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Impact of Disclosure of HIV Infection on Health-Related Quality of Life Among Children and Adolescents With HIV Infection

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Abstract

Background—Little is known concerning the impact of HIV status disclosure on quality of life, leaving clinicians and families to rely on research of children with other terminal illnesses.

Objectives—The purpose of this work was to examine the impact of HIV disclosure on pediatric quality of life and to describe the distribution of age at disclosure in a perinatally infected pediatric population.

Methods—A longitudinal analysis was conducted of perinatally HIV-infected youth ≥ 5 years of age enrolled in a prospective cohort study, Pediatric AIDS Clinical Trials Group 219C, with ≥ 1 study visit before and after HIV disclosure. Age-specific quality-of-life instruments were completed by primary caregivers at routine study visits. The distribution of age at disclosure was summarized. Six quality-of-life domains were assessed, including general health perception, symptom distress, psychological status, health care utilization, physical functioning, and social/role functioning. For each domain, mixed-effects models were fit to estimate the effect of disclosure on quality of life.

Results—A total of 395 children with 2423 study visits were analyzed (1317 predisclosure visits and 1106 postdisclosure visits). The median age at disclosure was estimated to be 11 years. Older age at disclosure was associated with earlier year of birth. Mean domain scores were not significantly different at the last undisclosed visit compared with the first disclosed visit, with the exception of general health perception. When all of the visits were considered, 5 of 6 mean domain scores were lower after disclosure, although the differences were not significant. In mixed-effects models, disclosure did not significantly impact quality of life for any domain.

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Conclusions—Age at disclosure decreased significantly over time. There were no statistically significant differences between predisclosure and postdisclosure quality of life; therefore, disclosure should be encouraged at an appropriate time.

Keywords

quality of life; HIV; children and adolescents

What's Known on This Subject

Current recommendations regarding diagnostic disclosure to children with HIV/AIDS are based on lessons from pediatric oncology. The limited number of disclosure-related QoL studies among HIV-infected pediatric populations have focused on psychological and emotional health, with inconsistent outcomes reported after disclosure.

What This Study Adds

This is the first longitudinal study to examine the impact of disclosure of HIV status on health-related QoL using multivariate analytical methods and broad-based QoL outcomes.

Since the advent of HAART, children with HIV experience a less symptomatic early course and survive to older ages^{1–4}, which increasingly raises questions about disclosure of diagnosis. Many families are reluctant to discuss the nature of the illness with their infected child or adolescent, yet delays in disclosure of HIV infection may potentially result in negative consequences. Lack of disclosure may impair treatment understanding and participation and increase psychological and behavioral problems.^{5–7} As children reach adolescence and begin risk-taking behaviors, knowledge about their disease becomes essential for both personal health maintenance and HIV prevention within the larger population.

Despite strong recommendations from the American Academy of Pediatrics that children and adolescents with HIV be told their diagnosis,⁸ published rates of disclosure among this population are widely varied, ranging from 18% to 77%.^{9–15} The rationale for HIV disclosure is based on the pediatric oncology model because of sparse empiric evidence from HIV-infected populations.^{6,16,17} Studies on childhood cancer report better long-term emotional health, improved self-esteem, and closer relationships with parents after disclosure.^{18–21} Yet, parents and guardians of children with HIV voice reasons that are not applicable to cancer for resisting disclosure, including the social stigma of HIV infection, guilt over perinatal transmission, and loss of another family member to AIDS.^{6,10,22} Research on the impact of HIV disclosure is limited and has focused primarily on psychological and emotional health outcomes, with varying results.²³ Thus, it is important to better understand the effect of HIV disclosure on health-related quality of life (QoL) to develop more effective disclosure strategies in this population.

Health-related QoL measures are designed to be multidimensional and provide a standardized approach to assess patient and caregiver perspectives of health and functioning, areas that are important considerations in the clinical management of chronic progressive illnesses, such as HIV infection.^{24–26} QoL instruments also capture aspects of health commonly missed by standard clinical end points, such as survival and disease progression. Our study sought to describe the distribution of age at disclosure and to evaluate the impact of disclosure on health-related QoL by assessing within-patient changes in QoL for those with ≥ 1 predisclosure and ≥ 1 postdisclosure QoL measurement.

