

Family Functioning in Adolescents with Perinatal HIV Infection

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Abstract

This study aimed to assess family functioning in adolescents with perinatal HIV infection receiving antiretroviral therapy compared with healthy controls. Correlations between self-reported and caregiver-reported family functions were also evaluated. A sample of 195 participants including 65 perinatally HIV-infected adolescents and 130 healthy controls were enrolled. The total family functioning score in HIV-infected adolescents was significantly lower than that in healthy controls by self-report (105.86 vs 115.41; $P \leq .001$). Caregivers of HIV-infected adolescents also reported lower scores of family functioning than those of controls (109.91 vs 114.98; $P \leq .001$). Among the HIV-infected group, there was no or minimal correlation between the self-reported and caregiver-reported total scores of family functioning. However, there were moderate correlations between self-reported and caregiver-reported family functioning total scores in the control group. Overall, HIV-infected adolescents reported lower family functioning than healthy controls. Improved functioning in the family may help with better adjustment in perinatally HIV-infected adolescents.

Keywords

HIV infection, adolescents, perinatal, family functioning

Introduction

With advances of antiretroviral therapy and medical health care, the evolution of HIV infection into a chronic disease has no greater impact than on the life of a child. Children with perinatally acquired HIV infection have been living through adolescence and beyond. However, there is increasing awareness, unlike other chronic illnesses, that these children have to face unique issues related to HIV itself and its treatment as well as the psychosocial impact including poverty, loss of parents, stigmatization, rejection by peers, and transmittable illness.¹⁻⁴ Children and adolescents living with HIV infection are at increased risk of emotional and behavioral problems.⁵⁻⁸ Psychosocial issues have been managed with various interventions in order to improve their well-being and quality of life.^{9,10}

HIV infection affects not only the child but also the family as well. The structure of their family has been changed, as well as its function. Children and adolescents with HIV infection have experienced grief and loss in their family. Many of them live with a single parent and/or have experienced multiple caretaking transitions due to parental illness or death; some may have to live with relatives, in foster care, or in an orphanage. Loss of a parent is one of significant stressors related to poor mental health outcomes.¹¹ Family functioning has been

found to affect adherence to treatment and other aspects of health outcome and well-being¹²; thus, evaluation and understanding the family function would provide information in order to improve the psychosocial health of children and their families.

Basically, family functioning refers to the ability to cope with stress, resolve conflicts, and coordinate between members; so that the family could be able to perform its roles and functions. Also, family functioning has been suggested as one of the factors affecting the quality of life.¹³ Family functioning is receiving increased attention in relationship to the adjustment to chronic health conditions.¹⁴⁻¹⁸ Each family member is influenced by the family dynamics and relationships, and adolescence is a period of significant physiological and psychosocial changes.¹⁹ Therefore, adjustment of the

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adolescents cannot be fully understood outside the context of family functioning. Adolescents living with HIV infection can be more complicated. Adaptive family functioning was found to be associated with a positive quality of life among adolescents with chronic medical conditions.¹⁶ A systematic review showed that worse family functioning was associated with greater child disability.¹² Functions of family involve the relationship, affects, and behaviors of family members. Previous studies have evaluated the family in terms of family functioning models. One of these models is the McMaster model that describes family function in various aspects including problem-solving, communication, family roles, affective responsiveness, affective involvement, and behavioral control.^{20,21}

Previous reports have revealed impaired family functioning in chronic illnesses compared with that of healthy controls.^{12,15} There is limited information whether there are differences between the family function of adolescents with perinatal HIV infection compared with normative family systems, that is, those families who do not have HIV infection. Therefore, the objective of this study aimed to assess family functioning reported by adolescents with HIV infection compared with that of healthy controls and their caregivers. Correlations of self-reported and caregivers-reported family functioning were also evaluated.

