# Disclosure of an HIV diagnosis to Children: History, Current Research, and Future Directions

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## Abstract

Disclosing the diagnosis of human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome (AIDS) to a child is a controversial and emotionally charged issue amongst both the health care communities and parents and caregivers of these children. This paper provides a systematic review of research on disclosure of pediatric HIV infection. The paper begins with a brief discussion of disclosure drawing from research on pediatric cancer. Next, we review the available research including patterns of disclosure, factors associated with disclosure and non-disclosure, and the effect of disclosure on psychological health and adherence. A review of published intervention studies is also included. While no consensus on when the diagnosis of HIV should be disclosed to a child or the psychological outcomes associated with disclosure was found, clinical consensus on several issues related to working with families was identified. We apply this literature to clinical practice and suggest avenues and directions for future research.

Since 1983 when HIV was first described in children, the epidemiology of pediatric AIDS has evolved significantly[1]. In the US, as well as in other high resource settings, the introduction of widespread HIV counseling, testing, and treatment with Antiretroviral Treatment (ART) during pregnancy has led to a dramatic drop in the rate of perinatal transmission, as well as significantly improved morbidity and mortality.[2] Many HIV-infected children who were not expected to survive childhood are entering adolescence and young adulthood. The prospect of a longer lifespan brings new challenges related to the impact of HIV infection on physical and mental health, as well as on normative developmental processes such as growth, peer relationships, puberty, and sexuality.[3]

With increased survival, one of the greatest psychosocial challenges that parents and caregivers of perinatally HIV-infected children face is disclosure of HIV serostatus to their infected children. HIV diagnosis disclosure entails communication about a potentially life threatening, stigmatized and transmissible illness and many caregivers fear that such communication may create distress for the child. In 1999, the American Academy of Pediatrics published guidelines stating that all adolescents should know their HIV status and that disclosure should be considered for school-age children.[4] Clinical reports have indicated positive outcomes associated with disclosure including the promotion of trust, improved adherence, enhanced access to support services, open family communication, and better long-term health and emotional well-being in children.[4–10] However, three decades into the HIV/AIDS epidemic,

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disclosure of perinatal HIV infection is often delayed until older childhood and beyond and few empirically based interventions or guidelines are available for assisting parents and providers to make decisions about disclosure.

Although the use of antiretroviral medications has reduced mother to child transmission of HIV dramatically in the US and other high resource countries,[11] with 2.2 million children (< 15 years) living with HIV/AIDS worldwide, and 640,000 children newly infected in 2004 alone,[12] diagnosis disclosure will be an issue that families, practitioners, and researchers will need to address for many years to come. This paper is the first that we know of to provide a systematic review of the research on disclosure of pediatric HIV infection, including rates and correlates of disclosure as well as the psychological impact of disclosure and non-disclosure on HIV-infected children. We undertook this review with the goal of synthesizing the literature and developing recommendations about the timing and conditions for disclosure to children. As the most extensive literature regarding diagnostic disclosure pertains to children with cancer, we begin this paper with a brief historical overview of lessons learned from the pediatric oncology experience.[13,14]

## Brief Historical Overview Of Illness Disclosure In Pediatric Cancer

Prior to the 1970's children living with cancer were given limited information about their diagnosis and prognosis. It was thought that they would have little understanding of the illness. Many thought it would be best to protect them from the emotional burdens their parents faced. However, in the 1970's several factors led to more open illness-related communication to children living with cancer, including: 1) improved survival rates, 2) the growing children's rights advocacy movement,[15] 3) the increasing need to enlist children's cooperation with difficult research protocols and aversive treatment regimens, and 4) the results of psychological research pointing to a continuum of cognitions through which children orient themselves to illness and death. [6,16][17] Also at that time, Waechter[18] found that children show acute awareness of, anxiety about, and preoccupation with their condition despite their parents' stance of protective communication.[19, 20] As providers challenged the notion of withholding medical information from children, studies consistently showed that open communication about cancer diagnoses improved children's psychological adjustment, with the positive effects lasting into adulthood for both the child and family members.[13,21–23] By the early 1990s, the critical question was not "Should the child be told?" but rather "How and when should the child be told?"