Methods

Study Population

This longitudinal analysis was based on data collected for the Pediatric AIDS Clinical Trials Group (PACTG) 219C prospective cohort study, which was designed to examine the long-term effects of HIV and antiretroviral therapies in children exposed in utero, postnatally, or both. HIV-infected or perinatally HIV-exposed children <21 years of age at entry were eligible for enrollment. Institutional review boards at participating sites in the United States and Puerto Rico approved the research protocol, and written informed consent was obtained from each child's parent/guardian. The study population used in this analysis was restricted to perinatally HIV-infected study participants ≥ 5 years of age, enrolled in PACTG 219C between September 15, 2000, and December 31, 2005. Patients were excluded if they did not have ≥ 1 predisclosure and ≥ 1 postdisclosure QoL measurement.

Data Collection

At study enrollment, a physical examination was performed, demographic information was recorded, and laboratory measurements were collected, including CD4⁺ cell percentage and HIV-1 RNA viral load. Children were assigned a Centers for Disease Control and Prevention (CDC) clinical classification.^{27,28} Clinical records were abstracted to obtain complete histories of antiretroviral therapy (ART) regimens and clinical diagnoses. Data on new diagnoses, laboratory immunologic and virologic measurements, ART use, and QoL were collected at routine study visits.

Disclosure status, age at disclosure, and the QoL outcomes were collected from the PACTG 219C parent/caregiver QoL form. Disclosure status (disclosed or not disclosed) was assessed by a question that asked whether the patient knows he/she is infected, and, if so, the age at disclosure. The actual date of disclosure was not collected; therefore, we used 2 approaches to estimate age at disclosure. The first approach was to estimate the age of the child at the midpoint between the last undisclosed visit date and the first disclosed visit date. The second approach was to use the first caregiver-reported age at disclosure, because the indicated ages were not always consistently reported over time.

QoL Instruments

The General Health Assessment for Children (GHAC) was used to gather QoL data. This modular tool, developed for use in PACTG 219, used previously validated instruments to evaluate 4 QoL domains: general health perception, symptom distress, psychological status, and physical functioning.²⁴ In addition, the GHAC measured social/role functioning and health care utilization. The GHAC demonstrates both good reliability and validity.²⁴ In this study, all of the previously validated QoL domains demonstrated good internal consistency with Cronbach's α scores ranging from .87 (general health perception) to .97 (physical functioning). QoL outcomes assessed with the GHAC have been studied in relation to negative life events,²⁹ antiretroviral therapy,^{30,31} severity of illness,³⁰ and pain³² in children and youth with HIV infection.

Outcome Measures

Each QoL domain score was constructed using multiple items.²⁴ Domain scores were standardized on a 0 to 100 scale and scored independently of other domains.³³ In rare cases, caregivers responded to the majority of questions within a QoL domain but failed to complete ≥ 1 item. In these instances, which occurred in <5% of domain scores overall, missing items were assigned the mean value of nonmissing items within that domain, provided that at least half of the items within the score were completed.³⁴ Reverse coding of all symptom distress,

physical functioning, and health care utilization items and some social/role functioning items was conducted to ensure that higher scores indicated better health.

Statistical Analyses

Frequencies and percentages were calculated for demographic and clinical variables at the first visit. Unadjusted mean domain scores were calculated at the first undisclosed visit, the last undisclosed visit, the first disclosed visit, and the last disclosed visit; within-subject changes were compared using the Wilcoxon signed-rank test. Descriptive statistics are presented for age at disclosure using both the first reported age and the estimated age at disclosure. The agreement between reported and estimated age at disclosure was assessed via a Spearman's correlation coefficient. Univariate linear regression was used to assess the association between age at disclosure and calendar time.

