Caregivers' Perception of HIV-Infected Dominican Children's Behaviour

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ABSTRACT

Caregivers (mothers and non-mothers) of HIV$^+$ children face many challenges related to both physical demands and emotional well-being. The perception of caregivers in the Dominican Republic, a country greatly impacted by HIV/AIDS, in regard to their children's behaviour, has not been investigated to date. To extend understanding of the potential behavioural issues involved in providing care to children without access to antiretroviral therapy, the Child Behaviour Checklist was administered to 52 caregivers of HIV$^+$ Dominican children (2–8 years old). Both mothers and non-mothers perceived significant pathological internalizing behavioural symptoms in immunosuppressed children, compared to children with less disease progression. Analyses of gender comparisons revealed that older female children were perceived as withdrawn/depressed by their caregivers. These findings suggest that children's disease status may be an important contributor to caregiver perception in mothers, as well as non-mothers and indicate that gender-specific relationships warrant further study.

La Percepción de los Encargados del Cuidado de la Salud en Relación con la Conducta de Niños Dominicanos Infestados por VIH

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RESUMEN

Los encargados del cuidado de la salud (madres y no madres) de niños HIV$^+$ enfrentan muchos retos, tanto en relación con las exigencias físicas cuanto con respecto al estado emocional de los niños. La percepción de los encargados del cuidado de la salud en República Dominicana – un país muy impactado por el VIH/SIDA – con respecto a la conducta de sus niños, no se ha investigado hasta hoy. A fin de extender la comprensión de los problemas potenciales de comportamiento implícitos en ofrecer cuidado a niños sin acceso a terapia antiretroviral, se administró la Lista de Conductas Infantiles – conocida en inglés como Chile Behaviour Checklist – a los encargados del cuidado de la salud de los niños dominicanos VIH$^+$ (2 – 8 años de edad). Tanto las madres como las no madres percibieron síntomas significativos de conducta de interiorización patológica en los niños inmunodeprimidos, en comparación con los niños con la enfermedad menos avanzada. Los análisis de las comparaciones de género revelaron que las niñas de más edad, pero no los varones, eran percibidas como retraídas/deprimidas por los encargados del cuidado. Estos hallazgos sugieren que el estatus de la enfermedad de los niños, puede ser un factor que contribuye de forma importante a la percepción de los encargados del cuidado de la salud, ya sean o no madres, e indioan que las relaciones específicas de género merece más estudio.

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INTRODUCTION

Caregivers of children with HIV face many challenges, such as depression, fatigue, exhaustion (1), similar to problems of those who care for children with life-threatening diseases (2). Diminished stamina and the physical demands of a HIV$^+$ child leave many caregivers without adequate time for self-care (3) and counselling (4). HIV, moreover, is associated with additional stressors, such as social stigma and isolation that may limit caregivers' willingness to seek assistance from formal agencies, for themselves or their families (3).

The stress of raising HIV-infected children may precipitate or exacerbate chronic psychological conditions in caregivers, impacting on their perception of the child's

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behaviour (3). Infected mothers often describe their children as exhibiting more internalizing (anxiety, somatic) behaviour problems than other caregivers (5). Additionally, grandmothers as primary caregivers, also experience the negative impact of caregiving on their physical and emotional stability (6). Fatigue has been related to financial concern and caring for the ill child, whereas emotional burden involves the lack of social support (6). Regardless of whom the primary caregiver (mother or non-mother) is, the needs of those caring for HIV-infected children are similar, with stress and coping needs frequently not met (1). Caregivers of children with HIV/AIDS would, undoubtedly, greatly benefit from the support of community and healthcare programmes (1–3, 7).

Worldwide, an estimated 2.1 million children younger than 15 years of age are living with HIV or AIDS, and more than 16 million children less than 15 years old have lost one or both parents to AIDS (8). Information regarding caregivers' perception of their HIV-infected children's behaviour, living in developing countries such as the Dominican Republic, is scarce. The Dominican Republic has one of the highest HIV prevalence rates (2.3% of adults) with HIV/AIDS being the leading cause of death for women of childbearing age (9). This high incidence of adult HIV infection has resulted in estimates of approximately 60 000 children in the Dominican Republic under 15 years of age "at risk" of being orphaned or displaced from their families within the next 5 to 10 years (10).

