Parents’ disclosure of HIV to their children

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Objective: Parents’ disclosure of their HIV serostatus to all of their children is described over time and the impact of disclosure is examined for their adolescent children.

Design: A representative cohort of parents living with HIV (n = 301) and their adolescent children (n = 395) was recruited and assessed repeatedly over 5 years.

Methods: Disclosures by parents living with HIV of their HIV status to their children were examined in three ways: (i) trends in disclosure over 5 years to all children; (ii) factors associated with parental disclosure; and (iii) the impact of disclosure on adolescent children (not younger children).

Results: Parents were more likely to disclose to older (75%) than to younger children (40%). Mothers were more likely to disclose earlier than fathers and they disclosed more often to their daughters than to their sons. Parents were more likely to disclose over time to children of all ages; disclosure did not vary according to parents’ ethnicity, socio-economic status, self-esteem, or mental health symptoms. Disclosure was significantly more common among parents with poor health, more stressful life events, larger social networks, and those who perceived their children experiencing more HIV-related stigma. Over time, poor health status and a self-destructive coping style were associated with higher rates of disclosure. Parental disclosure was significantly associated with more problem behaviors and negative family life events among their adolescent children.

Conclusion: Parental disclosure of HIV status is similar to disclosures by parents with other illnesses. Clinicians must assist patients to make individual decisions regarding disclosure.

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AIDS 2002, 16:2201–2207

Keywords: HIV, disclosure, adolescent adjustment, parents living with HIV, chronic illness

Introduction

Increasing numbers of families are living with a parent with HIV [1], creating challenges for parents to decide whether, how, and when to disclose their HIV status to their children [2–4]. Clinicians often encourage serostatus disclosure [5,6], yet there are few empirical data on which to base these recommendations [7,8]. Studies of disclosure of parents’ serostatus have been based primarily on qualitative observations [9,10] and case examples [11,12]. Therefore, the first goal of this study is to describe trends in the patterns of parents’ disclosures of HIV status to their children over time.

After documenting patterns of parent’s HIV disclosures, this paper examines the characteristics associated with such patterns. Health status was examined: parents with other diseases [13] disclose their health status more frequently to their children when their health deteriorates, as do hemophiliac fathers with HIV [7]. Effective parenting varies based on children’s age, sex, and the ethnic background of the family [14], as does disclosure.
to children of parental illness in previous studies [7,14–16]. Therefore, these factors were examined. HIV disclosure is lower if stigma is anticipated [17,18]. Therefore, we evaluated parents’ perceptions of their children’s HIV-related stigma, regardless of whether parents had disclosed to their children.

Disclosure may also be influenced by a variety of social cognitive factors. Persons with high self-esteem are more open [19], therefore, we hypothesized that parents living with HIV (PLH) who reported higher self-esteem may disclose more to their children. Moreover, mental health symptoms may increase the likelihood of disclosure of serostatus to their children [2], suggesting parents with mental health symptom may disclose more. In contrast, self-destructive or passive coping styles [20] were anticipated to be associated with fewer disclosures of serostatus to children. Thus, based on previous research, we examined the relationship of disclosure to self-esteem, emotional distress, coping styles, health status, ethnicity, perceptions of stigma, and their child’s age and sex.

Finally, in order to provide clinical recommendations on the benefits or costs of disclosure, the impact of disclosure on children’s behavioral and emotional adjustment is examined. In cross-sectional assessments of hemophiliac fathers [7] and mothers of younger children [21], parents’ disclosure of HIV infection is not related to the children’s adjustment. However, parents’ disclosure of serostatus to adolescents has been associated with a short-term negative impact on adjustment among adolescents [22]. This study examines the relationship between disclosure and adolescent children’s adjustment over 5 years.

Materials and methods

Participants

The New York City Division of AIDS Services (DAS) has a log of 95% of persons with AIDS qualified for social welfare benefits. From August 1993 to March 1995, 619 persons were logged by DAS. The eligibility criteria were: being HIV-infected; having at least one adolescent child aged 11–18 years; and permission of the case managers to enroll. During this period, only one PLH was referred to DAS per family. Of the 619 potential participants, 155 died prior to being approached and 35 cases managers evaluated that the research project could be potentially harmful to a family. Of the 619 PLH logged, 429 (69.3%) were eligible; of these 429, 65 (15%) were untraceable, 46 (10.7%) refused participation, and 11 (3%) were ineligible because of severe illness or incarceration. Thus, 71.5% (n = 307/429) of eligible PLH were recruited, reflecting 84% (n = 307/364) of the traceable PLH. Five years after recruitment, 149 (48.5%) of the PLH had died.