A multivariate mixed-effects model was fit within each separate domain to estimate the effect of disclosure on QoL while taking into account within-subject correlations between measurements over time and the influence of potential confounding variables. Covariates included demographic information (age, gender, race/ethnicity, primary caregiver, and primary caregiver education level), immunologic and virologic measures of health status (CD4%, viral load, and CDC class), ART regimen, number of hospitalizations since last visit, and negative life-event score. Negative life-event score, a caregiver-reported indicator of social/environmental context,³¹ was calculated as the unweighted sum of 18 possible life events (range: 0–18) that occurred in the previous 12 months.³⁵ Life events represented areas of financial stability, family structure, illness or death of family/friends, and changes in environment (eg, new school or mother starting work).

For each QoL domain, 2 random-effects models were considered, and the appropriate covariance structure was selected based on minimizing the Akaike Information Criterion. In the first model, which included 4 random effects (intercept, disclosure status, time in 6-month intervals, and the interaction between disclosure status and time), it was assumed that there was an increasing or decreasing trend in QoL scores before disclosure, a change in QoL at the time of disclosure, and then a possibly different trend over time in QoL scores after disclosure. In the second model, which included 2 random effects (intercept and disclosure status), it was assumed that QoL scores were, on average, constant over time until disclosure, at which time there may have been an increase or decrease in QoL, but then average QoL scores were again assumed to remain at this new constant level over time after disclosure. After fitting the multivariate model for each domain, we calculated and plotted predicted QoL score means for the reference group by time from disclosure. The use of a repeated-measures model with 395 children would provide 80% power to detect a difference of 3 to 5 points in QoL scores between undisclosed and disclosed children. Statistical analyses were performed by using SAS 9.1 (SAS Institute, Inc, Cary, NC).

Results

Baseline Patient Characteristics

Of the 2563 perinatally HIV-infected children and adolescents enrolled into the PACTG 219C Study as of December 31, 2005, 2325 were ≥ 5 years of age at their first QoL assessment. Caregivers of 1424 children (61%) reported disclosure of HIV infection, and 1014 of these were already aware of their HIV status at study entry. Of the remaining 410 children, 15 were excluded for being < 5 years of age at disclosure (according to reported age at disclosure), leaving 395 children with ≥ 1 undisclosed and ≥ 1 disclosed visit available for analysis.

The study sample reported QoL measurements at 2423 visits, including 1317 predisclosure visits and 1106 postdisclosure visits. The median number of visits per patient was 7 (range: 2–11 visits). The median time between the last undisclosed visit and the first disclosed visit was 280 days (interquartile range: 182–390 days). Table 1 summarizes the distribution of demographic and clinical variables at the first predisclosure visit. The study population was 50% male, 56% black, 31% Hispanic, and 13% white or other race/ethnicity. At the first visit, 19% of children were classified as CDC class C (AIDS), 71% had CD4% $\geq 25\%$ (no immune suppression), 40% had viral load ≤ 400 copies per mL (nondetectable status), and 72% were using an ART regimen of HAART with a protease inhibitor (PI). At the first visit, the source of QoL information was a biological parent for 39% of children, another relative for 25%, and another primary caregiver for 37%. Only 15 subjects (4%) had a change in the caregiver who reported on QoL between their first and last visit; exclusion of these subjects did not impact the results of the analysis.

Age at Disclosure

Among 395 subjects, 57% always reported the same age at disclosure at each visit, 35% had ≥ 1 inconsistent report of age at disclosure, and 8% failed to report age at disclosure. Among those who reported age at disclosure, the median age at disclosure was 11.0 years (interquartile range: 9.0–12.0 years; Fig 1). Discrepancies in reported age at disclosure within a single subject ranged from 1.0 to 12.0 years, with an average maximum difference in reports of 2.2 years. The median estimated age at disclosure at the midpoint between the last undisclosed and first disclosed visits was 11.0 years (interquartile range: 9–12 years). The first reported age at disclosure was highly correlated with estimated age at disclosure (Spearman's $r = 0.90$; $P < .001$). Older age at disclosure was associated with earlier year of birth (Pearson's $r = -0.79$; $P < .001$), suggesting that the age of disclosure has had a significant decline over calendar time (Fig 2).

