# Predictors of HIV/AIDS Confirmation and Differences by Guardian Status in HIV<sup>+</sup> Adolescents in Jamaica

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#### **ABSTRACT**

**Background:** Approximately 25% of the cumulative AIDS cases in Jamaica involve adolescents and young adults. However, the lives of adolescents living with HIV within Jamaica and the Caribbean have been understudied.

**Objectives:** (1) To describe the sociodemographic characteristics of HIV<sup>+</sup> Jamaican adolescents who have ever been a part of the Kingston Paediatric/Perinatal HIV Programme (KPAIDS) from September 1, 2002 to August 31, 2006 (2). To identify predictors of HIV/AIDS confirmation as well as factors associated or uniquely present in these adolescents by their guardian status.

**Methods:** Seventy-two HIV<sup>+</sup> adolescents, ages 10–19 years, were included. Factors studied included demographics as well as time to and time between HIV and AIDS confirmation. Data were analyzed by bivariate and multivariate statistics.

**Results:** The mean age of the adolescents was  $12.6 \pm 2.8$  years with slightly more males (52.8%) in the programme. There were equal proportions of adolescents living with HIV as with AIDS (43.1%). There were equal proportions who were lost to follow-up or deceased (8.3%). Twenty-two of them lived with parents, 25 with guardians and 18 in residential institutions. The primary mode of transmission was perinatal infection (68.1%), followed by sexual (20.8%), blood transfusion (2.9%) and unknown (8.3%). The mean time from HIV exposure to HIV confirmation and AIDS confirmation in mother-to-child transmission (MTCT) cases were  $8.0 \pm 2.9$  years and  $9.6 \pm 3.3$  years, respectively. In the multivariate analysis model, age and gender were significant in predicting time from HIV exposure to HIV confirmation.

**Conclusion:** The majority of HIV-positive adolescents reside with parents and guardians and this might indicate support in spite of stigma and discrimination. However, the mean time to HIV confirmation in MTCT cases is quite long and must be reduced.

# Predictores de la Confirmación del VIH/SIDA y Diferencias con Respecto al Estatus de Tutoría de Adolescentes con VIH<sup>+</sup>

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# **RESUMEN**

Antecedentes: Aproximadamente el 25% de los casos cumulativos de SIDA en Jamaica comprenden adolescentes y adultos jóvenes. Sin embargo, las vidas de los adolescentes que viven con VIH en Jamaica y el Caribe no ha recibido suficiente estudio.

Objetivos: (1) Describir las características socio-demográficas de los adolescentes jamaicanos VIH+ que hayan sido alguna vez parte del Programa Pediátrico/Prenatal de Kingston contra el SIDA (KPAIDS) desde septiembre 1 de 2002 a agosto 31 de 2006.

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(2). Identificar los predictores de la confirmación del VIH/SIDA así como los factores asociados o presentes de forma única en estos adolescentes con respecto a su estatus de tutoría.

**Métodos:** Se incluyeron setenta y dos adolescentes VIH<sup>+</sup>, con edades de 10 a 19 años. Los factores estudiados comprendieron los datos demográficos así como el tiempo hasta la confirmación de VIH y el SIDA, así como el tiempo entre la confirmación de ambos. Los datos fueron analizados mediante estadísticas divariadas y multivariadas.

**Resultados:** La edad promedio de los adolescentes fue  $12.6 \pm 2.8$  años siendo el número de varones ligeramente mayor (52.8%) en el programa. Las proporciones de adolescentes viviendo con VIH fueron iguales a las de los adolescentes viviendo con SIDA (43.1%). Hubo iguales proporciones perdidas al seguimiento o fallecidas (8.3%). Veintidós de ellos vivían con sus padres, 25 con tutores, y 18 en instituciones residenciales. El modo primario de transmisión fue la infección perinatal (68.1%), seguida por la sexual (20.8%), la transfusión de sangre (2.9%), y otros desconocidos (8.3%). Los tiempos medios desde la exposición al VIH hasta la confirmación de VIH y la confirmación del SIDA en los casos de transmisión madre a hijo (TMAH) fueron  $8.0 \pm 2.9$  años y  $9.6 \pm 3.3$  años, respectivamente. En el modelo de análisis multivariado, la edad y el género fueron significativos a la hora de predecir el tiempo desde la exposición al VIH hasta la confirmación del VIH.