In order to assess caregivers' perception of children's behaviour for the potential development of future interventions to reduce caregiver burden, the Child Behaviour Checklist (CBCL) was administered to 52 Dominican caregivers. The CBCL was selected based on its widespread use in transcultural settings and empirical approach to mental health problems (11, 12).

SUBJECTS AND METHODS

Participants

Caregivers (primary responsibility) of HIV$^+$ children aged 2–8 years, being followed at the National Mother-Infant Research Center (CENISMI)/Robert Reid Cabral Children Hospital (RRCCH) in Santo Domingo, Dominican Republic, were recruited during 2002–2003. Following approval from the Institutional Review Board (IRB) at CENISMI/RRCCH and the University of Miami's IRB, caregivers were approached during their regular, child's clinic appointment. All of the eligible, primary caregivers (n = 52) expressed interest. An explanation of the research procedures, its purpose and expected duration was given to each caregiver. Sufficient time to examine the consent form and ask any questions regarding the study was provided. Those caregivers with limited literacy (61.5%) were read the consent form and consented, in the presence of a witness, by signing with an "x".

The inclusion criteria were 1) caregiver consent and willingness to participate, 2) children aged 2 to 8 years with confirmed HIV$^+$ status. Demographic information was obtained, including the caregiver's age, education, occupation, socioeconomic status and relationship to the child. Since the majority of the children had been infected by vertical transmission (98%), mothers were assumed to be HIV$^+$ (13), although HIV status could not be confirmed due to the lack of a regular testing programme in the Dominican Republic.

Assessment

All caregivers (n = 52) were administered the CBCL (14, 15) to assess their perception of children's internal and external behaviour, as this tool is widely recommended when taking an empirical approach to mental health problems (11, 12). As a structured rating scale, the CBCL asks parents to rate their child's social and emotional problems using a scale of 0 (not true), 1 (sometimes true) or 2 (very true). In addition to a Total Score, the scale yields two factors (internalizing and externalizing) with seven syndrome scales (emotionally reactive, anxious/depressed, somatic complaints, withdrawn, attention problems, rule-breaking-behaviour and aggressive behaviour). The CBCL/1½-5 version was used for the younger children (2 to 5 years), and provides equivalent norms for females and males. The CBCL/6-18 version was used for the older children (6–8 years), with separate norms for boys and girls. Content, criterion-related and construct validity are well supported by studies on demographically similar referred and non-referred children (5, 14–16) (Table 1).

Table 1: CBCL profile for children

CBCL/1½–5 Empirically Based Scales for Boys and Girls

Internalizing			Externalizing		
Emotionally Reactive	Anxious/ Depressed	Somatic Complaints	Withdrawn	Attention Problems	Aggressive Behaviour
[1](0–5) [2](6–18)	[1](0–6) [2](7–16)	[1]0–4 [2]5–22	[1]0–4 [2]5–16	[1]0–5 [2]6–10	[1]0–20 [2]21–38

CBCL/6-18 Syndrome Scales for Boys and Girls

Internalizing			Externalizing	
Anxious/ Depressed	Withdrawn/ Depressed	Somatic Complaints	Rule-Breaking Behaviour	Aggressive Behaviour
[1]0–7 [2]8–26	[1]0-4/*0–3 [2]5-16/*4–16	[1]0–4 [2]5–22	[1]0-4/*0–5 [2]5-34/*6–34	[1]0–11 [2]12–36

[1]Normal; [2]Borderline/Clinical Range; (*) Separate norms for boys.

Due to limited literacy in most (61.5%) of the caregivers, the CBCL was administered as an interview by a trained Dominican Psychologist (RM, RC). Responses were noted on the CBCL scoring sheet, and explanations provided, if needed. A Spanish-authorized version of the instrument was used and six expressions were adapted to better repre-

sent the Dominican idiom: *"chiquito/menor"; "se hace pupú en la ropa/se ensucia encima"; "a propósito/deliberadamente"; "se come las uñas/se muerde las uñas";"vocea mucho/grita mucho"; "malas palabras/lenguaje obsceno"*.

