



Information Search -- HIV Disclosure to Children

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DISCLOSURE STATEMENT: AMERICAN ACADEMY OF PEDIATRICS (1999)

American Academy of Pediatrics, Committee on Pediatric AIDS. (1999). Disclosure of illness status to children and adolescents with HIV infection. *Pediatrics*, 103(1), 164-166.

Also available online:

<http://www.apa.org/pi/aids/aapediatrics.html>

Many children with human immunodeficiency virus (HIV) infection and acquired immunodeficiency syndrome are surviving to middle childhood and adolescence. Studies suggest that children who know their HIV status have higher self-esteem than children who are unaware of their status. Parents who have disclosed the status to their children experience less depression than those who do not. This statement addresses our current knowledge and recommendations for disclosure of HIV infection status to children and adolescents.

INTERNET RESOURCES

Baylor International Pediatric AIDS Initiative

Telling an HIV-infected Child of His Diagnosis. (2003).

<http://bayloraids.org/qa/january2003/>

The Body: The Complete HIV/AIDS Resource

Damson, L. (1997). *Should You Tell Your Children You Are HIV Positive?*

<http://www.thebody.com/bp/oct97/tell.html>

Gay Men's Health Crisis

Silverio, R. (2003). *To Disclose or Not to Disclose: The Dilemma Confronting Families Living with HIV/AIDS*.

<http://www.gmhc.org/health/women/disclosure2.html>

National Pediatric and Family HIV Resource Center

Complex Issue of HIV Disclosure to Children and Adolescents in the Forefront. (1999).

<http://www.thebody.com/nphrc/disclosure.html>

The National Women's Health Information Center

Women and HIV/AIDS: Revealing your HIV Status. (2005).

<http://www.4woman.gov/HIV/talking.cfm>

Parents of Kids with Infectious Diseases

Disclosing to Our Children: What the HIV Experience has Taught Us. (2003).

<http://www.pkids.org/10-03disclosingtokids.pdf&ei=p7V7QoflHrqYYP3n9Y8G>

The Well Project

Margolese, S. (2003). *HIV and Disclosure*.

http://www.thewellproject.org/Womens_Center/HIV_and_Disclosure.jsp

RESEARCH ARTICLES (2001-Present)

Armistead, L., Tannenbaum, L., Forehand, R., Morse, E., & Morse, P. (2001). Disclosing HIV status: are mothers telling their children? *Journal of Pediatric Psychology*, 26(1), 11-20.

OBJECTIVE: Mothers living with HIV face a complex set of child-rearing decisions, often within the context of many competing stressors. One difficult decision for HIV-infected mothers is whether to disclose their HIV status to their children. The purpose of this study is to provide information to HIV-affected families and the professionals working with them as they approach disclosure-related decisions. **METHODS:** Eighty-seven HIV-infected African American mothers and one of their children who was not HIV-infected were separately interviewed on two occasions. Mothers reported whether they disclosed their HIV status to the child and provided their assessment of the child's functioning. Children also completed an assessment of their functioning. **RESULTS:** Results revealed that less than one-third of mothers disclosed their HIV status to their children. Disclosure was associated with mother's income level and perceived severity of physical symptoms. In addition, children disclosed to were more often older and female. Contrary to expectation, disclosure was not related to child functioning. **CONCLUSIONS:** Professionals should note the low rate of disclosure among these families. In the absence of conclusive data regarding impact on child functioning, professionals must remain aware of the complexity of disclosure-related decisions when working with HIV-affected families, particularly in terms of the family and cultural milieu within which families operate.

Gerson, A. C., Joyner, M., Fosarelli, P., Butz, A., Wissow, L., Lee, S., Marks, P., & Hutton N. (2001). Disclosure of HIV diagnosis to children: when, where, why, and how. *Journal of Pediatric Health Care*, 15(4), 161-167.

Despite recent recommendations by the American Academy of Pediatrics that strongly encourage disclosure of human immunodeficiency virus (HIV) infection to school-age children, health care providers vary widely in their actual disclosure practices. Concrete guidelines for accomplishing disclosure are not currently available. Nondisclosure can result in a variety of problems, including anxiety, depression, phobias, and exclusion from peer support groups and medical camps. This article reviews the available literature on disclosure of HIV infection to children and describes the disclosure process used in a large, urban pediatric HIV clinic.

Kirshenbaum, S. B., & Nevid, J. S. (2002). The specificity of maternal disclosure of HIV/AIDS in relation to children's adjustment. *AIDS Education & Prevention*, 14(1), 1-16.