Conclusión: La mayor parte de los adolescentes VIH positivos residen con sus padres y tutores y esto podría ser un índice de apoyo a pesar del estigma y la discriminación. Sin embargo, el tiempo medio hasta la confirmación del VIH en los casos de TMAH es bien largo y tiene que ser reducido.

#### INTRODUCTION

One-third of the approximately 40 million people living with HIV/AIDS are aged 15–24 years and half of those newly infected are within this age group (1–2). An estimated 1700 children become infected with HIV everyday (3). The Caribbean has the second highest regional prevalence rate in the world (1). Approximately 5% of the estimated 440 000 people living with HIV/AIDS in the region are below age 15 years (1). AIDS is the leading cause of death in the 15 – 44-year age group (4).

The adolescents of Jamaica are at especially high risk for HIV because the incidence among this population has doubled annually since 1995. Furthermore, approximately 25% of the cumulative AIDS cases involve adolescents and young adults (5–7). From 1982 to 2001, the cumulative AIDS case rate was 10.1 and 27.32 per 100 000 for males and females ages 10–19 years, respectively (8). This is of concern since one-third of the country's population is between ages 10 and 24 years (5). Despite these high rates, only one study to date has looked at the lives of adolescents living with HIV/AIDS in the country (8). That study involved 25 adolescents who were seen at a HIV/AIDS outpatient facility and their sociodemographic and clinical characteristics are presented.

Numerous studies have shown that understanding the factors that affect HIV<sup>+</sup> adolescents can have considerable impact on how care and support programmes are organized as well as reveal ways to improve their lives. Firstly, concerns about privacy and confidentiality minimize adolescents' willingness to seek healthcare for sensitive problems and inhibit their communication with physicians (9). Secondly, HIV<sup>+</sup> adolescents need support dealing with their sexual development and sexual feelings (10). This is chal-

lenging to achieve in Jamaica since a child may be of the legal age to be sexually active but not of age for HIV/AIDS status to be formally disclosed to him/her (8). Thirdly, HIV<sup>+</sup> children and adolescents, especially those infected from mother-to-child transmission (MTCT), have to deal with the possible death of their parents. Coupled with the stigma attached to HIV/AIDS, this can place them at risk of discrimination, further isolating them when they need as much care and support as possible (3). One study showed that parents respond to stigma and discrimination in two ways, protective or instructive parenting. The first tries to preserve children's innocence and 'normal' childhood while the latter is used to prepare children through self-sufficiency and independence (11). Finally, one of the major factors affecting HIV+ adolescents is the lack of youth-sensitive, age-specific programmes where they can access care and services (9).

Using the Kingston Paediatric/Perinatal HIV Programme's (KPAIDS) database, (12) the only database in Jamaica that has extensive information on adolescents living with HIV/AIDS, the current study seeks to describe the sociodemographic characteristics of HIV-infected adolescents in Jamaica, to identify factors uniquely associated with the adolescents by guardian status and to assess what factors predict time to HIV confirmation and time to AIDS or death.