Study Visit, Disclosure, and QoL

At the first undisclosed visit, mean domain scores ranged from 81.3 for psychological status to 94.0 for health care utilization (Table 2). The mean domain score for general health perception increased by 1.1 points between the last undisclosed and first disclosed visit ($P = .04$). However, there were no other significant changes in mean domain scores based on comparing the last undisclosed to first disclosed visit or comparing the first undisclosed to the last disclosed visit, with all of the changes within 0.7 points. When all of the visits were considered, 5 of 6 domain mean scores were lower after disclosure, although the differences were not significant.

Disclosure was not significantly associated with QoL in crude or adjusted mixed-effects model analyses, indicating that QoL scores did not change because of disclosure of HIV infection status (Table 3). Figure 3 displays predicted scores for each of the 6 QoL domains over time before and after disclosure. There was a marginally significant decline in symptom distress scores ($P = .07$) over the study period. There were no significant changes over time in general health perception, psychological status, physical functioning, social/role functioning, or health care utilization domains. There was also no significant difference between time trends in QoL scores before and after disclosure of HIV status. For all of the domains, the more complex model structure allowing separate slopes for QoL changes before and after disclosure was preferable based on the Akaike Information Criterion, but there was no qualitative difference regarding the impact of disclosure on QoL for the simpler model structure.

Although disclosure of HIV status seemed to have no impact on QoL scores, other factors were associated with QoL. Girls scored significantly higher than boys in social/role functioning QoL, and blacks reported higher average scores than whites, whereas Hispanics had lower

average scores in all of the domains except psychological status. In 4 domains, subjects receiving no ART reported the highest average scores, and those receiving a regimen other than HAART with PIs had the lowest average scores. Subjects with more previous hospitalizations had significantly lower general health perception, and those with more negative life events had significantly lower symptom scores and physical functioning. Other covariates were not associated with any of the QoL domains but were retained in the model to control for confounding.

Discussion

The results of this investigation suggest that disclosure did not significantly affect QoL in a population of perinatally, HIV-infected children and adolescents. Although primary caregivers reported lower QoL scores after disclosure for all of the domains except social/role functioning, these differences were not significant, even after adjustment for demographic and clinical factors. Current recommendations regarding diagnostic disclosure to children with HIV/AIDS are based on lessons learned from pediatric oncology. However, the psychological benefits of disclosure apparent among youth with cancer may be offset by HIV-related stigma and discrimination toward the infected child and other family members.¹⁶ A more comprehensive understanding of the effect of HIV disclosure on QoL is important for developing appropriate strategies for disclosure to children and adolescents with HIV.

The limited number of disclosure-related QoL studies among HIV-infected pediatric populations have focused on psychological and emotional health, with inconsistent outcomes reported after disclosure. Anecdotal clinician reports describe beneficial effects of HIV disclosure to children with normal cognitive development, such as reduced anxieties and disruptive behaviors, increased family intimacy, and better long-term health and emotional well-being.^{2,16,17,36} In a study of 40 children informed of their HIV diagnosis in the context of a supportive environment, most youth (70%) had feelings of normalcy 6 months postdisclosure and positive psychosocial adjustment.³⁷ Bachanas et al⁷ reported that children and adolescents in families where disclosure has not taken place were more likely to report internalizing behavior problems and psychological adjustment problems. Riekert et al³⁸ found that children with HIV who knew of their diagnosis scored significantly lower on depression and anxiety measures than children who did not know their diagnosis. Other studies that examined the psychological impact of disclosure found little or no difference in psychological functioning between disclosed and nondisclosed children.^{5,23} Inconsistencies regarding the impact of disclosure on psychological and emotional QoL may be attributable to variation among QoL measures, limited sample size, or lack of multivariate methods. Furthermore, the majority of quantitative studies used cross-sectional designs, which only allow for the evaluation of the presence of associations. This is the first longitudinal study to date examining the impact of disclosure of HIV status on health-related QoL using multivariate analytical methods and broad-based QoL outcomes.

An interesting finding of this study was the significant decrease in age at disclosure over time. This may be the result of a decline in the social stigma surrounding HIV, as well as improved long-term survival because of advances in antiretroviral therapy, most notably, the introduction of HAART in 1996.^{3,4} More than two thirds of our population initiated HAART before their first study visit. As increasing numbers of HIV-infected children are surviving well into their adolescent and young adult years, knowledge about their own disease becomes essential for both personal health maintenance and HIV prevention within the larger population.² The decline in age at disclosure offers an additional explanation for inconsistent psychological and emotional QoL outcomes in the disclosure literature.