Several groups of investigators began to demonstrate that diagnostic disclosure to children is generally most successful if accurately mapped to their cognitive and emotional development. [16, 24] Disclosure may be seen as an ongoing process as the child develops cognitive, psychological, and spiritual awareness about the meaning of illness and death.[25] The work of Bibace and Walsh demonstrated that children's theories of illness and death corresponded with Piagetian stages of cognitive development, moving from pre-operational, to concrete and finally formal operational stages of reasoning about illness.[16] Hence, young children, even as young as 3, have some concept of death, although they often believe that the dead individual will come back to life. As they age, they begin to understand the permanency and irreversibility of death. Thus, practice evolved from one of secrecy to one that advocates presenting accurate information to a child in developmentally meaningful terms.

## Challenges To Applying Lessons Learned From Pediatric Oncology To Pediatric HIV Infection

Applying the evidence-based knowledge being practiced within oncology to pediatric HIV disease is difficult given significant differences in epidemiology, the multigenerational nature

of the illness, and the unique social stigma surrounding HIV transmission.[6] Pediatric HIV is most prevalent in poor, urban, and ethnic minority populations who have typically suffered years of discrimination and racism. Moreover, HIV infection is associated with stigmatized behaviors, such as high-risk sex, same-sex behavior, and drug use, and the fear of contagion has engendered a level of stigma beyond that associated with any other disease.[26] The majority of HIV-infected children acquired the virus from their mothers, and ensuing parental guilt about transmission distinguishes this disease from cancer and other life-threatening pediatric illnesses. Furthermore, unlike disclosing a cancer diagnosis, disclosure of a child's HIV diagnosis often leads to disclosure of other family secrets, including paternity, and parental history of sexual behavior and substance abuse.[27] Thus, not only are parents' decisions to disclose affected by their fears about the emotional consequences of disclosure for the child, but also their fears about the child's anger towards the parent, and the potential social consequences associated with the child sharing the diagnosis with others (e.g., ostracism, negative reactions from family, friends and school, lack of community support).

Similar to early trends in oncology, early in the AIDS epidemic long term survival was unexpected, and many parents and providers thought it best to protect children from the emotional burdens and societal prejudices associated with knowing their HIV/AIDS status. With the advent of new therapies in the mid 1990's and dramatic improvements in the mortality and morbidity of HIV infected children, changes in disclosure practices began to take place. [28] As children survived for longer periods of time, disclosure issues emerged related to pubertal development and sexuality, fear of contagion and transmissibility, and a need to promote adherence to complex and often toxic regimens.[29] The public health risks of non-disclosure, including non-adherence to medications that may result in drug resistant strains of HIV combined with risky sexual behavior that may result in transmission of the virus (including such drug-resistant strains), add a sense of urgency to the issue of disclosing the HIV diagnosis to youth living with perinatal HIV infection.

Within treatment centers, conversations about disclosure became a major focus of discussion between providers and caregivers. When some parents and guardians began asking healthcare providers to avoid using the words HIV and AIDS around their school-age children, providers became particularly concerned about the ethics of nondisclosure.[7,8,30, 31] Even within the professional community, a divide emerged between those who believed the child should know their status immediately and those who were concerned about the timing and consequences of diagnosis disclosure. In addition to concerns about stigma and the emotional consequences of disclosure, providers recognized that children with HIV are at risk for significant cognitive impairment, including specific problems with processing speed, memory, and other measures of executive planning and judgment that may impact their ability to understand and process information about their illness.[10, 32, 33] Even an adolescent who may be able to meet "mature minor" criteria for "competence", may have difficulty with disclosure due to "adolescent onset dementia," impairment of executive abilities, and deteriorating function.[34] For those with cognitive impairment, and/or decreased impulse regulation, consequences of disclosure may be damaging for both the child and the entire family.[25]