# **METHODS**

Setting

KPAIDS began in 2002 with the mission of preventing mother-to-child transmission of HIV while improving the quality of life for women, children and families who are infected or affected by HIV/AIDS (12). It is a joint collaboration between the Ministry of Health, Jamaica, and the University of the West Indies and the University Hospital of

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the West Indies. The programme identifies and treats HIV-exposed and HIV-infected children at four major children's centres – the University Hospital of the West Indies (UHWI), the Bustamante Hospital for Children, the Comprehensive Medical Centre and Spanish Town Hospital. These centres are found in the three parishes with the highest HIV rates in Jamaica: Kingston, St Andrew (KSA) and St Catherine (STC). The programme has since expanded by performing monthly outreaches in paediatric HIV/AIDS in four other parishes: St Ann, Clarendon, Manchester and St James. A database has been created to keep track of infected children and adolescents, morbidity, mortality and response to therapy. It also includes demographic and clinical variables for these adolescents.

#### **Participants**

Participants, ages 10–19 years, who have ever been a part of the KPAIDS programme from September 1, 2002 to August 31, 2006 were included in the study. Of the 76 adolescents in the KPAIDS database, 4 were subsequently found to be HIV negative and were excluded from these analyses, resulting in a final sample of 72. The majority of the adolescents were enrolled in the programme upon visiting the infectious disease clinics at the four main centres while others were already attending general paediatric clinics and were referred to the programme upon its creation.

# Variable Assessment

Descriptive factors taken from the database included age, gender, mode of transmission, guardian status, parish and health status of mother. Health status of mothers refers to whether it is known that the mother is dead or alive. Guardian status refers to the legal guardian of the adolescent and has three categories – institutional, parental and guardian. Residential institutions are official homes that care for HIV+children and adolescents who are wards of the state (eg whose parents can no longer provide for children or parents who have died).

Mode of transmission is also divided into four categories – MTCT, sexual, blood transfusion and unknown. The sexual category refers to adolescents who became infected through rape as well as through consensual intercourse. Adolescents under the age of 16 years who fall under the sexual category are statutory rape cases according to Jamaican law. Adolescents over the age of 16 years are either rape cases or consensual inter-course cases. All rape cases were reported to the authorities. Age is defined as the mean of the eligible ages that the adolescent was a part of KPAIDS. As such, an adolescent who was 13 years of age in 2002 and 17 in 2006 was re-corded as age 15 years. Age was then made into a three-level variable for analysis with ages 10–12 years being early adolescence, 13–16 years adolescence and 17–19 years late adolescence.

Relevant dates used in the analysis included date of HIV exposure, date of HIV confirmation test and date of

AIDS diagnoses. As KPAIDS primarily cares for HIV-infected infants, the dates of HIV exposure are only known for adolescents who contracted the virus from their mother. As such, all analysis involving time from HIV exposure includes only those who are MTCT. Mother-to-child transmission or perinatal transmission of HIV/AIDS may occur during pregnancy, at birth or during breast feeding. As such, the date of HIV exposure/infection was presumed to be at the time of birth. HIV confirmation test date refers to the date when a HIV test was conducted to affirm or discover if the adolescent was infected. The analysis of time between HIV confirmation and AIDS diagnosis includes all those who have those dates.

#### Statistical Methods

SAS (Statistical Analysis System, Version 9.1.3) was used to conduct descriptive statistics. T-test or the variance F-test is used for continuous variables while chi-square or the Fisher's exact tests are used for categorical data. The software is also used for bivariate and multivariate as well as the survival analyses.

#### **RESULTS**

The demographic characteristics of the 72 adolescents who have ever been in KPAIDS are shown (Table 1). The mean

Table 1: Description of the sample

Characteristic	n (%)*	
Age (years), mean ± SD Sex	12.6 (2.8)	
Male	38 (52.8)	
Guardian status		
Parental	22 (33.9)	
Guardian	25 (38.5)	
Institutional	18 (27.7)	
Parish		
KSA	32 (50.0)	
STC	20 (31.3)	
Other	12 (18.8)	
Current health status		
$HIV^+$	31 (43.1)	
AIDS	31 (43.1)	
Dead	6 (8.3)	
Lost to follow-up	4 (5.6)	
Mode of transmission	` ′	
MTCT	49 (68.1)	
Sexual	15 (20.8)	
Blood transfusion	2 (2.9)	
Unknown	6 (8.3)	
Sexual transmission	, ,	
Consensual	5 (33.3)	
Rape	10 (66.7)	
Health status of mother	· · ·	
Alive	16 (33.3)	
Dead	32 (66.7)	
HIV Exp. to HIV confirm. (years), mean ± SD	$8.3 \pm 2.8$	
HIV Exp. to AIDS (years), mean $\pm$ SD	$10.5 \pm 1.9$	
HIV Confirm to AIDS (years), mean ± SD	$1.8 \pm 1.9$	