This study is limited by missing information regarding the disclosure process. Caregivers reported disclosure as a yes/no variable; however, the process and context within which the disclosure occurred are unknown. Although disclosure has commonly been examined as a single, binary event, the process is increasingly being viewed as an ongoing progression from nondisclosure to disclosure.^{16,39} Another limitation is the possibility of less reliable caregiver reports of QoL for adolescents compared with younger children. Compared with self-reports, proxy reporting by parents and caregivers has been shown to be closely correlated for younger children but more variable for older children.^{40,41} Despite these limitations, our longitudinal data allowed us to examine the relationships between QoL and disclosure, time from disclosure, and their interaction. We were unable to demonstrate that disclosure significantly impacts QoL over time.

The PACTG 219C cohort is the largest pediatric HIV cohort in the world, representing 22% of the perinatally infected US population. These analyses had excellent power, and the results are generalizable to the US perinatally infected population. Multivariate mixed-effects models were used to estimate the effect of disclosure on QoL, which are particularly important for taking into account the within-subject correlations between measurements over time and the influence of potential confounding variables. To our knowledge, this is the most in-depth and comprehensive analysis of the impact of disclosure on health-related QoL.

Conclusions

This study suggests that HIV disclosure does not significantly change QoL scores and that diagnostic disclosure to children with HIV should not be delayed because of fear of a negative impact on QoL. Disclosure is occurring at younger ages, which may suggest a decline in the stigma and fear surrounding an HIV diagnosis. Additional work is needed to describe important factors that are related to optimal strategies in disclosing an HIV diagnosis. Such knowledge may offer critical guidance to pediatric providers in counseling caregivers of HIV-infected children and adolescents.

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Abbreviations

HAART	highly active antiretroviral therapy
QoL	quality of life
PACTG	Pediatric AIDS Clinical Trials Group
CDC	Centers for Disease Control and Prevention
ART	antiretroviral therapy
GHAC	General Health Assessment for Children

PI

protease inhibitor

Figure 1.

Distribution of age at disclosure. A, Reported age at disclosure. B, Reported and estimated ages at disclosure, where age at the midpoint between the last predisclosure visit and the first postdisclosure visit are presented for 31 subjects without reported age at disclosure.

Figure 2.

Mean age of disclosure reported by caregiver according to year of birth for 395 subjects with both predisclosure and postdisclosure visits (age at the midpoint between the last predisclosure visit and the first postdisclosure visit is presented for 31 subjects without reported age at disclosure).

Figure 3.

Predicted scores for 6 QoL domains for 395 subjects with both predisclosure and postdisclosure QoL assessments. All of the models are adjusted for age (5–9, 10–11, 12–13, and ≥ 14 years), gender, race/ethnicity (white non-Hispanic/other, black non-Hispanic, or Hispanic), CD4% ($<14\%$, $15\%–24\%$, or $>25\%$), viral load (≤ 400 or >400 copies per mL), CDC class (N/A/B or C), primary caregiver (biological parent, other relative, or other/unknown), primary caregiver education level (grade 1–11 or high school graduate or higher), antiretroviral regimen (HAART with PI, other therapy, or not on ART), number of hospitalizations since last visit (0, 1, or ≥ 2), negative life-event score (0, 1, or ≥ 2), disclosure, time since disclosure, and the interaction between disclosure and time since disclosure. Time of disclosure is denoted by the line at month 0.

