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## **Observational Study**

# Evaluation of the Impact of Human Immunodeficiency Virus Infection on the Mental Health and Quality of life of Children and Adolescents

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## Abstract

**Introduction:** HIV infection has been identified as a major cause of morbidity and mortality in children and adolescents. The vulnerabilities of Children and Adolescents Living with HIV (CAHIV) are multiple. Stigmatization or self-stigmatization may also be present. To our knowledge, no local study has yet looked at the mental health of these CAHIV. The authors' aim was to assess the impact of HIV infection on the mental health and quality of life of CAHIV followed in the unit.

**Methodology:** We conducted a mixed-method, cross-sectional, descriptive study. It took place from September 30, 2021, to January 31, 2022. It concerned children and adolescents living with HIV 1, aged 7 to 12 years, followed regularly at the CAHIV care unit of the Centre Hospitalier National des Enfants Albert Royer.

**Results:** 20 CAHIV were included, with 12 girls and 8 boys. The sex ratio (M/F) was 0.66. The mean age was 10.6 years, with extremes of 8 and 12 years. 13 (65%) CAHIV were orphans, including 5 (25%) double orphans, 5 (25%) maternal orphans, and three paternal orphans. 5 (25%) CAHIV had diffuse dermatoses. 5 (25%) had memory complaints and concentration problems. Sleepiness was the most prevalent psychosomatic symptom. It was present at 50% of CAHIV. 3 (15%) CAHIV suffered from mild depression according to the Hamilton Depression Scale. 17 (85%) suffered from anxiety according to the Hamilton Anxiety Scale.

**Conclusion:** HIV infection raises many psychopathological issues in CAHIV. Their diagnosis and management are essential to improve therapeutic compliance and reduce antiretroviral treatment failure.

## Introduction

Mental health is defined by the WHO as the state of well-being resulting from a positive sense of identity, the ability to manage thoughts and emotions, to establish social relationships, to learn, and to acquire an education enabling full participation in society [1]. In 2021, 88% of the world's 2.73 million [2.06 - 3.47 million] children and adolescents living with HIV (CAHIV) resided in sub-Saharan Africa [2]. In this region, HIV infection has been identified as a major cause of morbidity and mortality among children and adolescents. The vulnerabilities of CAHIV are multiple. They are often orphans of one or both parents and have been entrusted to different guardians over the years [3]. The early loss of parental figures can lead to affective deficiency and attachment disorders. Many have experienced late and/or accidental disclosure of their HIV status [4,5]. This late disclosure may lead the adolescent to develop adjustment or oppositional disorders or, in some cases, risky behavior. In an accidental situation, this can constitute a real psychotrauma. They have experienced delayed growth and puberty [6], which can have a negative impact on their self-esteem and perception of their body image. Added to this, may be stigmatization or self-stigmatization, in all their forms, which will condition the way they integrate into social, affective, and sexual life [7]. It can lead to anxiety depressive disorders, or even suicidal behavior or equivalents.

Mental health disorders have been reported at 25% to 50% of CAHIV [8,9]. When left undiagnosed and untreated, these disorders can lead to risky behaviors such as substance abuse, unprotected sex, poor adherence to antiretroviral treatment, psychological decompensation, and in extreme cases, selfharm or even suicide [1]. Prevalence studies suggest that between 10% and 50% of children, adolescents, and young adults living with HIV in sub-Saharan Africa have symptoms of depression, predicting poorer HIV prevention and treatment outcomes [10,11]. In our clinical experience at the CAHIV Care Unit, these children and adolescents often have a life course marked by early trauma of various origins: either the death or illness of one or both parents or abandonment, fosterage, or intra-familial adoption. No local study has yet looked at the mental health of these CAHIV. The authors' aim was to assess the impact of HIV infection on the mental health and quality of life of CAHIV followed at the unit.

## Methodology

The authors conducted a mixed, cross-sectional, descriptive study. It lasted four (04) months, from September 30, 2021 to January 31, 2022. It involved children and adolescents living with HIV 1, aged 7 to 12 years, followed regularly at the CAHIV care unit of the National Hospital Centre of Children Albert Royer (CHNEAR). The free and informed consent of the parents or guardians was obtained, in addition to the assent of the child or adolescent. The study was authorized by the management of the Albert Royer Children's Hospital. We conducted semi-directive interviews. We used an interview guide and internationally validated questionnaires. These were the Hamilton Depression Scale, the Hamilton Anxiety Scale, the Edmonton Psychosomatic Symptom Assessment Scale (ESAS), and the AUQUEI Quality of Life Questionnaire (primary picture). The Hamilton Depression Scale consists of 17 items graded from 1 to 4 to identify depressive symptoms. The anxiety scale comprises 14 items graded from 1 to 4. The ESAS explores psychosomatic symptoms over the last 24 hours. In this study, we focused on pain, fatigue, and drowsiness. The primary AUQUEI is a pictorial questionnaire comprising 32 items grouped into five life domains (health, family, school life, autonomy, and self-esteem). The principle is to assess the child's feelings in relation to each item. The questions on the Hamilton Depression Scale relating to genital symptoms (loss of libido and menstrual disorders) were not addressed. Auquei item 1 "At the table with your family, say what you're like" was changed to "Around the bowl with your family, say what you're like". In Senegal, meals are eaten around the bowl, not at the table. It was important to put the child back into an appropriate socio-cultural context to capture his emotions at this moment. These socio-cultural adaptations to the assessment tools were minimal. For Hamilton, the French term "effroi" was difficult for the children and had to be translated into Wolof, the main local language in Senegal, as "titangue bu reey". This can lead to bias. The low proportion of adapted or translated questions (less than 5% overall) ensures the metrological qualities of the tools used. A precaution was taken by the team. The results were discussed in a multi-disciplinary staff meeting, and the team noted good consistency. For a future study, it would be interesting to adapt the tool and validate a local version. Qualitative data such as children's drawings were collected and commented on. Children's drawings are powerful objects of elaboration and projection. They are both a message and a selfportrait. It's an intermediary space where children can express themselves without constraints. It is a medium for dreams, imagination, fantasies, and conflicts [12]. The analysis of the drawings was inspired by the T-Made methodology [13]. We focused on content and valence.