Exp = exposure; KSA = Kingston and St Andrew; STC = St Catherine \*Numbers may not sum to 72 due to missing data and percentages may not sum to 100% due to rounding.

age of the adolescents was  $12.6 \pm 2.8$  years. There were slightly more males (52.8%) in the programme. There were equal proportions of adolescents living with HIV as with AIDS (41.7%) as well as equal proportions who were lost to follow-up and dead (8.3%). Twenty-two (33.9%) of the adolescents lived with parents, 25 (38.5%) were with guardians and 18 (27.7%) lived in residential institutions. The majority of the adolescents' mothers were dead (66.7%).

The primary mode of transmission was MTCT (68.1%), followed by sexual (20.8%), blood transfusion (2.9%) and unknown (8.3%). Of those who were infected sexually, 66.7% were raped and 33.3% were consensual. Eight of the rape cases were statutory.

majority of sexual transmission cases lived with parents. The current health status of the adolescents, gender and time to HIV, AIDS and time between HIV confirmation and AIDS did not significantly differ by guardian status.

Age and gender were significant in predicting time from HIV exposure to HIV confirmation. In comparison to the 10–12-year age group, the 13–16-year age group had a significantly longer time to HIV confirmation with a mean difference in time of 3.99 years. Males have a significantly shorter time to HIV confirmation than females, p-value of 0.013 (Table 3). For each unit increase in age, there was a 31% decrease in the hazard of time to AIDS confirmation or death from HIV exposure (Table 4). Death of the mother or

Table 2: Description of the sample, by guardian status\*

Characteristic	Parental (n = 22)	Guardian (n = 25)	Institutional (n = 18)	$\mathbf{P}^{\dagger}$
Age (years), mean ± SD	$13.2 \pm 3.0$	12.1 ± 2.3	11.3 ± 1.3	0.046
Female, n (%)	12 (54.6)	8 (32.0)	10 (55.6)	0.194
Parish, n (%)	21 (33.3)	25 (33.3)	17 (27.0)	0.008
KSA	13 (61.9)	13 (52.9)	6 (35.3)	
STC	3 (14.3)	6 (24.0)	11 (64.7)	
Other	5 (23.8)	6 (24.0)	0 (0.0)	
Current health status, n (%)	22 (33.8)	25 (38.5)	18 (27.7)	0.193
$HIV^+$	6 (27.3)	12 (55.6)	6 (33.3)	
AIDS	13 (59.1)	6 (27.3)	11 (61.1)	
Dead	1 (4.6)	3 (12.0)	1 (5.6)	
Lost to follow-up	2 (9.1))	2 (8.0)	0 (0.0)	
Mode of transmission, n (%)	22 (33.9)	25 (38.5)	18 (27.7)	0.009
MTCT	11 (50.0)	20(80.0)	16 (88.9)	
Sexual	9 (40.9)	3 (12.0)	1 (5.6)	
Blood transfusion	2 (9.1)	0(0.0)	0 (0.0)	
Unknown	0 (0.0)	2 (8.0)	1 (5.6)	
Health status of mother, n (%)	17 (21.3)	20 (42.6)	10 (21.3)	< 0.001
Alive	13 (76.5)	2 (10.0)	0 (0.0)	
Dead	4 (23.5)	18 (90.0)	10 (100.0)	
HIV Exp to HIV confirm. (years), mean $\pm$ SD	$8.2 \pm 3.4$	$7.2 \pm 3.9$	$8.1 \pm 2.5$	0.662
HIV Exp to AIDS (years), mean ± SD	$10.5 \pm 2.6$	$9.4 \pm 3.5$	$10.3 \pm 1.8$	0.634
HIV Confirm to AIDS (years), mean ± SD	$1.4\pm1.6$	$1.8\pm2.2$	$2.2\pm2.1$	0.550