Although the American Academy of Pediatrics[4] recommendations supported disclosure to older children and all adolescents, few concrete guidelines were provided to support healthcare providers and families in this process. A number of studies addressing disclosure related issues have been published since this report, yet to our knowledge, there has not been a systematic review of the literature on disclosure of HIV status to HIV-infected children that would serve to inform the development of efficacy-based interventions or the development of clinical guidelines. Thus it is the goal of this paper to review and synthesize the literature on a) patterns of disclosure; b) factors associated with disclosure and nondisclosure; c) the psychological impact of disclosure on both the child and family; d) disclosure and antiretroviral adherence

in children; and e) disclosure intervention studies. It is our hope that this report will identify gaps in knowledge and serve to assist in the development of clinical guidelines for providers.

## METHODOLOGY

### Search Strategy

The review that follows is based on studies that were conducted as a result of the changing epidemic of pediatric HIV. Given the limited literature in this area, published abstracts from international conferences and dissertations are included in the review. Relevant articles and abstracts were identified through an online search of the databases Medline and PsycInfo using the keywords: HIV, DISCLOSURE, CHILD, PEDIATRIC. Reference lists of retrieved articles were examined for additional studies that fit the inclusion criteria and the relevant articles were also retrieved for review.

**Inclusion Criteria—**Articles found using the above search strategy were examined to confirm that they:

- Included HIV positive children or adolescents under the age of 18 infected perinatally or early in life in the sample;

- Reported information about the disclosure process, disclosure rates or correlates of disclosure among children or adolescents infected perinatally or early in life;

- Were reported in English (no exclusions made based on country that the study was conducted in).

**Data Extraction—**For all eligible studies, the authors' names, year of publication, study design, instruments, sample characteristics (population, sample size, mean age and age range of the participants, mean age of disclosure), rates of disclosure and outcomes of disclosure (if measured) were entered into a table. This resulted in the review of 22 studies (Table 1).

### Results

**Patterns of Disclosure:** Early psychosocial research studies were designed to assess the prevalence and predictors of both disclosure and non-disclosure. This work elucidated various patterns of disclosure, ranging from non-disclosure to partial disclosure to full disclosure. Although complete nondisclosure (no mention of HIV or of any illness) does take place, particularly in the child's early years, partial disclosure is actually more common. Partial disclosure[35] is the term used for describing situations in which children are given some but not all information about their illness. They may be informed of the need to take medicine in order to keep their virus or "illness" at bay, or learn how their virus or "illness" can be transmitted without learning that their virus or "illness" is called HIV or AIDS. For example, a child in one study reported " I take pills so that my soldiers which are in my blood can be more efficient to fight micobes" (p 981).[7] When full disclosure occurs, children are told the name of the illness (HIV and/or AIDS), disease specific information (e.g., how the virus works, how it is transmitted), and how they acquired the disease.

Funck-Bretano and colleagues[7] were among the first to describe these various patterns of disclosure. Among 35 Parisian families, the authors found that non-disclosure (23%) and deception (20%) were common, particularly in young children, with complete nondisclosure coinciding with secrecy about the illness or a caregiver's denial of the child's illness. Partial disclosure was the most common (40% of the cases), was often viewed by some caregivers as a step towards full disclosure. Partial disclosure often occurred in conjunction with illness deception.[7] Deception often entailed caregivers, frequently out of concern for the child's psychological well-being, telling their children only about a co-morbid condition (e.g. asthma,

cancer), and attributing all medical needs (e.g., appointments, medication) to that less-stigmatized condition.