## Results

### Socio-demographic characteristics

20 CAHIV were included, with 12 girls and 8 boys. The sex ratio (M/F) was 0.66. The mean age was 10.6 years, with extremes of 8 and 12 years. 13 (65%) were orphans, including 5 (25%) double orphans, 5 (25%) maternal orphans, and three paternal orphans. 5 (25%) had diffuse dermatoses. They were all enrolled in elementary school (1 in CI class, 4 in CE1, 2 in CE2, 7 in CM1, 6 in CM2 class). They came from different administrative regions of Senegal. 17 were Muslim and 3 Christian. Their parents were unmarried in 62% of cases, divorced (14%) and married (24%).

## **Clinical features**

All were on Antiretroviral Therapy (ART). 15 (75%) were on first-line treatment and 5 (25%) on second-line. According to the WHO recommendation of July 2021, and the national guidelines, all patients with virologic suppression were switched to a dolutegravir ART regimen [14]. Over the study period, the treatment with zidovudine, lamivudine, and

nevirapine was the main treatment before the switch. The treatment with Abacavir, Lamivudine, and dolutegravir was used for the switch and also for the second line during the study period. The average duration of ART was 5.5 years, with extremes of 1 and 10 years. 3 (15%) CAHIV expressed concern about their studies. 2 (10%) expressed concerns about their family. 3 (15%) felt lonely. 5 (25%) verbalized fears and worries. 7 (35%) expressed feelings of sadness. 4 (20%) expressed anger and frustration. 2 (10%) expressed a loss of interest in usual activities (anhedonia). 10 (50%) wanted to understand their disease and treatment. 4 (20%) wanted to know what resources were available to support them. 5 (25%) had memory complaints and concentration problems. Sleepiness was the most prevalent psychosomatic symptom. It was present in 50% of patients (Table 1).

There were 3 (15%) CAHIV who suffered from mild depression according to the Hamilton Depression Scle. Also, 17 (85%) suffered from anxiety according to the Hamilton Anxiety Scale.

## **Quality of life**

There were 16 (80%) who had an impairment in the familyrelated quality of life domain, 15 (75%) had an impairment in the health domain, 6 (30%) had an impairment in the functional autonomy domain, 7 (35%) had an impairment in the school life domain and 2 (10%) had impaired self-esteem.

## **Drawings**

We asked the children to draw themselves either before and after the start of treatment, or before and after the announcement of their status. We present here a sample of these drawings (Images 1–4).

Psychosomatic symptoms	Number (n)	Proportions (%)	Average ESAS score (extremes)
Pain	12	60	2,4 [0-9]
Fatigue	7	35	1,5 [0-7]
Anxiety	5	25	1,25 [0-10]
Sleepiness	10	50	2,45 [0-9]



**Image 1:** Self-portrait of MG, 11 years old before starting ART. Comments: In this image (Image 1), 11-year-old MG appears disharmonious. Her support is not solid. Her existence is devoid of "color"; everything is perceived in black. She doesn't seem able to feel "positive" emotions. This image, MG's selfperception, dates back to the time when ART had not yet been initiated.



#### Image 2: Self-portrait of 11-year-old MG after starting ART.

Comments: In Image 2, MG's second representation of herself, she appears more harmonious in her physical appearance (more symmetrical legs). Her posture is more balanced. Her face is more relaxed, and she sees the world not in black but in color. The change in the proportion of her hands may reflect a greater ability to tackle the challenges of her life.



**Image 3:** Self-portrait of TD, a 10-year-old teenager, before the announcement of her HIV status.

Comments: In this drawing (Image 3), 10-year-old TD portrays herself with a facial expression reflecting many questions. TD's gaze is turned towards herself rather than forward.



**Image 4:** Self-portrait of TD, a 10-year-old teenager, after learning her HIV status. Comments: TD's evolution is striking through this representation of herself. She looks happier and more relaxed. Her gaze is directed towards the future. The time spent questioning herself has diminished in proportion to her self-image (Image 4).

