intercourse, I didn't dare cross the line [having sex] (...) I know that before my first time, I took my medication every single day. I took a blood test to be sure that I was at least undetectable, because I really dreaded the idea that I could infect someone.</i>
	There was a certain anticipated guilt about the idea of transmitting the virus to a partner, which would imply a major existential upheaval.	<i>Fatima, 22 years old: Because I might destroy, so to speak, someone's life.</i>
	Among the patients who knew they were undetectable, some continued to use a condom, despite their knowledge of the U=U slogan, because they were afraid of transmitting the virus to their sexual partners.	<i>Mathieu, 19 years old: Even if they persuade you not to worry, there is no risk of transmission, in my mind, it will always be like that until the end. (...) For me, I think that I'll continue to a condom, even if I know it is undetectable, there will always be that fear of transmission.</i>
Fear of transmitting HIV to the partner had repercussions on their sexual practices and pleasure.	Some female participants avoided any oral sex, as they considered it was particularly at risk of onward transmission. Other participants simply abstained.	<i>Lina, 22 years old: It lasted an extremely long time, I didn't want my partner to give me pleasure like that [cunnilingus]. (...) it took a lot of people, different sources, evidence on the Internet to accept that.</i> <i>Thomas, 19 years old: I have to be cautious and avoid these urges.</i>
	Certain participants reported a complicated sexual life or incomplete sexual pleasure.	<i>Ahmed, 19 years old: But it has a negative effect [on sexuality]. It's true, sex life is really complicated, frankly even for me, I don't have any advice to give.</i> <i>Tina, 23 years old: It's as if I needed to control myself, as if I didn't have the right to be free (...) to make the most of it.</i>
Participants did not protect themselves from their partner's STDs and few considered the risk of unwanted pregnancy.	Protecting themselves against STDs of their sexual partners was not mentioned. When this was questioned, these infections seemed trivial to them in comparison with the severity of their HIV-status.	<i>Romane, 18 years old: I never thought about screening for STDs.</i> <i>Sarah, 23 years old: You have the worst thing of all, it can't be (...) any worse. (...) For me, if I am HIV-positive, anything like hepatitis and all that, I'm immune to it.</i>
	Five participants mentioned the risk of unwanted pregnancy.	<i>Sylvie, 21 years old: He decided: "I'm fed up with condoms, I want to do without them" (...) First of all I asked him: "I hope you're not going to make me pregnant".</i>

PHIV participants need to be reassured, and seek to normalize HIV.

In the last section of the interview, participants were invited to share their recommendations to help young PHIV individuals to enjoy their sexuality (Table n°6). Among recommendations that frequently emerged were the following: a great need for reassurance about their health and their sexuality; a desire to normalise HIV among their HIV-negative peers (through social media or TV series for example); and the need for healthcare professionals to reiterate information about sexuality.

Table 6. Categories related to PHIV participants' recommendations on how healthcare professionals should help them and empower them regarding their romantic relationships and their sexuality.

Main categories	Verbatim
Reassurance about the medical prognosis and the normality of their sexuality.	<i>Lina, 22 years old: I think it's important to be reassured at each appointment (...) and to be told that our sexuality is the same as for everyone else.</i>
Breaking isolation by creating social spaces for friendly conversations, without judgment, among peers and if possible within the families.	<i>Alexandra, 20 years old: Testimonies from others really helped me a lot.</i> <i>Julie, 21 years old: If only I had the family's support, it would be great.</i>
Taking the initiative to repeatedly inform young PHIV individuals about sexuality, and in particular explaining what to do in case of problems.	<i>Adrien, 20 years old: You can only feel fulfilled from the moment you know what to do in all circumstances and you know what to avoid.</i> <i>Valentin, 21 years old: I don't think they will talk about themselves. For me in any case, I wouldn't be able to.</i>
Changing people's representations of HIV infection by de-demonising and normalising HIV through TV series and the social media targeting their HIV-negative peers.	<i>Romane, 18 Years old: Educating others, the people around us, and showing them that it is not that serious.</i> <i>Alexandra, 20 years old: The militants (...) who talk about it on social media (...) they de-demonise what it's like to live with the illness.</i>
Continue to seek for a cure for HIV infection.	<i>Marc, 23 years old: One day, there will be a cure, which will eradicate this disease.</i>

Discussion

This qualitative study carried out on 25 participants aged 18 to 25 years old and living with HIV since childhood, enabled us to explore their affective life and their sexual health 7 years after the U=U slogan was created ^{25,26}. It shed light on their difficulties, their needs and their coping strategies. Romantic life was characterised by renouncement and difficulties generated by telling or not telling their romantic partners about their HIV status. The decision to tell or not to tell differed according to gender. Young men tended to disclose their HIV status whereas young women did not consider doing so before marriage. When it comes to education about sexuality, many participants reported solitude. All participants had learned about the U=U slogan at hospital, with varying interlocutors: doctors, nurses but also psychologists and healthcare professionals in therapeutic education programs. Despite their knowledge of the U=U slogan, participants remained very worried about the risk of transmitting HIV to their partners, with negative repercussions on their sexual health.

