

# Behavioural Symptoms of Children with HIV Infection Living in the Dominican Republic

R Mendoza<sup>1</sup>, M Hernandez-Reif<sup>2</sup>, R Castillo<sup>1</sup>, N Burgos<sup>3</sup>, G Zhang<sup>4</sup>, G Shor-Posner<sup>3</sup>

## ABSTRACT

**Objective** The purpose of this report is to describe behavioural problems encountered in a group of Dominican children living with Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) in the Dominican Republic. They were not receiving antiretroviral treatment.

**Method** The participants were 43 children with HIV infection (2 to 8 years of age) who were attending an immunology clinic in the largest paediatric hospital in the Dominican Republic. All of the participants were vertically infected with the HIV virus (mother-to-child transmission) and had a very low socio-economic status. The children's caregivers were administered the Child Behavioural Checklist (CBCL) by trained psychologists to determine the caregivers' perception of the children's behavioural problems. Behavioural findings were examined according to the CBCL age format: younger children (under 5 years of age) and older children (over 6 years of age).

**Results:** Descriptive statistics revealed a high proportion of the children, both younger (approximately 40%) and older (46%) scored in the borderline/clinical ranges for internalizing problems, including anxiety, withdrawn-depressed and somatic complaints. In addition, 46% of the older children were perceived as having externalizing problems (rule breaking and aggressive behaviour).

**Conclusion:** These findings suggest that a high incidence of behavioural and mood problems may be prevalent among Dominican children with HIV. The findings are discussed in terms of future research to examine other risk factors that might contribute to the high rate of maladaptive behaviours observed in the present report, including the contribution of socio-economic status, caregiver illness, caregiver education and parental loss.

# Síntomas de Conducta de los Niños Infectados por VIH en la República Dominicana

R Mendoza<sup>1</sup>, M Hernandez-Reif<sup>2</sup>, R Castillo<sup>1</sup>, N Burgos<sup>3</sup>, G Zhang<sup>4</sup>, G Shor-Posner<sup>3</sup>

## RESUMEN

**Objetivo.** El propósito de este reporte es describir los problemas conductuales hallados en un grupo de niños dominicanos que viven con el virus de la inmunodeficiencia humana/síndrome de la inmunodeficiencia humana adquirida (VIH/AIDS) en República Dominicana, sin recibir tratamiento antiretroviral.

**Método.** Los participantes fueron 43 niños (de 2 a 8 años de edad) infectados por el VIH, que asistían a una clínica inmunológica en el mayor hospital pediátrico de la República Dominicana. Todos los participantes estaban verticalmente infectados por el virus del VIH (transmisión de madre a hijo), y tenían un estatus socioeconómico bajo. Con el propósito de determinar la percepción que los encargados del cuidado de los niños tenían de los problemas conductuales de estos, psicólogos profesionales aplicaron a los cuidadores infantiles el instrumento conocido como la Lista de Control de la Conducta del Niño (CBCL). Los hallazgos conductuales fueron examinados de conformidad con el formato de edad de la CBCL: niños menores (por debajo de los 5 años de edad) y niños mayores (más de 6 años de edad).

From: CENISMI/Robert Reid, Cabral Children Hospital<sup>1</sup>, Santo Domingo, Touch Research Institutes<sup>2</sup>, Department of Paediatrics, Division of Disease Prevention<sup>3</sup>, Department of Psychiatry and Behavioural Sciences, University of Miami-School of Medicine, and Miami-Dade County Health Department/ Florida Department of Health<sup>4</sup>, Miami, FL.

Correspondence: Dr G Shor-Posner, University of Miami School of Medicine, Department of Epidemiology and Public Health, Center of Health Promotion and International Research, 1120 NW 14<sup>th</sup> Street, Room 922 (D93), Miami, Florida 33136 USA. e-mail: gshor@med.miami.edu.