Funck-Bretano et al., reported that only 17% of their sample had been made fully aware of their HIV illness. Since then, other studies have focused on the prevalence of full HIV disclosure for school age children, adolescents and young adults and have produced inconsistent findings. Studies relying on caregiver report have found that 10% to 75% of HIV + children in the samples have been told about their HIV status.[7, 9, 29, 36–47]

**Factors associated with non-disclosure and disclosure:** Across studies, several factors have been associated with a caregiver's decision not to disclose the HIV diagnosis to their child. Most commonly cited is a belief that a child is "not old enough or ready" [38,48] or is not sufficiently mature to understand and/or cope with the diagnosis.[43,47] Several studies found that caregivers were concerned that if they disclosed, their child would not keep the diagnosis private, related family secrets might be disclosed outside the home, or that children would be exposed to ostracism and negative reactions from community and family. [38,43,47,48] Many HIV positive mothers have reported the concern that their child will be angry with them for transmitting the virus.[48,49] Finally, although one would expect timing of disclosure to be associated with CD4 count, number of hospitalizations, medication doses, or perceived severity of illness, no consistent finding has been reported. [9, 25, 37, 47]

A number of quantitative studies have examined correlates of disclosure to HIV-infected children. Caregivers who disclose early tend to be HIV negative,[31,47,50] have older children, [9] report greater satisfaction with their social support system,[47] have greater family expressiveness,[42] higher SES,[47] and live in an urban area.[25] Full disclosure of child serostatus has been associated with lower maternal depression and better quality of parent-child interactions.[9,42,47] Caregivers who decide to disclose the diagnosis to their child cite many reasons for this decision including opposing or tiring of secrets, believing in a child's right to know their health status, concern that their child will learn the diagnosis elsewhere, fear the child would get involved in sexual activities without protection and hope that disclosure will lead to improved health care or motivate their child to improve medication adherence. [48,51] Children who have been informed of their diagnosis by their caregivers tend to be older, have a higher IQ, and have increased parent-rated child anxiety and a greater number of major life events. [25,42]

**Psychological Impact of Full Disclosure:** A handful of studies have examined the psychological impact of both non-disclosure and disclosure with mixed results. Bachanas and colleagues found that among 36 HIV-infected children, ages 6–16, those in families where disclosure had not taken place were more likely to report internalizing behavior problems and their caregivers reported more overall psychological distress.[36]

To assess the impact of the child's knowledge of his/her diagnosis, Hardy and colleagues[40] examined communication styles of three groups of preschool children (N=20 per group) one with cancer, the second with HIV, and the third healthy controls. Nineteen of the 20 children living with cancer and five of the 20 children living with HIV knew their diagnosis. Using a model of an examination room, children were asked to place dolls representing the child, parents, and medical staff in the room. Children with cancer (and healthy controls) placed dolls representing the staff and parents significantly closer to the child doll than children with HIV Furthermore, significantly more children with HIV removed the staff/parent doll from the room or turned the staff/parent doll's back to the child doll, reflecting a common practice of talking about the child's HIV status in whispers or outside the room, and suggesting that communication around the child is closed and isolating. However, it is not clear how many of these children had experienced full disclosure, and in other analyses[52] the investigators found

no differences in parent or child coping between disclosed or nondisclosed group for children living with HIV or cancer.

One study found increased problems among disclosed children. New and colleagues found significantly higher scores (more behavior problems) on the Internalizing Behavior Problem Scale (e.g., anxiety, depression, withdrawal) of the Child Behavior Checklist (CBCL) for children (N=57) who knew their HIV status versus those who did not know, as well as a trend toward higher scores on the Externalizing Behavior Problem Scale (attention problems, aggression, conduct).[53] This latter study was cross-sectional in nature so it is not clear which came first…the problem behavior or the disclosure.