Children's Disease Status

All children, being cared for in this study, had documented HIV-seropositive status (two ELISA, confirmed by Western Blot, or compliance with clinical criteria based on CDC definition). Immunologic status was based on age-specific $CD4^+$ T-lymphocyte counts according to the CDC classifications (17) (Table 2).

Table 2: CD4 CDC Classification for Children

Immunologic Category	Age of Child 1–5 years CD4 cells/mm^3	6–12 years CD4 cells/mm^3
1) No evidence of suppression	$ 1000	$ 500
2) Evidence of moderate suppression	500–999	200–499
3) Severe suppression	<500	< 200

Statistical Analyses

The data were analyzed using SPSS version 11.5 for Windows (18). Following descriptive statistical analyses, mean variables were compared using Student's t-test, Fisher's exact, and chi-square tests, with p values < 0.05 considered significant.

RESULTS

Sociodemographic

Caregivers

As the majority of HIV^+ Dominican children were infected through vertical transmission, mothers were assumed to be infected as well (13). This could not be confirmed, as there is no regular HIV testing programme in the Dominican Republic. The HIV status of non-mothers was unknown. A similar proportion of mothers (50%) and non-mothers [(50%) – grandmother (n = 16, 61.5%), aunts (n = 3, 11.5%), fathers (n = 3, 11.5%), other family members (n = 3, 11.5%) and non-family (n = 1, 4%)], were caring for the HIV^+ children. Mothers and non-mothers were of similar education, socioeconomic status and occupation. Mothers were significantly younger ($p < 0.001$) than non-mother primary caregivers. A significant proportion of older children (71%) were living with a non-mother ($p < 0.01$), whereas the younger children were cared for equally by mothers (58%) and non-mothers (42%). Relationships between the demographic variables and study outcomes were not significant (Table 3).

Children

In the total group, the mean CD4 cell count for females was 1114 ± 959 cells/mm^3 and 933 ± 646 cells/mm^3 for males. More of the males tended to be in school (87.5%) compared to females (33%, $p < 0.09$). The majority (82%) of the younger children (< 6 years) had CD4 cell counts $ 500 cells/mm^3, with similar counts among females and males. Whereas most of the young children (2–5 years) were female (68%, $p < 0.01$), in the older group (n = 14, $ 6 years of age), most were male (57%). The majority (86%) of the older children had CD4 cell counts $ 200 cells/mm^3 with a similar proportion among females (83%) and males (88%).

Major Outcomes

As illustrated in the Figure, caregivers (*ie* mothers [23%] and non-mothers [33%]) of immunocompromised children were three times more likely to report internalizing borderline/clinical behaviour than caregivers (*ie* mothers [9%] and non-mothers [18%]) of children with less immunosuppression (OR = 3.5, 95% CI 0.93, 13.64; $p = 0.03$). No significant differences were found for externalizing behaviour (Figure).

Perception of healthy (normal) behaviour tended to be higher for children cared for by the mother (15/22), compared to the non-mothers (6/16, $p = 0.06$). Borderline/clinical behaviour in the children cared for by non-mothers

Table 3: Caregivers' characteristics

Variables	Caregivers – Demographics (n = 52) All (n = 52)	Mothers (n = 26)	Non-Mothers (n = 26)	*p*-value
Age (yrs)	40.0 ± 14.0	32 ± 0.7.1	48.0 ± 17.1	< 0.001
Education				0.45
None	6 (11.5%)	2 (8%)	4 (15%)	
Elementary	26 (50%)	12 (46%)	14 (54%)	
Other (Jr High, Technical)	20 (38.5%)	12 (46%)	8 (31%)	
Household Income (pesos)	2 977 ± 2 185	3 227 ± 2 519	2 727 ± 1 806	0.42
Occupation				0.17
Homemaker	32 (61.5%)	16 (61.5%)	16 (62%)	
Employed	17 (32.7%)	7 (27%)	10 (38%)	
Unemployed	3 (5.8%)	3 (11.5%)	0	
Younger Children (1½ to 5 years)	38 (73%)	22 (58%)	16 (42%)	0.26
Older Children (6 to 8 years)	14 (27%)	4 (29%)	10 (71%)	< 0.01