Methods

Study Design and Participants

A cross-sectional study of adolescents with perinatal HIV infection was conducted in the Pediatric Infectious Diseases Clinic at Chiang Mai University Hospital, a tertiary care hospital in Northern Thailand. Eligible HIV-infected adolescents were consecutively enrolled between July 2014 and February 2015. To be included, they had to be 11 to 18 years of age, under highly active antiretroviral therapy (HAART), and having caregivers who could provide information and accompany them to the hospital. All perinatally HIV-infected adolescents have been disclosed of their HIV status and were followed up regularly in the clinic. Those with major neurological impairment, living in an orphanage, or unable to understand the Thai language were excluded from the study. The orphanage setting is different from a family setting as there were no specific caregivers for each child. The caregivers could not provide data regarding family functioning, so adolescents living in orphanages were not included in this study. A demographically matched group, including healthy controls of a similar age and gender without chronic illnesses, was randomly selected from a local public school to be a comparison group. The adolescents from both groups were asked to complete family functioning questionnaires to evaluate functions of their family. Their caregivers were also asked to complete the questionnaires independently.

Measures

Family functioning was assessed by the Chulalongkorn Family Inventory (CFI)²² that was designed to assess the self-perception of their family. The CFI consists of 36 questions derived from the McMaster Family Assessment Device (FAD).^{20,21} The FAD is divided into 7 dimensions including problem-solving, communication, family roles, affective responsiveness, affective involvement, behavioral control, and general overall functioning. Lower scores of the CFI indicate less healthy family functioning. Informed consents from parents or caregivers and assents from adolescents were obtained from all participants. The study protocol was approved by the ethics committee of the Faculty of Medicine, Chiang Mai University.

This study aimed to examine the difference between the 2 groups (adolescents with HIV infection and comparison peers). From the results of family functions of adolescents with chronic diseases,^{12,23} to detect the difference of 2.42 of the family index score, a number of 60 cases and 120 controls and α of .05 would yield a power of 0.90.²⁴

Data Analysis

Data were analyzed using the SPSS Statistics, Version 22.0 (IBM Corp, Armonk, New York) for Windows. Descriptive variables were presented as mean, standard deviation, and frequency or percentage, as appropriate. Raw scores of the total and subscales scores of the CFI were used in this study. Qualitative variables were compared by the χ^2 test. For quantitative variables, the Student *t* test was used to compare the 2 variables. Pearson correlation was used to determine the association between self-reported and caregiver-reported family functioning scores. A *P* value of less than .05 was considered statistically significant.

Results

A 195 participants including 65 HIV-infected adolescents and 130 controls were enrolled. The mean age was 14.8 (2.13) years with 52% males. There were 83% of these adolescents who experienced loss of one or both parents. Thus, they had lived with 1 parent or with their grandparents with low household income. Demographic characteristics of participants are shown in Table 1.

The total scores of family functioning rated by adolescents, as well as all multiple domains, were significantly lower in the HIV-infected group than those of the control group. Caregivers of infected adolescents reported a significantly lower family functioning than those of the controls for total score and some aspects, including communication, affective involvement, behavioral control, and general functioning, as shown in Table 2. Among the HIV-infected group, there was no or minimal correlation between the self-reported and caregiver-reported total scores of family functioning. The agreement was found in problem-solving and general functioning domains. However,

Table 1. Characteristics of HIV-Infected Adolescents and Healthy Controls.

Characteristics	HIV-Infected Adolescents, n = 65	Healthy Controls, n = 130	p Value
Age (years), mean (SD)	14.82 (2.09)	14.79 (2.16)	.96
Male gender, n (%)	34 (52.31)	67 (51.52)	.92
Primary caregiver			
One or both parents, n (%)	41 (63.08)	130 (100)	<.001
Relatives or foster parents, n (%)	24 (36.92)	0 (0)	
Family status			
Couple, n (%)	11 (16.92)	83 (63.85)	<.001
Divorced, n (%)	8 (12.31)	38 (29.23)	
Widowed, n (%)	19 (29.23)	9 (6.92)	
Remarried, n (%)	3 (4.62)	0	
Foster or living with relatives, n (%)	24 (36.92)	0	
Monthly family income, mean (SD) ^a	18163 (23550)	22071 (18039)	.52
Duration of HAART (years), mean (SD)	8.94 (3.09)	-	-

Abbreviations: HAART, highly active antiretroviral therapy; SD, standard deviation.