While the DAS was mandated to serve only persons with AIDS, not all parents had AIDS diagnosis: at recruitment, only 40% self-reported an AIDS diagnosis (n = 119), 42% were HIV symptomatic (n = 126), and 19% were without HIV symptoms (asymptomatic; n = 56). The sample was recruited during the period when a CD4 cell count < 200 × 10^6/l was a new AIDS criterion, leading parents not to recognize their status. Only 82% knew their CD4 cell counts; among these parents the mean CD4 cell count was 187 × 10^6/l (standard deviation, 177.5). Self-reports of CD4 cell counts were highly correlated to CD4 cell counts in medical chart reviews [23].

Intervention

These data were collected as part of a randomized controlled intervention study [20] with n = 153 families in intervention and n = 154 in the control condition. Delivered in two modules (23 sessions), module 1 addressed parents’ ability to cope with negative affect related to their health status, to make disclosure decisions, and to reduce problem behaviors. Module 2 included both parents and adolescents. Parents learned to parent while ill and make custody plans; for adolescents it focused on reducing problem behaviors, improving parent–child relationships and reducing emotional distress. We monitored additional counseling services received regarding disclosure issues; 36 parents received these services at some point over 5 years.

Procedures

Highly trained interviewers conducted assessments in participants’ homes using laptop computers every 3 months for the first 2 years of the study, and then at 6-month intervals to 5 years (n = 15 assessments). The follow-up rates were lowest during the first year (mean PLH, 68.5%; mean adolescents, 66.5%), and increased with training during the second year of follow-up (mean PLH, 85%; mean adolescents, 81.5%). The rates for years 3, 4 and 5 continued to increase for PLH (88.1%), but were slightly lower (76.4%) for adolescents. PLH and adolescents each received US$ 25 per interview.

Assessments

PLH

HIV-related disclosures to each child

For each child in their family (adolescents and younger children) disclosures were rated as: 1, told the child nothing of their diagnosis; 2, disclosed that he/she was ill; 3, disclosed that he/she had a chronic illness; 4, disclosed that he/she was infected with HIV; 5,
disclosed that he/she had AIDS; or 6, disclosed that he/she was dying. Based on pilot work, the seriousness of the disclosure was anticipated to be rank-ordered on the 1–6 categorization. Multiple categories could be endorsed for each child at each assessment. Therefore, in addition to recording the highest level of disclosure, disclosures were classed as: not having occurred (0), if parents told nothing, that they were ill, or chronically ill; or as having occurred (1), if parents disclosed an HIV or AIDS diagnosis, or that they were dying.

**Socio-demographic characteristics**
These included sex, age, living situation, and socio-economic status.

**HIV diagnosis and health status**
This included the date of the parent’s identification as being HIV seropositive, being symptomatic or asymptomatic for HIV, and their CD4 cell counts.

**The Brief Symptom Inventory (BSI)**
The BSI [24] included the parents’ rating of the level of severity for each of the 53 symptoms during the previous week on a scale from 0 (not at all) to 4 (extremely) yielding a global score for emotional distress ($\alpha = 0.97$).

**Problem behaviors**
The sum of the presence (1) or absence (0) of unprotected sexual intercourse, alcohol use, drug use, and contact with the criminal justice system was calculated for each assessment period.

**The Rosenberg Self-esteem Scale**
The Rosenberg Self-esteem Scale [25] includes a 10-item scale with endorsements of self-perceptions ranging from 1 (strongly agree) to 4 (strongly disagree) scale ($\alpha = 0.85$).

**Family life stressors and stressful life events**
These were expressed as a sum of the presence (1) or absence (0) of 14 stressful family events (e.g. arguments between parents; $\alpha = 0.66$), and six stressful life events (e.g., change of residence; $\alpha = 0.61$).

**Coping styles**
Coping styles [26] were rated on a scale of 1 (never) to 5 (always) scale for 40 items that yields seven subscale scores (positive action, self-destructive escapism, passive problem solving, passive action, spiritual hope, non-disclosure, and seeking social support; $\alpha = 0.46–0.88$).