Conversely, in a sample of 61 HIV-infected children with a mean age of 8.9 (range 6–11) Riekert and colleagues found children who knew their diagnosis reported significantly lower scores on depression and anxiety measures than children who did not know their diagnosis. [54] The remainder of the studies examining the psychological impact of disclosure found little or no difference in psychological functioning between disclosed and nondisclosed children. Mellins et al [9] examined a cohort of 77 parent-child dyads with a mean child age of eight years (range 3–13); the average age of disclosure was seven. Thirty percent of the cohort was aware of their diagnosis. Although the authors noted a trend for less depression among the children who knew their status, there were no statistically significant differences in emotional and behavioral problems between children who knew and did not know their diagnosis. Similarly, Lester and colleagues studied 51 families (children's ages 4–13) and failed to find a statistically significant difference between disclosure groups in psychiatric diagnoses based on medical chart view.[42] In an older cohort, (mean age 10.5, range 5–19), Wiener and colleagues[47] interviewed 99 parent-child dyads about HIV disclosure. Seventy-five percent of the children had been told about their HIV status (mean age of disclosure was 7.5). While standardized psychological instruments were not used, 65% of those disclosed to felt that they were told at the right time and 86% by the right person. Fifty-nine percent of these children reported that their life had either not changed much or were not sure how their life changed since learning their diagnosis, while 30% felt their life had changed for the worse and 11% reported that it had changed in a positive direction.

There has been only one report that examined whether early disclosure is better than disclosing the diagnosis to the child at an older age. Of 40 HIV-infected adolescents and young adults, the authors found no relationship between timing of disclosure and psychological adjustment, social support, or the adolescent's own decision to disclose his or her HIV status to others.[55]

**Disclosure and Adherence in Children:** Pediatric HIV providers generally believe that disclosure is important for helping children understand the need for ART and for creating trusting relationships that facilitate adherence,[56] yet research on disclosure and adherence is not conclusive. In a recent qualitative study some caregivers reported that their children became more adherent to antiretroviral medications after learning their diagnosis while others reported less adherence following disclosure.[39] Two quantitative studies have indicated that children who know their HIV status may be less likely to adhere.[57,58] It is conceivable that the relationship between disclosure and adherence may be explained by the relationship between child age and disclosure. That is, both disclosure and non-adherence tend to occur as children age, particularly as they reach adolescence. However, at least one study found a relationship between disclosure and worse adherence even after controlling for child age [58] and a second study found that disclosure was associated with worse adherence, but older age was not.[57] It could be that once children become aware of their HIV status, caregivers expect their children to take the medication independently, without supervision and reminding.[51] For various reasons, children who are given complete responsibility for adhering to their medical regimens may fail to consistently adhere. [59] Length of time since disclosure and emotional reactions to

disclosure may also affect results. For example, children who have only recently learned their diagnosis may react with extreme denial, anger, or hopelessness that is likely inconsistent with taking medications that remind them of their HIV. Alternatively, children who know they are HIV-positive may be less willing to take their medication in front of others, for fear that others will "find out" and ostracize them. Unfortunately, because disclosure was not a primary focus of the above studies, and research has not more thoroughly examined the interplay between disclosure and ART adherence, it is difficult to draw solid conclusions or make recommendations.

**Intervention studies:** There is a dearth of research describing the development and evaluation of interventions to facilitate disclosure. The only published disclosure intervention study located for this review evaluated a disclosure model for pediatric patients living with HIV in Puerto Rico.[51] Developed to address many of the barriers to open communication about pediatric HIV, their five-step intervention targeting providers, caregivers, and HIV+ children involves: a) Trainings for health professionals in developmentally appropriate disclosure; b) caregiver educational sessions and peer support groups; c) child assessment sessions throughout the process; d) combined family and staff disclosure sessions; and e) post-disclosure family groups for education and support. The investigators reported that their intervention model promotes healthy psychological adjustment and better adherence in children. Six months post disclosure, 70% of the participating youths endorsed feeling 'normal' and parents and caregivers reported that approximately 58% had improved adherence. Although the majority of youths (85%) and caregivers (97%) thought the disclosure was a positive event, and many youth felt more supported by parents (58%), grandparents (48%), clinic staff (48%) and others as a result of the intervention, there was not a comparison group with which to contrast these results. Other interventions results are anecdotal and unpublished.