**Resultados.** Las estadísticas descriptivas revelaron que una alta proporción de niños, tanto menores (aproximadamente 40%) como mayores (46%), alcanzaron puntuaciones en los rangos clínicos/límites de problemas de internalización, incluyendo ansiedad, depresión con retraimiento, y quejas somáticas. Además, del 46% de los niños mayores se tuvo la percepción de que tenían problemas de externalización (rompimiento de las reglas y comportamiento agresivo).

**Conclusión.** Estos hallazgos sugieren que prevalece una alta incidencia de problemas conductuales y anímicos entre los niños dominicanos con VIH. Los hallazgos se discuten en término de una investigación futura a fin de examinar otros factores de riesgo que podrían estar contribuyendo a la alta tasa de comportamientos maladaptativos observados en el reporte presente, incluyendo la contribución del estatus socioeconómico, la enfermedad de los propios cuidadores, la educación de los cuidadores y la pérdida de los padres.

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## INTRODUCTION

Children with Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) experience behavioural and mood disorders, including depression, anxiety, attention deficit, hyperactivity, aggressive behaviour and adjustment difficulties (1–5). These behavioural and mood problems might increase the child's physical symptoms and reduce, even more, the quality of the child's life. Other stressors that negatively impact on the HIV-infected child include orphanhood, poverty, parental illness and parental education (6–9).

Early identification of behavioural and mood difficulties should facilitate earlier interventions for children with HIV/AIDS. In the literature, behavioural problems appear to be more pronounced in children with HIV with less resources or access to treatment. For example, high levels of aggressive behaviour and anxiety, bruxism (grinding of the teeth at night) and rocking movements have been described in children with HIV living in India (4). Educational level of the parent/caregiver, unemployment and parental/caregiver health status also augment behavioural problems for children with HIV disease (10). For example, seronegative children born to HIV positive parents experience higher levels of depression and anxiety (11, 12), attention problems, aggression and delinquency (13). Other common difficulties for children born to mothers infected with HIV include social adjustment and externalizing problems (eg aggressive and rule-breaking behaviour), anxiety and depression (14).

Information is limited regarding the prevalence of behavioural and emotional problems in HIV children living in the Caribbean where the pandemic of paediatric HIV/AIDS is characterized primarily by vertical HIV transmission from mother to child. Prior work included a neurodevelopmental assessment of 28 children infected with HIV in the Dominican Republic, a country with the second highest incidence of HIV/AIDS in the Caribbean. Results of this pilot study revealed neurological anomalies in 39% of the children and cognitive delays in 59% of the group (15).

This paper presents preliminary behavioural data reported by the caregivers of HIV-1 infected children who were making a routine visit to an immunology clinic at the main

paediatric hospital in the Dominican Republic. The present exploratory and descriptive study extended the previous study by reporting on behavioural symptoms (internalizing and externalizing problems) and mood disorders displayed by young Dominican children with HIV who were not yet receiving antiretroviral treatment. As a first step in determining potential behavioural problems and mood disorders of Dominican children infected with HIV, the children's caregivers were surveyed with a standardized Child Behaviour Checklist (CBCL).

It was hypothesized that the Dominican children infected with HIV would present with a higher incidence of internalizing problems (ie depression, anxiety) than published norms for non-referred same age children because the majority of the children lived in financially disadvantaged homes, which would be expected to contribute to greater internalizing problems. Also, greater physical, cognitive and social delays were expected among the Dominican children because these have been associated with lack of antiretroviral treatment (16), and because at the time of this study (2003–2004) antiretroviral treatment was not readily available in the Dominican Republic. The data in this report were later used as baseline data for an intervention study which was previously reported (17, 18). The current study did not include a control group as the primary objective was simply to survey the types of behavioural problems that might be evident in a convenience sample of HIV-infected children attending an immunology clinic.