**Perceived stigma**
Perceived stigma experienced by children was rated as present (1) or absent (0) on five items (e.g., recent HIV-related assaults; $\alpha = 0.82$).

**Social support**
Social support reflected the number of important persons listed; the mean number of network members was 3.79 (standard deviation, 2.44; range, 1–14).

**Adolescents**
Similar to parents, adolescents were interviewed regarding their: (i) self-esteem using the Rosenberg Self-esteem Scale; (ii) emotional distress using the Brief Symptom Inventory; and (iii) problem behaviors. In addition, adolescents completed the Parental Bonding Instrument with 25 items that reflect two inversely-related dimensions: (i) care (12 items; $\alpha = 0.83$); and (ii) overprotection (13 items; $\alpha = 0.72$) [27,28].

**Data analysis**
All disclosure data were organized by the child to whom the disclosure was made. Time from parental notification of HIV status to their disclosure to each child was calculated. Observations were censored at the time of parental death or 60 months following recruitment, whichever came first. Kaplan–Meier curves were plotted to examine the time from the date of notification of HIV status to disclosure based on parental sex, child sex and age. Using SUDAAN software [29], Cox proportional hazard models were conducted, controlling for family membership (as there was more than one child per family). Variations in the rate of mothers and fathers’ disclosures were examined for their sons and daughters (sex of parent × sex of child interaction).

To examine factors associated with disclosure, three separate analyses were conducted. First, using logistic regression in SAS software, the factors associated with disclosure were examined when disclosure had occurred at the time of recruitment. In each of these analyses, the time since notification of serostatus, age and the sex of the parent and the child were controlled. Parent’s education, emotional distress, problem behaviors, self-esteem, family life events, stressful life events, and coping styles were examined as potential factors associated with disclosure. In a second analysis using SUDAAN software, predictors of disclosure were observed prospectively among those who had not disclosed at the time of recruitment, but who eventually disclosed to one or more of their children over the next 5 years. In this second analysis, control and predictive variables were examined that were similar to the variables used in the first set of regressions.

Finally, the impact of parental disclosure on adolescent children’s adjustment was analyzed. As many parents had disclosed prior to recruitment, it was difficult to interpret the impact of disclosure for censored observations. Therefore, the patterns over time for each index of adolescent adjustment based on parents’ disclosures at the time of recruitment were examined. Simultaneously, the slope and intercept for each index of
adjustment were estimated for children to whom parents disclosed over the course of the study. Mixed effects models [30] were used to compare the slope and intercept for adolescents who were monitored prospectively and those for whom disclosure had occurred prior to study initiation. Adjustment was defined in terms of emotional distress, self-esteem, problem behaviors, and parental bonding.

Results

Description of the sample
Six parents did not report whether they had disclosed to their children; therefore, these participants were excluded from future analysis. Of the 301 PLH, 247 (82%) were mothers; 34.5% were African–American, 44.5% were Latino, 11% were white and 10% were of other ethnic backgrounds; and the mean age was 38.0 years old (SD, 5.6 years). Ethnicity, intervention condition and receiving any counseling did not emerge as significant predictors of disclosure in any analysis and so data for these factors are not presented.

Among 301 PLH, there were 787 children at the time of recruitment: 10% (n = 82) were 5 years old or younger; 23% (n = 182) were aged 6–11 years; 24% (n = 191) were aged 12–14 years; 26% (n = 208) were aged 15–17 years, and 16% (n = 124) were aged 18 years or more. There were no sex differences in the distribution of children’s ages. Overall, 48% were female. At the time of recruitment, children were a mean of 12.7 years old (SD, 4.9 years; median, 14 years). Eight children were born after recruitment.

Disclosure and associations with sex and age
About 30% of the parents disclosed to at least one child within 1 month of diagnosis, 6% disclosed within 2–3 months; 11% disclosed at 4–12 months, 16% disclosed within 1–3 years, 21% disclosed more than 3 years after diagnosis, and 12% did not disclose to any of their children prior to their death (i.e., among the 354 children of the 146 parents who died). At disclosure, most parents not only disclosed their HIV status, but they also discussed their AIDS diagnosis and possible death.