**Discussion—**Despite recommendations from the Academy of Pediatrics in 1999[4] to promote disclosure of HIV serostatus to children as soon as is developmentally appropriate, disclosure of HIV to children infected perinatally or early in life still remains a difficult and controversial issue for families and providers. Relatively few research studies have been conducted that evaluate: 1) The actual disclosure process as it unfolds over time; 2) the most appropriate timing and determinants of disclosure; 3) the psychosocial effects of HIV disclosure; 4) the impact of disclosure on adherence and sexual behavior; and 5) the most effective strategies for full disclosure. Lessons learned from pediatric oncology are still applied to HIV disclosure, even though the population of children affected by HIV differs dramatically, in terms of socioeconomic and cultural variation, and the incomparable social stigma that surrounds HIV/ AIDS.

The studies summarized in this article present mixed findings on the impact of disclosure, with some showing benefits, others risks, and still others showing no mental health differences between youth who know and don't know their diagnosis. Based on the studies thus far, there is no clear evidence that children who have experienced full disclosure have better or worse psychological outcomes than those who have not, despite the fact that secrets maintained in a family have been associated with unhealthy adjustment in other populations of children coping with chronic health conditions [6,18–20, 60–67] and despite very strong clinical consensus that patients and their families do, indeed, benefit from disclosure.[68]

**Methodological Limitations:** The primary limitation of all of studies to date on disclosure of perinatal HIV infection is the restricted sample size. Given substantial reductions in maternal-to-child transmission of HIV in the United States and other high resource countries with access to antiretroviral treatment, the number of pediatric HIV cases has been significantly reduced. Thus, many of the samples, recruited from single institutions, are simply too small to allow detection of significant differences between disclosure groups, especially when controlling for

important demographic variables such as the age of the child. Another limitation of most studies described here is that the interviews simply ask if the child is aware of or has been told his or her diagnosis without acquiring any in-depth information on what type of information was given, when full disclosure occurred, and how many times disclosure was discussed. In addition, most of these studies were designed to assess something other than disclosure, which resulted in great variability between studies in terms of sample size, study setting, patient demographics and measurements used.

Other weaknesses in the literature limit the conclusions that can be drawn. Variations in the definitions of disclosure, disease status, and demographic factors such as age may account for some of the differences across studies. It is also possible that clinics treating pediatric HIV (where some studies were conducted) may foster different cultures of disclosure—some of which may be more inclined toward early disclosure and others that may tend towards later disclosure. Most studies have used cross sectional and qualitative designs, making it impossible to identify predictors of non-disclosure and the timing of disclosure as well as the long-term sequalae of both disclosure and non-disclosure. Some studies have failed to include both child and caregiver reports, perhaps because nondisclosure makes it difficult to prospectively assess a child's perspective regarding the disclosure process. Moreover, memory issues and history effects may negatively affect retrospective studies.

Lack of consensus in existing studies may also stem, in part, from the difficulty of studying an evolving process. Research has often examined disclosure as a single, binary event. Over time, it has increasingly been viewed as a process of moving from non-disclosure to full disclosure. While full disclosure may transpire in a single encounter, most commonly it is an ongoing process in which pieces of information are discussed over time or at different developmental stages as clinicians and parents see fit.[6,10] Partial disclosure is often viewed as appropriate when children are younger and the specific name of the illness may not hold meaning for them or be as important in helping them cope with their fears about symptoms and medications.[3] For example, a child might first be told they have to take medication to help their body fight illnesses in general; several months or years later they may be told that they have a "blood disorder" (without the name), and then finally that they have HIV. Even when told the name of their disease, a potentially charged moment, children's ability to cognitively and emotionally absorb the information in one session may be limited[6]. Cognitive and developmental imitations of children as well as children's capacity for denial and magical thinking also play a role in a child's processing of the diagnosis. It may require multiple sessions and time for children to fully understand the name of their disease, its health consequences, and their medical needs. Investigations need to capture the child's ability to cognitively and emotionally process this information accordingly.