Disclosure experience of 58 HIV-seropositive women was examined as a multi-faceted process comprising eight variables: level, seriousness, breadth, frequency, source, secrecy, age at first disclosure, and time since disclosure. The majority of children (57%) were told that their mothers had HIV/AIDS and were given additional information about mothers' health (64%) including prognosis of potential death (68%). Most were disclosed to by their mothers (75%) and were not asked to keep disclosures secret (66%). For most (68%) discussion regarding mother's health was infrequent. Children, on average, were first disclosed information at age 7 and had been aware of information for 3 years. Disclosure characteristics were related to demographics of mothers and children. Hierarchical multiple regression analyses showed that children asked to keep disclosures secret tended to display more behavior problems than children not asked to keep secrets. However, the specificity of disclosure did not otherwise predict children's adaptive functioning.



Lee, M. B., & Rotheram-Borus, M. J. (2002). Parents' disclosure of HIV to their children. *AIDS, 16*(6), 2201-2207.

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.

Lester, P., Chesney, M., Cooke, M., Whalley, P., Perez, B., Petru, A. et al. (2002). Diagnostic disclosure to HIV-infected children: How parents decide when and what to tell. *Clinical Child Psychology and Psychiatry, 7*(1), 85-99.

The objective of this study was to assess parental decision-making about illness disclosure to human immunodeficiency virus (HIV)-infected children. This is a cross-sectional study of 51 children with HIV infection based on parent interviews, child cognitive testing, clinical assessments and medical records. Only 43% of children had been told their HIV diagnosis. Qualitative analysis of parental decision-making about illness disclosure varied by child developmental level. Factors influencing parental decision to disclose the child's HIV status including parental communication style, parental illness, child's rights, treatment adherence, child questions and provider pressures, whereas concerns about HIV stigma and potential emotional distress were most frequently identified as reasons for non-disclosure. Central decision-making factors for parental HIV disclosure and reported outcomes of disclosure are described. Pediatric HIV disclosure represents a complex task for parents caring for the HIV-infected child, one in which the child's development and the family's community should be considered in the setting of a potentially stigmatizing infectious illness.

Lester, P., Chesney, M., Cooke, M., Weiss, R., Whalley, P., Perez, B., Glidden, D., Petru, A., Dorenbaum, A., & Wara, D. (2002). When the time comes to talk about HIV: factors associated with diagnostic disclosure and emotional distress in HIV-infected children. *Journal of Acquired Immune Deficiency Syndromes, 31*(3), 309-317.

OBJECTIVE: To determine factors related to the timing and probability of nondisclosure of HIV status to perinatally HIV-infected children, and to explore factors associated with emotional distress in HIV-infected children. **METHODS:** This is a cross-sectional study of 51 HIV-infected



children based on medical records, parent interviews, and child assessments. RESULTS: 1) Probability of earlier age of disclosure is associated with higher child IQ ($p = .04$) and more family expressiveness ($p = .01$); 2) controlling for child age, disclosure status at time of study is associated with major life events, but not with medical status; and 3) factors associated with increased parent-rated anxiety in HIV-infected children in univariate analyses are: HIV disclosure ($p = .04$), other major life events ($p = .001$), higher medication dose frequency ($p = .01$), and child age ($p = .01$). Increased depression is associated only with more medication doses ($p = .02$). CONCLUSION: These data indicate that higher child IQ and greater family expressiveness increase the probability of earlier diagnostic disclosure to HIV-infected children. Factors associated with emotional distress highlight important areas of clinical attention. These data suggest that diagnostic disclosure may not necessarily minimize emotional distress, indicating the need for further evaluation of the appropriate timing and type of disclosure for pediatric HIV.

Letteney S, LaPorte HH. (2004). Deconstructing stigma: perceptions of HIV-seropositive mothers and their disclosure to children. *Social Work Health Care*, 38(3), 105-123.

This study addressed the perceptions of stigma and disclosure behavior of HIV-seropositive mothers. Eighty-eight HIV-seropositive women in New York City completed two independent measures of stigma, the Perceived Stigma Scale and the Devaluation-Discrimination Measure. Disclosers (67%) and nondisclosers (33%) were similar in most sociodemographic characteristics-marital status, race, religion and employment, with the exception of age and education. Significant differences were found between disclosure groups in the use of secrecy as a stigma management tool and in perceived devaluation-discrimination associated with an HIV diagnosis. Nondisclosers to children were significantly more likely than disclosers to use secrecy as a stigma management tool ($t = -2.76$; $p = .01$), and to feel devalued and discriminated against as a result of HIV serostatus ($t = 3.11$; $p = .01$). Disclosure of parental HIV serostatus to children is an important aspect of continuous care and custody planning. Secrecy and perceptions of devaluation and discrimination related to HIV diagnosis should be seen as barriers to disclosure of serostatus to children.