Disclosure varied based on the sex of both the parent and the child. The Kaplan–Meier curves in Fig. 1 demonstrate a significant difference in the probability of non-disclosure based on the parents’ sex. Mothers disclosed significantly earlier and were more likely to disclose than fathers [hazard ratio (HR), 2.02; 95% confidence interval (CI), 1.25–3.26; P = 0.0041], after controlling for the random effect of family membership and children’s age. Mothers were also significantly more likely to disclose earlier to their daughters than to their sons (HR, 1.33; 95% CI, 1.09–1.62; P = 0.004), controlling for family membership and children’s age (Fig. 2). The disclosure rates among fathers, however, did not vary based on the children’s sex (P = 0.29).

There were significant differences in disclosure based on the age of the child, as shown in Fig. 3. The bars on Fig. 3 indicate, for each age group, the percentage of children to whom the parents had disclosed over 5 years. Parents were significantly more likely to disclose to their older children (P < 0.0001). When the child was aged 4–6 years, about 10% of children were told of their parents’ serostatus. At around age 10–12 years, parents had disclosed to 40% of their children and by 13–15 years, the percentage of parents who had disclosed had increased to 60%. Based on the Cox proportional hazard model, the estimated probability of disclosure was plotted for each age group for 1, 3, and 5 years following notification of parental HIV status.

The percentage of families in which no child was told
about parental HIV status decreased from 48% to 12% over time; the percentage of families in which all children were told increased over time from 26% to 60%. However, the percentage of families in which only some of the children knew their parents’ HIV status was relatively constant over time (20–30%), creating a family secret.

Parental factors associated with disclosure

At the time of recruitment, parents’ disclosures were not significantly related to the parents’ level of emotional distress on the BSI (P = 0.09). Disclosure rates were also independent of self-esteem (P = 0.42), education (P = 0.91), financial status (P = 0.38), and problem behaviors (P = 0.83). However, disclosures were significantly related to parents’ stressful life events and their family life events (P = 0.0013 and P = 0.02, respectively). The number of stressful life events and family life events was higher among parents who had disclosed than among parents who had not disclosed. Parental HIV status at recruitment (AIDS, symptomatic, asymptomatic) was also related to disclosure: parents with a more severe diagnosis were more likely to disclose to their children (P = 0.026). Disclosure rates were also significantly associated with parents’ perceptions of the HIV-related stigmatization of their children (P = 0.035); parents who had disclosed reported that their children experienced significantly more HIV-related stigma than did parents who had not disclosed [odds ratio (OR), 2.81; 95% CI, 1.07–7.35; P = 0.035]. Lastly, there was a relationship between disclosure and social networks: parents with larger social networks (P = 0.004) were more likely to disclose to their children.

At recruitment, parents had not disclosed to 334 of their 787 children. Over the next 5 years, parents disclosed to 104 of these children (31%). Prospective survival analysis indicates that parents who disclosed were significantly more likely to have AIDS or to be symptomatic for HIV (P = 0.035). They also used more self-destructive coping styles than non-disclosing parents (P = 0.017). Yet, our prospective analysis did not reveal a relationship between parental disclosure and emotional distress, self-esteem, perceptions of stigma, problem behaviors, education, ethnicity, other coping styles or financial status.

The impact of disclosure on adolescents

At recruitment, 32% of adolescents (n = 127) learned of their parents’ HIV status within the previous year, 26.5% (n = 105) were disclosed to from 1 to 3 years prior to recruitment, and 20% (n = 81) were told of their parents’ serostatus more than 3 years earlier; 82 adolescents (20%) received no disclosure regarding their parents’ HIV status. The changes over time for problem behaviors and negative family events were similar for the three subgroups learning of the disclosure prior to recruitment. Therefore, analyses focused on the differences between adolescents learning parental serostatus prior to recruitment (n = 313) or later (n = 82).

Problem behaviors were significantly higher among adolescents knowing parental serostatus at recruitment compared to those who were non-disclosed (P = 0.035). However, problem behaviors decreased over time among the disclosed (slope = −0.00217) and increased among the non-disclosed (slope = 0.003), a significant difference (P = 0.009). A similar pattern was seen for negative family life events. At recruitment, disclosed adolescents reported significantly more negative family life events than non-disclosed adolescents (P = 0.017). However, those events decreased over time among disclosed adolescents (slope = −0.01) and were significantly different from non-disclosed adolescents (slope = 0.000; P < 0.0001). Adolescents who knew their parents’ serostatus were not different in terms of emotional distress, self-esteem, or parental bonding.