Table 1
Characteristics of 395 Perinatally HIV-Infected Children at the First Predisclosure Study Visit

Variable	Data
Age, y	
Mean $\pm$ SD	9.1 $\pm$ 2.3
CDC class, n (%)	
N/A	127 (32)
B	149 (38)
C	75 (19)
Missing/unknown	44 (11)
CD4%	
Median	30.0
<15%, n (%)	29 (7)
15%–24%, n (%)	77 (19)
$\geq$ 25%, n (%)	280 (71)
Missing/unknown, n (%)	9 (2)
HIV RNA, copies per mL	
Median	1564.5
$\leq$ 400, n (%)	159 (40)
401–5000, n (%)	91 (23)
5001–50 000, n (%)	96 (24)
>50 000, n (%)	40 (10)
Missing/unknown, n (%)	9 (2)
ART, n (%)	
HAART with PI	284 (72)
Other therapy	104 (26)
Not on ART	5 (1)
Missing/unknown	2 (1)
Primary caregiver, n (%)	
Biological parent	153 (39)
Other relative	97 (25)
Other/unknown	145 (37)
Primary caregiver education, n (%)	
Grade 1–11	135 (34)
High school graduate or higher	215 (54)
Missing	45 (11)
Negative life-event score	
Median	1.0
0, n (%)	188 (48)
1, n (%)	66 (17)
$\geq$ 2, n (%)	140 (35)
Missing, n (%)	1 (0)

Table 2
Unadjusted Mean Domain Scores According to Disclosure Status and Visit

QoL Domain	Predisclosure			Postdisclosure			P		
	First Visit	Last Visit	All Visits	First Visit	Last Visit	All Visits	First vs Last ^a	Last vs First ^b	Undisclosed vs Disclosed ^c
General health perception	84.4	83.9	84.5	85.0	84.3	84.4	.96	.04	.70
Symptom distress	92.6	92.2	92.4	92.1	92.1	92.3	.37	>0.999	.72
Psychological status	81.3	80.7	81.5	80.6	81.9	81.3	.93	.10	.51
Physical functioning	82.9	82.0	82.6	82.6	82.9	82.0	.70	.44	.89
Social/role functioning	83.3	83.5	83.2	82.9	83.7	83.4	.83	.60	.81
Health care utilization	94.0	93.9	93.9	93.2	93.6	93.4	.34	.26	.61

QoL scores for each domain range from 0 to 100, with higher scores indicating better QoL. P values are based on Wilcoxon signed-rank tests comparing mean QoL scores.

^aData show first undisclosed visit versus last disclosed visit.

^bData show last undisclosed visit versus first disclosed visit.

^cData show the mean of all undisclosed versus the mean of all disclosed, within-subject comparison.

Table 3
Unadjusted and Adjusted Effects of Disclosure on QoL Scores

Domain	Unadjusted for Covariates ^a			Adjusted for Covariates: Full Model ^b			
	Effect of Disclosure		Effect of Time by Disclosure	Effect of Disclosure		Effect of Time by Disclosure	
	Estimate	P		Estimate	P		
		Estimate	P		Estimate	P	
General health perception	0.546	.61	−0.076	.82	0.410	−0.040	.91
Symptom distress	0.588	.30	0.154	.45	0.588	0.170	.41
Psychological status	0.164	.87	0.488	.20	0.005	0.448	.23
Physical functioning	0.686	.73	−0.283	.68	0.536	−0.333	.63
Social/role functioning	0.423	.65	0.004	.99	0.380	0.002	>0.999
Health care utilization	−0.261	.63	0.079	.63	−0.275	0.075	.64

Data are based on fitting a mixed-effects model for each domain. The effects of disclosure represent the difference in QoL scores between predisclosure and postdisclosure visits. Negative values indicate poorer QoL scores after disclosure.

^a All of the models have effects of disclosure adjusted for time since disclosure (6-month intervals) and the interaction between disclosure and time since disclosure.

^b Full model is adjusted for age (5–9, 10–11, 12–13, and ≥14 years), gender, race/ethnicity (white non-Hispanic/other, black non-Hispanic, or Hispanic), CD4% (<14%, 15%–24%, or >25%), viral load (≤400 or >400 copies per mL), CDC class (N/A/B or C), primary caregiver (biological parent, other relative, or other/unknown), primary caregiver education level (grade 1–11 or high school graduate or higher), antiretroviral regimen (HAART with PI, other therapy, or not on ART), number of hospitalizations since last visit (0, 1, or ≥2), negative life-event score (0, 1, or ≥2), time since disclosure, and the interaction between disclosure and time since disclosure.