## **Discussion**

## **Family history**

It was reported that 62% of CAHIV were born out of wedlock. Considering the cultural weight associated with out-of-wedlock

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pregnancies in Senegalese society, which is predominantly Muslim [15], we feel it is important to question the degree of emotional investment mothers make in their children. How do they perceive this child, witness to their transgression of societal rules? The mother is socially stigmatized, rejected, and isolated because of this transgression. This family history of rejection and stigmatization is passed on to the child. Indeed, Bergeret [16] tells us that the "prehistory of the child is in the history of its parents". This leads us to question the quality of mothering and attachment. The hypothesis of an avoidant attachment, in Mary Ainsworth's [17] sense of the term, is likely in these children.

There were 13 (65%) who were single or double orphans, including 10 (50%) from their mothers. In the cultural context of Africa in general, and Senegal in particular, the notion of orphan may differ from that of the West [18]. Indeed, in Africa, the presence of parental substitutes may allow the emergence of new father and mother figures. Indeed, the Ortigues couple already described the African Oedipus, the role of parents' collaterals in children [19]. However, the increasing westernization of Senegalese society is calling this paradigm into question. Indeed, recent studies on fosterage show the negative psychopathological repercussions of this social phenomenon [20,21]. In our current context, holding and handling necessarily require the presence of the biological mother, a "good enough" mother. In fact, 10 (50%) CAHIV expressed anger towards their late mother.

HIV causes the family unit to break up, with the premature death of one or both parents. Sometimes, even if the father is still alive, he is rejected by the maternal family as the person who caused the death of their daughter or sister. This is the case with the father of one of the children being followed. The feeling of anger towards the deceased parent observed in the majority of cases, reflected a breakdown in the family system, with the absence of a paternal substitute for some CAHIV.

## Quality of life and HIV

We found a deterioration in all domains (family, health, school life, functional autonomy, and self-esteem) of quality of life according to the AUQUEI. The health domain was the most affected, with a feeling of discomfort with treatment or illness expressed by 75% of CAHIV. This finding differs from the study by Thoni G et al, who found three domains to be impaired: family, health, and self-esteem [22]. Paradoxically, this last domain was the least affected in our study. This lesser impairment of self-esteem could be linked to the regular support provided by peer groups and social mediators to all the children and adolescents in the unit's active file.

## Hospital attendance and psyche

There were 10 (50%) children and adolescents who reported problems understanding the disease and treatment in the ESAS. Likewise, 3 (15%) expressed feelings of loneliness. For some, the announcement process had not yet been completed. These children were not only required to go to hospital, but also to take medication, and had been doing so regularly for several years. So what could be going on in their psyches? Does this make them different from the other children around them? These are two legitimate questions to ask. We have noted that the feeling of being different leads them to a situation of self-stigmatization and a tendency to isolate themselves. This underscores the importance of early diagnosis and appropriate, ongoing communication at every stage in the overall management of CAHIV.

#### **Psychosomatic symptoms and HIV**

In our study, the presence of psychosomatic symptoms (drowsiness, pain, and fatigue) reinforces the close links between psyche and soma. HIV insinuates itself into the body and psyche. Its presence generates physical and/or mental pain, and a feeling of continuous fatigue. These symptoms are a source of anxiety. All these aspects have negative repercussions on night-time sleep, hence the strong tendency to daytime sleepiness. The latter has a negative impact on learning processes since memory consolidation takes place during deep, slow-wave sleep. In this study, 7 (35%) CAHIV had difficulties at school.-

As reported, 5 (25%) EAVVIH had dermatoses. These were associated with poor compliance with treatment. These skin lesions can also be linked to a lack of psychic and physical contentment of the skin. According to Anzieu [23], these cracks in the skin refer to an over-fullness translating into a continuity of the two skins.

## Anxiety, depression and HIV

This study shows an 85% prevalence of anxiety and 15% of depression among CAHIV. This is in line with other studies [10,11]. These studies have reported prevalences ranging from 10% to 50%. HIV infection is a risk factor for the onset of depression in CAHIV. The high prevalence of anxiety in our population was probably linked to the socio-environmental and communication difficulties faced by CAHIV. In fact, they were plagued by numerous questions, with no suitable, dedicated space in which to address them.

The small size of this sample and the lack of previously adapted and validated versions of the anxiety, depression, and quality of life assessment tools are limitations. Future studies would be well advised to develop such tools. A controlled study would enable us to better assess the psychological burden of HIV infection in our context.

## Conclusion

HIV infection in children and adolescents poses a real challenge to their psycho-affective development. It affects their bodies, their psyches, and their quality of life. In our context, it disrupts the family system, which is essential to the development of the child and adolescent. It is a major risk factor for the onset of anxiety and even depression, psychopathological manifestations that have a negative impact on ART compliance and are a source of therapeutic failure. The mental health of CAHIV must be a priority for care teams.

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Delegation of tasks from mental health professionals to community health workers is the only way to democratize the management of mental health issues. Indeed, our context is characterized by a shortage of human resources in mental health.

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