Discussion

There are strengths and weaknesses to the current study. New York City, representing one-third of the AIDS cases in the USA, logs all persons diagnosed with AIDS allowing us to examine a cohort representing 71.5% of the eligible cases. Fortunately, the refusal rate (10.7%) was low. One of the strengths is that the PLH were primarily African–American and Latino, persons frequently understudied [31]. Another strength is that follow-up rates were high over 15 assessments over 5 years. However, the repeated assessments may lead to reactive self-reports [32]. Furthermore, because this analysis is linked to an adolescent intervention study, PLH that had only young children (<12 years) are not
The parents in this study are likely to be older than parents with only younger children. Also, we do not have comprehensive assessments of the adolescents’ HIV status; although we do know that none of the adolescents were infected perinatally and only one adolescent has tested HIV positive over the 5 years.

Given the sample, the parents’ HIV disclosures appear to be similar to disclosure patterns of other types of sensitive information [33–37] and HIV disclosure to partners in other populations [7,22,38,39]. Mothers disclose more than fathers and more to their daughters than to their sons. Older children are more likely to receive a disclosure. Parent’s disclosures increased as their health deteriorates, although most disclosures occur 2–4 years prior to death (49%) rather than close to death (7% within 1 year). One unexpected finding emerges: disclosure does not vary by ethnicity, as was shown by earlier research [7].

Most importantly, disclosure appears normative; over time, parents were much more likely to disclose, regardless of the age and sex of the child. Within 3 months of their diagnoses as seropositive, 36% of parents disclosed. In most families (60%), all children knew their parents’ HIV status. Therefore, interventions encouraging disclosure will only speed up a naturally occurring process in a country such as the USA.

However, disclosures impact adolescents negatively; intervention challenges emerge about how to reduce this impact. The clinical literature suggests that family secrets are destructive [40]. About 20–30% of families in this sample report having such a secret among some of the children over time. It may be that all children within the family know the parent’s serostatus, but there is a tacit agreement among family members not to acknowledge this. Because of ethical concerns, we could not inquire from adolescents about their parent’s disclosures; future research must identify a methodology to overcome this barrier and examine the impact of secrets regarding HIV status on families.

Unexpectedly, the negative impacts of disclosure on both parents and their adolescent children persist for a considerable period of time. Parents who disclose report significantly more stressful life events, family stressors, and perceive that their children experience HIV-related stigma. Simultaneously, adolescents who are told about their parents’ serostatus report more problem behaviors and more negative family events. These findings indicate significant costs to the parents and their children for disclosing: clinicians should consider these costs in recommending disclosure.

When parents wait a long time to disclose, self-destructive coping styles are related to disclosing to their children. Perhaps such disclosures are precipitated by negative events (such as parental relapse into substance abuse); qualitative research must clarify the relationship. In addition there is a long list of factors related to disclosure that has been found in families with cancer [37,41]. Parent’s mental health status, self-esteem and SES are unrelated to disclosure in this study.

As the quality and duration of life for PLH has increased [42], there appears to be less urgency to disclose one’s serostatus to children. In this study, disclosures are common, but associated with a cluster of negative outcomes for both parents and their adolescent children for an extended period. Because PLH now routinely visit physicians, the medical setting offers a venue for providing support regarding decisions about whether, when and how to disclose their serostatus to their children.

In particular, as more than one-third of parents disclose very soon after their HIV diagnosis, post-test counseling with seropositive parents should encourage a delay in disclosure until the parent deals with their own feelings of anger, fear or depression prior to disclosing to their children. The parent then has an opportunity to plan their disclosure and not to use the disclosure to get support for themselves from their child. The parent will be better prepared to support their child.

If parents are discouraged from disclosing, an implicit message is communicated that HIV is stigmatizing and must be hidden. We are not advocating hiding one’s status. Yet, without appreciation of the long process involved when disclosing, parents are likely to be unprepared for the consequences of disclosure. Individual parents must consider their own families’ circumstances and each child within that family when making their decision whether, when and how to disclose.

**Acknowledgements**

This paper was completed with the support of National Institute of Mental Health grants #1ROI MH49958-04 and P30 MH58107. We thank the parents, caregivers, adolescents, and staff and collaborators.

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