EXP = exposure; KSA = Kingston and St Andrew; STC = St Catherine

The mean time from HIV exposure to HIV confirmation and AIDS confirmation in MTCT cases were  $8.0 \pm 2.9$  years and  $9.6 \pm 3.3$  years, respectively. The mean time from HIV confirmation to AIDS confirmation was  $1.9 \pm 2.0$  years.

More comprehensive information about the adolescents by guardian status is displayed (Table 2). There were differences (p < 0.05) across guardian status by age, parish, mode of transmission and health status of mother. The mean age of adolescents living with parents was significantly older than adolescents residing with guardians and the state. Approximately the same percentage of adolescents living with guardians and in residential institutions were perinatally infected. As expected, those whose mothers were dead were living with guardians, in an institution or with others. The

Table 3: Bivariate and multivariate analyses predicting time to HIV confirmation

Characteristic	F(T) - value	Pr >F	Beta (SE)*	P
Age (years)	3.16	0.009		
10–12			Reference	-
13-16			3.99 (1.04)	< 0.001
17–19			0	_
Gender	1.59	0.177		
Female			Reference	_
Male			-2.03 (0.74)	0.009
Parish	0.50	0.608		
Guardian's status	0.01	0.988		
Health status of mother	1.17	0.251		

<sup>\*</sup> Multivariate model N = 49

<sup>\*</sup> Numbers may not sum to totals due to missing data and column percentages may not sum to 100% due to rounding.

<sup>&</sup>lt;sup>†</sup>p-value for analysis of variance F-test (continuous variable) or  $\chi^2$  test or Fisher's exact test (categorical variable).

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Characteristic	Hazard ratio (95% CI)	p	Hazard ratio (95% CI)*	p
Age (years)	0.68 (0.47, 0.98)	0.040	0.69 (0.48, 0.99)	0.049
Gender	, , ,		. , ,	
Female	Reference	_	Reference	_
Male	0.61 (0.29, 1.29)	0.198	1.02 (0.44, 2.33)	0.970
Parish				
KSA	Reference	_		
STC	0.68 (0.28, 1.66)	0.395		
Other	1.07 (0.37, 3.11)	0.906		
Guardian status				
Institutional	Reference	_	Reference	_
Parental	0.57 (0.22, 1.28)	0.155	1.13 (0.43, 2.96)	0.798
Guardian	0.88 (0.42, 2.74)	0.876	0.52 (0.20, 1.38)	0.191
Health status of mother				
Alive	Reference	_		
Dead	0.55 (0.19, 1.57)	0.259		

Table 4: Bivariate and multivariate analyses predicting time to AIDS/death

sexual acquisition of infection were associated with a decreased risk of progression from confirmation of HIV infection to a diagnosis of AIDS.

#### DISCUSSION

The majority of adolescents living with HIV/AIDS in this study reside with parents and guardians. This indicated that the parents and guardians were willing to bring their children in for medical care and may suggest support for the adolescents in spite of past reports of stigma and discrimination (4). Studies have shown that living in a supportive family environment helps to develop positive self-identity and self-esteem, provides individual attention and love and prepares adolescents for life and healthy social interaction (3).

The creation of residential facilities for children and adolescents living with HIV/AIDS has provided a safe haven where their disease can be managed properly. These facilities include caregivers, practical nurses, housekeepers and cooks (13). Without such facilities, the adolescents would have remained in hospitals or even on the streets since children and adolescents are placed in these homes because they had been abandoned or their parents were dead. For the medical care of these vulnerable institutionalized children and adolescents, the staff of KPAIDS arranged for them to attend UHWI's weekly infectious diseases clinics.