Mellins, C. A., Brackis-Cott, E., Dolezal, C., Richards, A., Nichoas, S., & Abrams, E. J. (2002). Patterns of HIV disclosure to perinatally HIV-infected children and subsequent mental health outcomes. *Clinical Child Psychology and Psychiatry*, 7(1), 101-114.

Increasing numbers of perinatally HIV-infected children are surviving into their teens and beyond. Research and clinical reports suggest that many HIV-infected children, particularly those younger than 13 years, do not know they are HIV infected owing to parental concerns about the impact on their mental health. This study examines patterns of HIV status disclosure to 77 perinatally HIV-infected ethnic minority children (aged 3-13 years), and explores the association between knowledge of HIV status and emotional and behavioral outcomes. The majority of children in this study (70%) did not know their HIV status. On average, children who knew their HIV status were older and tended to have lower CD4%. Child knowledge of HIV status was not associated with gender, ethnicity, caregiver education, parent-child relationship factors, type of placement (biological vs adoptive), or other health status indicators. As hypothesized, HIV status disclosure to infected children did not result in increased mental health problems. There was a statistical trend for children who knew their HIV status to be less depressed than children who did not know. Also, greater social disclosure (e.g. communication of child's status to family and friends) was found when the child had an AIDS diagnosis or lower CD4%, as well as when the



caregiver was HIV negative, African American and not the child's biological parent. In conclusion, pediatric HIV infection remains a highly stigmatized issue that is difficult to discuss with the infected child and others. Yet, contrary to the beliefs of many caregivers, disclosure did not result in increased mental health problems.

Murphy, D. A., Steers, W. N., Dello Stritto, M. E. (2001). Maternal disclosure of mothers' HIV serostatus to their young children. *Journal of Family Psychology, 15*(3), 441-450.

Mothers' disclosure of their HIV serostatus to their noninfected young children and factors associated with disclosure were investigated among 135 families. Overall, 30% of the mothers had personally disclosed their serostatus to their children. Mothers who disclosed reported higher levels of social support in their lives than mothers who did not disclose. Children whose mothers had disclosed to them displayed lower levels of aggressiveness and negative self-esteem compared to children whose mother had not disclosed. These findings indicate that for this sample, no negative effects were observed among young children to whom mothers have personally disclosed their HIV serostatus.

Murphy, D. A., Marelich, W. D., & Hoffman, D. (2002). A longitudinal study of the impact on young children of maternal HIV serostatus disclosure. *Clinical Child Psychology and Psychiatry, 7*(1), 55-70.

A longitudinal analysis of the psychological well-being of 81 young children ages 6-11 living with their HIV symptomatic or AIDS diagnosed mothers was conducted. Specifically, the relationship among mothers' disease severity, maternal disclosure of HIV, and children's psychological well-being was investigated. The children were assessed over three time points (i.e. baseline assessment, 6-month and 1-year follow-up). Two categories of maternal disclosure (disclosed before baseline, no disclosure at any of the three time points over 1-year), and two categories of disease severity (< 500 T-cell count across all assessments, 500+) were created. A series of 2 x 2 x 3 repeated measures MANOVAs was used to assess the effects of the maternal disclosure and disease severity across time on children's psychological well-being. Results showed significant within-group time effects for child depression, suggesting a decrease in depression over time. Interaction results of time and maternal disclosure revealed only a few significant changes over time. However, significant decreases over time for child depression were noted among children whose mothers' CD4 cell counts remained at 500+ across the three assessment periods. Implications for future research and for psychosocial needs of these families are discussed.

Murphy, D. A., Roberts, K. J., & Hoffman, D. (2003). Regrets and advice from mothers who have disclosed their HIV+ serostatus to their young children. *Journal of Child and Family Studies, 12*(3), 307-318.

Qualitative interviews were conducted with mothers ($N = 47$) who had disclosed their HIV status to their child. Mothers described their preparation and the process of the disclosure event, and discussed any regrets they had about disclosing or the process of disclosing. They were also asked what advice they had for other HIV-positive mothers who were trying to determine whether to disclose their serostatus to their young children. Overall, the majority of the mothers (68%) did not regret disclosing their HIV status. Regrets fell into five categories: preparation, timing, context, content, and outcomes of the disclosure event. Based on these findings, mothers who



have not disclosed their serostatus to their children need assistance with behavioral practice and support in order to prepare for the process. Furthermore, follow-up support for the children may be beneficial.

Schmidt, C. K., & Goggin, K. (2002). Disclosure patterns among HIV+ women. *American Clinical Laboratory, 21*(2), 40-43.

No abstract available.

Schrimshaw, E. W., & Siegel, K. (2002). HIV-infected mothers' disclosure to their uninfected children: Rates, reasons, and reactions. *Journal of Social and Personal Relationships, 19*(1), 19-43.