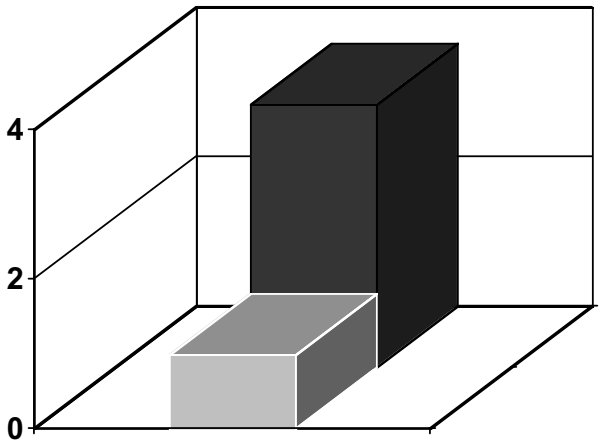

Figure: Immunocompromised children (*ie* young and old (black bar) were three times more likely to be perceived as displaying internal borderline/clinical behaviour by their caregivers (mothers and non-mothers) than children (*ie* young and old) with less immunosuppression (gray bar) at $*p = 0.03$.

and mothers, was noted in the following subscales: emotionally reactive (19% *vs* 9%), anxious/depressed (44% *vs* 14%), somatic complaints (44% *vs* 27%), withdrawn (13% *vs* 5%). Caregivers' perception of internalizing behaviour was similar for the female and male children.

Evaluation of external borderline/clinical behaviour indicated that attention problems (6%) were noted only in children cared for by non-mothers; aggressive behaviour were reported by a similar percentage of mothers (9%) and non-mothers (6%). Caregivers' (mother and non-mother) perception of the children's externalizing behaviour did not differ as a function of the child's gender.

The mothers and non-mothers rated the older children similarly on internalizing (anxious/depressed, withdrawn/depressed, somatic complaints) behaviour, with 43% of the total caregiver group indicating borderline/clinical behaviour in the older children. Similarities were also found in the proportion of mothers (50%) and non-mothers (40%) who described their children as displaying borderline/clinical behaviour within the internalizing subscale.

Withdrawn/depressed (internalizing) symptoms differed significantly for female and male children. Overall, girls (4.3 ± 2.1) were more likely to be perceived as displaying borderline behaviour than boys (2.3 ± 1.4, $p = 0.04$). Specifically, non-mothers rated 50% of the females as borderline, and all of the boys as exhibiting normal behaviour. Gender differences were not evident in caregivers' perception of internalizing anxious/depressed behaviour (4.3 ± 3.0 [girls] *vs* 4.4 ± 4.0 [boys]) or somatic complaints (4.0 ± 3.0 *vs* 3.4 ± 3.0). Thirty-six per cent of the caregivers (5/14) and 50% of the non-mothers reported borderline/clinical externalizing behaviour in the older children. Rule-breaking and aggressive behaviour were similar in females (1.2 ± 1.2; 6.0 ± 3.9) and males (3.4 ± 2.4; 8.1 ± 4.0).

DISCUSSION

This is the first systematic study to characterize the behavioural perception of caregivers in the Dominican Republic towards their HIV-infected children, extending earlier studies of caregivers and their school age HIV$^+$ children in developed countries (5, 6, 16, 19–22). Information was obtained using the CBCL, as it has been widely used to assess caregivers' perception of children's behaviour in developing, as well as developed countries, and with both HIV and non-infected children (5, 16, 23–26).