## SUBJECTS AND METHODS

### Participants

The sample comprised 43 Dominican children (mean age = 4.3 years; range: 2–8 years) infected with HIV and living in the Dominican Republic. All were from low socioeconomic backgrounds, 60% of the children were girls and 51% lived with their mothers. All of the children were vertically infected with the HIV virus. Their HIV seropositive status was confirmed with two ELISA tests and by Western Blot, or compliance with clinical criteria based on CDC definition (Medical Chart Review). Children were excluded if 1) the HIV status was undetermined, 2) new opportunistic infection

was evident, 3) they had been hospitalized for acute infection during the previous 30 days, 4) there was indication of physical abuse, or 5) they were born addicted to a substance. In all, but one case, children living with a caregiver other than their mother did so because the mother had died from complications related to HIV/AIDS.

### **Procedures**

Children and parent/caregivers were referred by their attending physician to an independent physician who provided information about the study and obtained written informed consent from the caregiver. None of the children were aware of their HIV status according to the caregivers and the children's physician. The study had Institutional Review Board approval from the University of Miami School of Medicine and Ethical Committee approval from the Robert Reid Cabral Children's Hospital in the Dominican Republic. All of the key personnel in the study (study physician, independent physician, psychologists) received education and certification on Human Subjects Research by the University of Miami.

### **Assessment**

#### *Child Behavioural Checklist (CBCL)*

Two Dominican clinical psychologists were trained to administer and score the Child Behaviour Checklist (CBCL) (19), an instrument designed to assess behavioural, emotional and social functioning in children from 1½ to 18 years of age. The CBCL is comprised of a Preschool form (1–1/2 to 5 years of age) and a School-age form (6–18 years of age) and has been used in both clinical and research settings. In addition, the CBCL has been validated with populations of children with different physical, psychological, social and ethnic conditions, including Spanish-speaking children (20–24). Content validity, criterion-related validity and construct validity are well supported by studies on demographically similar referred and non-referred children (19).

The CBCL was completed by the caregiver usually but due to the sociocultural characteristics of the group that participated in this study, many of the caregivers had difficulty reading and filling out the questionnaires alone. The CBCL recommended procedure was used for respondents with poor reading skills (19). This procedure involved the psychologist/interviewer reading the questions on the form and writing down the caregiver's responses on the scoring sheet (19). A Spanish authorized version of the instrument was used, and six expressions were adapted to better represent the Dominican idiom.

### **RESULTS**

The CBCL 1–1/2 to 5-years was completed for 32 children and the CBCL 6 to 18 years was completed for 11 children. The data are described by age group below (younger vs older children).

#### *Younger Children*

Seventy-four per cent of the children (32/43) assessed were under 5 years of age (mean age = 3.9, SD=1.6) and the majority (68.7%) were female. Approximately 60% of the younger children resided with their mothers. Fifty-eight per cent of the caregivers had less than a 6<sup>th</sup> grade education and 42% had the equivalence of a high school diploma, confirming that the sample was from a lower socio-economic status.

Analyses of the CBCL for the younger children revealed that approximately 40% of this group scored in the borderline/clinical range for internalizing problems. For these children, anxiety (25%) and somatic complaints (31.25%) were the greatest problems. Externalizing problems (*ie* acting out) were evident for approximately 20% of the children. These problems, which were in the borderline/clinical range, were associated with aggressive behaviours (6.26%) and attention problems (3.13%). Other problems (*eg* overtired, will not eat, cries) including sleep problems (*eg* nightmares, sleeps little, talks or cries in sleep) fell into the borderline/clinical range for about 30% of the children.

Additionally, 15% of the children met DSM-IV criteria for affective problems (dysthymia, major depression) and 15% for anxiety problems. One child was classified as Pervasive Developmental Disorder (PDS), another child met criteria for Attention Deficit/Hyperactivity Disorder (ADHD) and one child was classified as borderline oppositional/defiant (OD).

#### *Older Children*

Twenty-six per cent of the children were older than five years of age (mean age = 6.3, SD=2.2), and in this subsample, most (67%) were male. Almost three-quarters of the older children (72.7%) resided with someone other than their mothers, reflecting the high mortality rate for adults with HIV/AIDS in the Dominican Republic. Fifty-five per cent of the caregivers had less than a 6<sup>th</sup> grade education and 45% had the equivalence of a high school diploma, suggesting that the older and younger children were comparable in socio-economic status.