Focused interviews were conducted with a sample of 45 HIV-infected mothers to identify the reasons women offer for disclosing or not disclosing the illness to their uninfected children, the women's perceptions of their children's reactions to such disclosure, and what effects this disclosure may have on subsequent relationships with their children. Two-thirds (66%) of the mothers had disclosed their HIV infection to one or more of their children. Disclosure rates varied according to age of the child, mother's current disease stage, and whether the child lived with the mother. Mothers reported many reasons for disclosing their HIV infection to their children, including wanting to educate their children about HIV, wanting their children to hear it from them, wanting their children to know before they became very ill, and wanting to be honest with their children. Reasons for nondisclosure included believing that their children were too young or immature, believing it would be too much of an emotional burden for their children, not wanting their children to experience rejection, not wanting their children to fear losing their mother, and wanting their children to recover from previous losses. Although adverse reactions were reported in a few children, most mothers reported that their children, although emotional at first, experienced little, if any, lasting negative impact. Indeed, many reported that the relationship with their children had become closer following disclosure.

Shaffer, A., Jones, D. J., Kotchick, B. A., Forehand, R. (2001). Telling children: Disclosure of maternal HIV infection and its effects on child psychological adjustment. *Journal of Child and Family Studies, 10*(3), 301-313.

We present descriptive information pertaining to mothers' decision to disclose their HIV infection status to their children, examine correlates of disclosure, and compare mother and child reports of psychosocial adjustment difficulties as a function of disclosure. In contrast to prior studies, a longitudinal (pre-disclosure to post-disclosure) design was used. Participants were 99 inner-city African American mothers and one of their non-infected children. At the last assessment, a majority (68%) of children were not aware of their mother's HIV status; however, most mothers planned to disclose eventually. Of the children who knew their mother's HIV status, almost all had been told by their mothers. Mothers reported a significant increase in child behavior problems and a decrease in mother-child relationship quality from pre- to post-disclosure. Children reported a significant increase in their understanding of HIV/AIDS, but no significant behavioral changes. Clinical implications of the findings and directions for future research are discussed.

Vallerand, A. H., Hough, E., Pittiglio, L., & Marvicsin, D. (2005). The process of disclosing HIV serostatus between HIV-positive mothers and their HIV-negative children. *AIDS Patient Care*



and STDs, 19(2), 100-109.

The current study explores the impact of HIV disease on mothers as they face the task of balancing their own physical and psychological needs with the needs of their families as well as the additional burden of deciding whether to disclose their HIV status to their children. Qualitative interviews were conducted with 35 women and 19 children 10-18 years of age. Mothers were interviewed about the experience of being an HIV-positive mother and issues regarding disclosure. Children were also interviewed about the experience of having a mother who is HIV-positive and issues regarding disclosure. The decision to disclose was dependent on the child's developmental level, the degree of the mother's illness, and in some cases this decision was taken from mothers when someone else disclosed their HIV status to their children. Positive aspects of disclosure from the mother child dyads included open, honest communication, and closer relationships between mothers and their children. Common negative themes emanating from the data included fear, uncertainty, forced secrecy for fear of being ostracized based on the stigma associated with the disease, behavioral changes in the children, and shifting responsibilities between the mother and the child. Findings of the study suggest that disclosure, and all it entails, remains a vital issue for mothers who are HIV-positive. In addition, the findings reflected that children and their mothers have very different perspectives regarding the process and the effects of disclosure of the mother's HIV status. Clinical implications and recommendations for further research are discussed.

BOOKS & OTHER PRINTED MATERIALS

Tasker, M. (1992). *How Can I Tell You? Secrecy and Disclosure with Children when a Family Member has AIDS*.

The Teresa Group. (1999). *How Do I Tell My Kids? A Disclosure Booklet about HIV/AIDS in the Family*.

Many adults believe HIV does not affect children. The truth is, children live in families where one or more family member may be living with HIV. If an adult is living with HIV, there is probably a child in his or her life who is affected by HIV/AIDS.

This booklet is for adults who are thinking about telling their children that a family member has HIV.

VIDEOS

“Don’t Shut Me Out: HIV & Parents Struggling with Disclosure”

The Center for Special Studies. (1997).

<http://www.aidsnyc.org/shut.html>

“It’s Like This”

HIV Center for Clinical and Behavioral Studies

<http://www.hivcenternyc.org/videos/vidlik.html>

“What’s Best for You: Families Living with AIDS Talk about Disclosure”

National Pediatric HIV Resource Center. (1994).

<http://wellme.stateart.com/productions/health/hivaids/whatsbestforyou/>