^aFor couple family with biological parents.

there were moderate correlations between self-reported and caregiver-reported family functioning total scores in the control group ($r = 0.55$, $P = .01$), as shown in Table 3. Discrepancies between the perception of adolescents and caregivers regarding family functioning were greater in the HIV-infected group than the control group.

Discussion

The findings in this study revealed that adolescents with perinatal HIV infection perceived poorer family functioning than healthy controls. Since in a family with an HIV-infected child, there would be some family members who are sick or have died, the family has had to rearrange their structure or the child has to move. In addition, there were more issues such as financial, health care, and schools to be rearranged as well. Although improving the quality of life of these children and adolescents with the advance of HAART and comprehensive health care including psychosocial issues, family functioning may be another issue that needs to be assessed for better understanding of adolescents' adjustment.

Living with HIV infection results in an impairment of the family balance and relationships between each member, inability to solve problems in the family, lack of attention to the rules of a family, and finally disruption of an organized family.^{13,18} Therefore, this leads to lower scores in all domains and general overall family functioning in HIV-infected adolescents. Interventions may emphasize on coping with crises, problem-solving, respecting the principles and rules of the family, and improving communication in the family.

There was limited information regarding family functioning of HIV infection in comparison with healthy controls. However, in a study of family function of pediatric HIV infection and cancer, most caregivers reported healthy family functioning with no difference in functioning between both groups.²⁵ Families of children with chronic pain were reported to have poorer family functioning than healthy populations in a systematic review.¹² Family functioning measured from the perspective of both caregivers and children also had an independent relationship with behavioral problems.²⁶

Interestingly, although both self-report and caregiver report revealed lower perception of family functioning in the HIV-infected group, there was no or little correlation between self-reported and caregiver-reported family function. Similar to the report that the agreement between informant reports of assessments is often a low-to-moderate level,²⁷ in which adolescents tend to report less favorable views of family functioning, relative to parent reports.²⁸⁻³¹ However, there were moderate correlations between the self-reported and caregiver-reported family functioning total score in the control group. Thus, discrepancies of adolescents and caregivers perceived family functioning were greater in the HIV-infected group than those in controls. The greater discrepancies were found to be associated with more psychosocial problems in children and adolescents.^{28,32,33} Furthermore, parent-adolescent family functioning discrepancies were found to be associated with an increased risk of HIV risk behaviors in adolescents.³⁴

Although this study demonstrated poorer functions of families of the HIV-infected group compared with a control group and informants from both adolescents and their caregivers' perspectives, there were some limitations that needed to be addressed. First, the study was cross-sectional. A longitudinal study is needed to evaluate whether issues regarding family functioning adjust over time or it can represent risk or protective factors regarding the adolescents' needs. Second, the study was from 1 tertiary care center in an Asian country where the family context may be different from other parts of the world, and the results could not be generalized. Third, the sample of HIV-infected adolescents was small, although they were all recruited with the exclusion of living in an orphanage and at a specific adolescent age group. Extended study to include more study sites or to sites with different setting might be warranted to provide more understanding on adolescents living with HIV and their family function. The factors associated with poor family functioning could not be determined due to small samples. Greater understanding of the risk factors for poor functioning would help to better provide intervention to the unique needs of these adolescents and families. The risk factors for poor family functioning reported in chronic health conditions were older child age, less children in the home, and lower household income.¹⁶

Conclusion

In summary, these findings support previous reports and clinical recommendations to incorporate family adjustment

Table 2. Family Functioning from Self-Report and Caregiver Report in HIV-Infected Adolescents and Healthy Controls.