Children in the present study were being followed at the Robert Reid Cabral Children's Hospital, the largest paediatric hospital in Santo Domingo, Dominican Republic, and had been infected, primarily, through mother-to-child HIV transmission (13). Most (58%) of the young (less than 5 years of age) HIV$^+$ children were being cared for by their mothers. It was anticipated that mothers would report more behavioural problems in their children, than other caregivers, due to the likelihood of their own illness. Surprisingly, more mothers tended to report "normal" behaviour than non-mothers. Approximately twice as many non-mothers (62%), as mothers (32%) reported younger children as exhibiting emotionally reactive, anxious behaviour and experiencing somatic complaints (internalizing symptoms). Additionally, six per cent of the non-mothers reported borderline/clinical attention problems in the younger children; whereas all mothers (100%) described normal behaviour. A similarly small percentage of mothers (9%) and non-mothers (6%) described the younger children as displaying aggressive behaviour. What is unknown from this study is whether behavioural problems reported by the caregivers were related to the burden of caring for an HIV$^+$ child or reflected personal psychosocial difficulties. Future research will be needed to determine whether additional emotional stressors, bereavement and immediate burden of care could be contributing to the heightened perception of caregivers (3, 4).

It is important to note that over 70% of the older children in this study (aged 6 years and older) were being cared for by a non-mother. The loss of the mother, as a caregiver, among the older group of children supports data that HIV/AIDS is the leading cause of death for women of childbearing age in the Dominican Republic (9). Of interest, our findings indicated no significant differences in the perception of the older children's behaviour between mothers and non-mothers. Both, mothers and other caregivers, reported similar internalizing and externalizing problems consistently within the borderline/clinical range for their children, suggesting that coping with the added stress of the disease on a daily basis may contribute to caregiver burden, regardless of caregiver status (1).

Both mothers and non-mothers were more likely to report internal borderline/clinical behaviour in children (*ie*

younger and older) with greater immune dysfunction. This suggests that disease progression may be an important contributing factor in caregivers' perception. As the HIV disease progresses in the untreated child, the caregiver may perceive the child as experiencing more problematic behaviour (1, 3, 4), or perhaps, as the children become more immunosuppressed, they display more behavioural decompensation. While it is not unexpected that caregivers of children with advanced disease progression face multiple challenges, several other factors may also be influencing caregivers' perception. Particularly, in countries with limited resources for treatment and care, the social, economic and emotional stressors within the home environment (1) may impact the perception of those caring for HIV-infected children.

Reports of the caregivers in this study also revealed that more girls exhibited withdrawn/depressed symptoms (internalizing) than boys. This finding is consistent with other reports that HIV+ girls present with more anxiety (internalizing) disorders than HIV+ boys (24). Differences in the Mellins' report (24) did not appear to be related to disease status, but were consistently correlated with the caregivers' demographic (*ie* gender and maternal education) characteristics. In a recent study conducted by Erol *et al*. (26) with non-HIV infected young Turkish children, responses from the CBCL indicated higher anxious/depressed (internalizing) scores for girls than boys. Interestingly, this finding was not correlated with the children's age, or parental employment status, but urban residence was found to be a significant factor contributing to the significant differences in gender. In McKelvey *et al* (23) study, however, older (12–18 years) Vietnamese girls were found to present with more internalizing problems while boys were reported to have more externalizing problems. Gender differences were not found among the younger (4–11 years) age group of Vietnamese children, suggesting that a significant interaction of gender and age contributed to differences in behavioural problems. The high proportion of abnormality in the girls' behaviour, as perceived by the caregivers in the present report and the findings from other studies across different cultures, warrants further study of gender-specific relationships, regardless of HIV serostatus. These would include assessing differences within age group strata, ethnic and cultural parental rearing preferences between boys and girls (23), and their living situation (26).

The findings of this study, while based on a small sample size, highlight the importance of increasing awareness among healthcare providers regarding the many potential factors that may impact caregivers' perception of their children's behaviour. Independent assessments of caregivers' job satisfaction, attitudes toward children, anxiety, living condition and depression, would increase understanding of potential caregiver burden. Additionally, information related to the children's physical, mental, language and social-emotional development, along with teachers (21), and perhaps, ratings of other relatives close to the children, could provide a more comprehensive profile of behavioural problems of HIV+ children. Future research will be necessary to enhance understanding of the behavioural dynamics of those involved in caregiving situations and to acquire further insight into developing early childhood intervention services that will promote a positive relationship between child and caregiver.

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