Taking into account different scoring templates for boys *versus* girls, analyses on the 6–18 yr CBCL version revealed that almost half of the children (46%) scored in the borderline/clinical range for internalizing problems. Difficulties were mainly associated with the children being withdrawn/depressed (46%) or complaining of somatic symptoms (27%).

Because of the small sample size for this age group, data were combined for the males and females for the older group. One child was diagnosed with anxiety. Approximately half of the children (46%), moreover, were experiencing externalizing problems, with most of this group being classified in the borderline/clinical range (36%). When rule-breaking and aggressive behaviours were combined, scores

fell closely within the range of borderline/clinical for approximately 33% of the group. Total problem scores were also close to the borderline/clinical range for approximately half of the children, with 36% of the children's scores falling in the clinical range.

## DISCUSSION

This is the first exploratory study to evaluate behavioural and emotional functioning in young Dominican children (between two and eight years of age) who were vertically infected with the HIV virus. Forty per cent of internalizing problems was reported for the study children under 5-years of age, including borderline/clinical levels of anxiety, depression and/or somatic complaints. Approximately one in five of the children in the study, under 5 years of age, displayed externalizing problems, in the borderline/clinical range, in the form of aggression and/or attention problems. Moreover, 15% of the children under 5-years of age met DSM-IV criteria for affective problems (or depression) and/or for anxiety, and three children met diagnostic criteria for behavioural disorders, including Pervasive Developmental Disorder, ADHD and Oppositional/Defiant. The high proportion of behavioral problems may be related to bereavement issues, as a considerable number (40%) of the children under 5-years had already lost their mother to HIV/AIDS.

A large proportion (45%) of the older HIV positive children (6–8 years old) also presented with behavioural/emotional problems, with the foremost mood problem being withdrawn/depressed (45%), followed by somatic behavioural complaints (27%). Externalizing problems were also evident for 45% of the children in the older age group, with aggressive and rule-breaking behaviours evident in the clinical range for 10% of the older children. The higher incidence of internalizing and externalizing problems in the older children is perhaps not surprising, due to the large percentage (almost 75%) of these children being cared for by relatives or a neighbour because of the loss of their mothers to HIV/AIDS. Although the caregivers expressed that the infected children were not aware of their HIV/AIDS status, it is likely that the 6 and 7-year old children were more cognizant of their physical condition, as well as the loss of their mother as the primary caregiver. This might explain the elevated negative behavioural and emotional symptoms observed for this age group.

Other factors that may have contributed to the overall high incidence of impaired behavioural and mood disorders in the Dominican children infected with HIV include low socio-economic status, caregiver education and medical status and child neglect. The contribution of each factor may be difficult to determine, however, there may be interaction or additive effects that cannot be isolated. Moreover, the lack of available antiretroviral therapy, may have contributed to the behavioural problems reported in the children, given that at least one study reported reduced behavioural problems

following the initiation of antiretroviral medication for children with HIV (25). Future research will be necessary to determine the incidence of behavioural and mood disorders in a non-infected age- and socio-economic-matched group of Dominican children without HIV.

The current findings reveal elevated levels of behavioural and mood dysfunction for young Dominican children infected with HIV (6 to 8 years of age) who are not receiving antiretroviral treatment. It is recognized that because the majority of the children did not attend school, the caregivers' perception of the children's behavioural and mood problems could not be corroborated with those of an alternate adult, such as the children's teachers. In another paper, we present data on the caregivers as mothers *versus* others' perception of the children's behaviours (26). Assessment of the child's own perception of mood and behaviour would be important to document as well as the mother versus other's perception of the child's behaviour. Nevertheless, the current findings indicate a high prevalence of behavioural problems in the sample of young Dominican children with HIV who were not receiving antiretroviral therapy. These results underscore the potentially high incidence of behavioural problems in young Dominican children living with HIV/AIDS and without access to antiretrovirals, indicating the need for early evaluation of mental health problems, and strategies to reduce the psychosocial burden of children affected by HIV/AIDS.

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