	HIV-Infected Adolescents, n = 65	Healthy Controls, n = 130	Mean Difference, (95% CI)	P Value
Self-report, mean (SD)				
Problem-solving	12.62 (1.38)	13.68 (1.46)	-1.07 (-1.50 to -0.64)	<.001
Communication	17.17 (2.02)	18.05 (2.25)	-0.89 (-1.54 to -0.23)	.008
Roles	11.92 (1.52)	12.97 (1.37)	-1.05 (-1.47 to -0.62)	<.001
Affective responsiveness	8.68 (1.23)	9.36 (1.26)	-0.69 (-1.06 to -0.31)	<.001
Affective involvement	11.35 (1.93)	12.78 (1.81)	-1.42 (-1.98 to -0.87)	<.001
Behavioral control	12.97 (2.28)	14.51 (1.89)	-1.54 (-2.15 to -0.93)	<.001
General functioning	31.14 (3.32)	34.05 (3.29)	-2.92 (-3.90 to -1.93)	<.001
Total score	105.86 (8.95)	115.41 (8.70)	-9.55 (-12.18 to -6.92)	<.001
Caregiver report, mean (SD)				
Problem-solving	13.15 (2.03)	13.46 (1.70)	-0.31 (-0.85 to 0.24)	.27
Communication	17.57 (1.97)	18.25 (2.23)	-0.68 (-1.32 to -0.03)	.04
Roles	12.42 (1.30)	12.61 (1.81)	-0.19 (-0.69 to 0.31)	.45
Affective responsiveness	9.31 (1.01)	9.41 (1.19)	-0.10 (-0.44 to 0.24)	.56
Affective involvement	11.65 (1.77)	12.98 (1.90)	-1.34 (-1.90 to -0.78)	<.001
Behavioral control	13.54 (1.80)	14.37 (1.78)	-0.83 (-1.37 to -0.30)	.002
General functioning	32.43 (3.27)	33.86 (3.84)	-1.43 (-2.53 to -0.34)	.01
Total score	109.91 (8.53)	114.98 (9.22)	-5.08 (-7.77 to -2.38)	<.001

Abbreviations: CI, confidence interval; SD, standard deviation.

Table 3. Correlation between Self-Reported and Caregiver-Reported Family Functioning in Adolescents from Both Groups.

Caregiver Report	Problem-Solving	Communication	Roles	Affective Responsiveness	Affective Involvement	Behavioral Control	General Functioning	Total Score
Perinatal HIV-infected group (n = 65)								
Self-report								
Problem-solving	0.32 ^a	-0.10	0.20	0.20	-0.08	0.15	0.10	0.12
Communication	0.15	0.14	0.03	-0.03	-0.07	-0.06	0.09	0.05
Roles	-0.04	-0.08	0.17	-0.10	-0.13	-0.04	0.07	-0.03
Affective responsiveness	0.13	-0.06	-0.05	0.13	-0.13	-0.10	0.05	-0.04
Affective involvement	0.11	-0.19	-0.08	-0.18	-0.06	-0.12	-0.05	-0.13
Behavioral control	0.11	-0.26 ^b	0.03	-0.04	0.19	0.03	-0.03	-0.01
General functioning	0.19	0.02	0.19	-0.04	0.00	-0.01	0.28 ^b	0.15
Total score	0.18	-0.14	0.11	-0.05	-0.09	-0.06	0.11	-0.01
Healthy control group (n = 130)								
Self-report								
Problem-solving	0.42 ^a	0.09	0.09	0.30 ^a	0.22 ^b	0.09	0.39 ^a	0.41 ^a
Communication	0.23 ^a	0.19 ^b	-0.08	0.24 ^a	0.09	0.21 ^b	0.23 ^a	0.28 ^a
Roles	0.19 ^b	0.20 ^b	0.11	0.22 ^b	0.25 ^a	0.12	0.20 ^b	0.34 ^a
Affective responsiveness	0.22 ^b	0.08	0.06	0.27 ^a	0.12	0.11	0.17	0.26 ^a
Affective involvement	0.11	0.05	0.13	0.13	0.25 ^a	0.18 ^b	0.16	0.27 ^a
Behavioral control	0.05	0.06	0.09	0.28 ^a	0.23 ^a	0.44 ^a	0.11	0.32 ^a
General functioning	0.36 ^a	0.21 ^b	0.15	0.36 ^a	0.33 ^a	0.15	0.48 ^a	0.51 ^a
Total score	0.36 ^a	0.21 ^b	0.12	0.41 ^a	0.34 ^a	0.29 ^a	0.42 ^a	0.55 ^a

^aP = .01.

^bP = .05.

assessment in the team care for patients and their families of HIV infection as well as chronic health conditions. Future study with long-term assessment should replicate these findings in larger samples.

Authors' Note

The study was approved by the ethics research committee of the Faculty of Medicine, Chiang Mai University.

Declaration of Conflicting Interests



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