In our study, participants reported that dating was challenged and conditioned by their HIV status, which many authors have already reported in the literature ^{7,15,16,32}. In our sample, participants' gender appeared to influence their decision whether or not to let their romantic partner know about their HIV-status. Most young women considered that telling their partner was only required if marriage occurred, and this was not questioned. Contrastingly, young men questioned disclosure, and most of them wanted to tell their partner as they considered this allowed to build a healthier relationship. These gendered differences could be understood through the lens of intersectionality. This concept, (a term coined and concept developed by Crenshaw at the end of the eighties) is a reference to how individuals make decisions when at the intersection of several social stances ³³. We hypothesise that, in addition to their young age, their ethnic origin and their HIV-status, social and cultural norms weigh heavier on girls and women, to the point that the choice of whether or not to share their HIV-status is taken away. Further studies are required to confirm or disprove this hypothesis.

While quantitative studies have outlined the fact that young PHIV individuals show similar behaviour in terms of sexual health to that of their HIV-negative peers, the present qualitative research has evidenced the fact HIV-status had a negative impact on our participants' sexual health. Concerns of transmitting HIV to their partner was a central issue, as previously reported

in literature ^{19,22-24}. Having said that, we were surprised to observe that the knowledge of the U=U slogan did not change this preoccupation among our participants, including those who knew that their viral load was undetectable at the time of the interview. Furthermore, we could also wonder whether this preoccupation of transmitting HIV to their partners does not reflect the preoccupations of health professionals and the adults in the general population. We hypothesise that the extent of this preoccupation is such that it overshadows their partner's potential STDs, leading to a situation where they simply do not consider the risk of protecting themselves. We may have to rethink sexual education programs for this specific population, with a particular focus on the place given on preventing HIV onward transmission to their partners but also the place given on prevention from their partners' STDs.

Our study was the only one in France and one of the few qualitative studies that reported the experience of 25 young adults living with HIV since childhood. While it has provided new insights on the different modes of self education on sexuality, further research is needed. It is still unclear how young adults living with perinatally-acquired HIV find, understand and use information on sexuality and to what extent this information influences their decisions regarding sexual health. Furthermore, our study took place in Paris, France. Exploring sexual health of young adults living with perinatally-acquired HIV in Sub-Saharan Africa since the advent of the U=U slogan would be very valuable.

Some limitations need to be considered when interpreting our results. The primary limitation was the potential social desirability bias stemming from a single interview per participant, possibly contributing to the absence of significant themes such as sexual violence. Secondly, recruiting participants exclusively from two units within the same hospital limits the generalizability of our findings to other patient populations. However, participants were recruited from French tertiary care units where a significant number of young PHIV participants receive care. We reached out to other units in France, but they had too few eligible patients. Finally, the study's participants of individuals who attended their hospital appointments, thus limiting the generalizability of the findings to patients who do not attend hospital appointments. These patients have probably different concerns as they are more likely to have a detectable viral load.

Our study revealed that HIV-status had a negative impact on participants' romantic relationships and sexual health. Despite being aware of the U=U slogan, participants remained worried about transmitting HIV to their sexual partners, even among those who knew that their viral load was undetectable at the time of the interview. Although there cannot be a one-size-fits-all approach for sexual education, our findings underscore the importance of further

exploration into strategies to meet this population's needs in terms of sexual health. This include efforts to provide reassurance about sexuality, and about the importance of protecting themselves from other STDs. Promoting sexual health among adolescents living with a highly stigmatized sexually transmitted disease is a real challenge, but it is a responsibility that falls upon us as professionals.

Authors' Contributions

All authors have read and approved the final article.

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Additional Files

S1 provides description of the semi-structured interview guide. S2 provides the coding tree used to analyse the interviews. S3 provides categories linked to the participants' life setting.

Conflict of Interest

The authors have no conflicts of interest relevant to this article to disclose.

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