The majority of those in the institutions and KPAIDS were perinatally infected. As KPAIDS focusses on HIV-infected infants and prevention of MTCT, this result was not surprising. The mean age in the programme is rather young because the older adolescents may be receiving care at the programme and treatment sites in Jamaica that cater for the older age groups. As such, the small number of 15 for sexual transmission may not be representative of that transmission category. Five of the fifteen sexual transmission cases contracted the virus *via* consensual sexual intercourse. However, the fact that ten of the fifteen adolescents in the study were

raped and of those ten, eight were statutory is cause for concern. All the cases were officially reported to the authorities and some resulted in court trials. While it cannot be determined that infection with HIV was a result of the specific reported sexual assault, eight adolescents contracted the virus before the legal age of consent. In 2004, carnal abuse represented the highest incidence, 413, of child abuse cases reported to the police statistics, which was a 9.5% increase over 2003. Incest was the second highest, with 15 more cases (a total of 42) over the previous year. The Child Development Agency passed the Child Care and Protection Act in March 2004 to help improve standards of care and services in order to achieve the holistic development of children (14). Enforcement of the law must become top priority given the fact that the child/adolescent will not only endure emotional trauma as a result of sexual attack but is at risk of living with an incurable disease.

There is a long time to HIV confirmation in these adolescents. An average of eight years indicated that many adolescents were not receiving the appropriate medications if they were exhibiting HIV-related symptoms. Moreover, this may be the cause for the short time, 1.9 years, between HIV confirmation and AIDS confirmation. The long time may be a result of several reasons. Firstly, some of the children/ adolescents that entered KPAIDS were known to have HIV and received appropriate medications but the date of their previous HIV testing was not in their medical charts. As such, to have a HIV test on record, KPAIDS tested the child. Therefore, the long time might actually be shorter. Secondly, a programme such as KPAIDS did not exist until 2002. Therefore, persons had no programme to assist them especially those living outside of the major city areas. This is coupled with the fact that ARV treatment was expensive. In 2004, the Jamaican National HIV/AIDS Programme won a grant from the Global Fund to scale-up public access to antiretroviral drug therapy (12). Studies are needed to assess

<sup>\*</sup> Multivariate model n = 47; KSA = Kingston and St Andrew; STC = St Catherine

how effective is the scale-up in incorporating the well-being of adolescents living with HIV. Thirdly, some parents were in denial, not believing that they had HIV and hence, their child could not have it. Moreover, parents died without family members knowing their status and thus their children were not tested. It was only when the child became sick with a HIV-indicator disease that he or she might have had a HIV test done. Fourth, stigma creates fear among parents and relatives who may prefer not to have the children tested to prevent discrimination and ostracism in case they were positive. As such, the number of actual infected children and adolescents not receiving the necessary care may be a lot more.

Hopefully with the creation of programmes such as KPAIDS, the long time to HIV confirmation among children and adolescents will be reduced as measures have been taken to diagnose and treat infants, children and adolescents who are infected with HIV. This includes chemoprophylaxis with highly active antiretroviral drugs (Combivir® and Kaletra®) for the mother and zidovudine and nevirapine for the HIVexposed infant with follow-up HIV DNA PCR testing of the HIV-exposed infants at age six weeks and three months, exclusive formula feeds, limited immunologic monitoring and commencing ARVs. The HIV-exposed and HIV-infected children and adolescents are regularly followed in outpatient settings and their hospitalizations are closely monitored by a core group of several dedicated paediatricians and nurse managers (12). Though KPAIDS is treating the children and adolescents medically, more studies are needed to analyze the everyday living situation of this group. Moreover, studies on how the Jamaican health system is identifying and managing the care of adolescents living with HIV, especially given a new funding source, are also needed.

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