**Recommendations for Future Research:** Despite significant advances in HIV treatment and care, children continue to be born with HIV infection, and disclosure of HIV infection to children remains a pertinent issue. In settings where the numbers of children living with HIV are unfortunately high, longitudinal research is both possible and critical for understanding the processes of disclosure. Studies designed to flush out factors that promote or hinder communication between children, parents, and providers around illness are clearly needed. Additionally, we need a better understanding of how to develop and evaluate interventions that promote communication about illness and take into consideration: 1) Age and development; 2) cultural factors that influence communication as well as concepts of illness and death; 3) family variables; 4) quantity and quality of social support; 5) mental health; and 6) a child's neurological and cognitive functioning. Additionally, there is a need to know how to help providers make decisions about disclosure when the interest of the child and caregiver may be disparate. Because the psychological complexity of disclosure can not be captured solely by uniform administered measures, a range of research approaches are needed. For example,

qualitative research can more intimately address the quality of parent-child interactions post disclosure, while population studies can assess the impact of disclosure on school functioning and immunological functioning. Furthermore, prospective qualitative interviewing of children and caregivers at multiple time-points spanning multiple years will be a useful means of exploring how the process of disclosure unfolds over time. Pairing qualitative interviews with more structured assessments of psychological and physical functioning will help researchers to obtain a clearer sense of the predictors and outcomes associated with the disclosure continuum.

**Implications for Clinical Care—**Diagnostic disclosure to the perinatally infected child remains one of the most clinically challenging issues for families and providers in part due to the tremendous stigma that still exists. In many ways, we have not moved much beyond one of the first reviews of disclosure and pediatric HIV by Michael Lipson[63] in which he stated, "We need to change our concept of a disclosure moment into the idea of participation in a dialogue, a process of discussion." (p. 10) Moreover, the process of disclosure must reflect a child's developmental understanding of illness and death over time as suggested in the pediatric oncology literature.

Undeniably, as the population of perinatally infected children or those infected early in life age into adolescence and young adulthood, the public health issues of non-adherence, sexual transmission of HIV, and particularly drug resistant strains of the virus[69] warrant an understanding of the ethical, moral and legal obligations of families and providers to inform children about their diagnosis so that they can make informed decisions and choices.[69] Adolescence is a time of intense social pressure to "fit in" and be "normal". Adolescence is also a time of increased experimentation with sexual behavior and drug use. Many perinatally infected adolescents are living with multidrug resistant virus, secondary to inadequate adherence and years of partially suppressive therapy prior to the introduction of more powerful ART, [64] meaning that risky behavior among these youths not only provides opportunities for transmission of HIV—it also creates the potential for transmitting ART-resistant strains of the virus to others. Making decisions about sexual behavior and adhering to complex regimens that disrupt one's lifestyle can be a difficult challenge for anyone, but particularly for youths who may or may not know that they have a stigmatized and sexually transmissible disease. For youths with HIV who know their diagnosis, the decision whether or not to disclose their status to friends, teachers, employers, and especially potential romantic partners has been a primary concern. [55, 70, 71] For youth who remain unaware of their diagnosis, ethical and legal conflicts also arise. For example, when there is a lack of concordance between parent and child readiness for disclosure of the child's status (e.g., the parents don't want to disclose and the child is beginning to engage in risk behavior), what are the obligations of the provider? Currently many providers will not disclose if the parents do not want disclosure to occur out of both respect for parents wishes and concerns that parents will remove the child from treatment. However, as children age into older childhood and adolescence, providers become increasingly uncomfortable with secrecy, particularly when adherence and sexual behavior are issues. At this time, there are limited laws or practice guidelines for providers in these situations to consult. [72, 73]

**Guidelines for Clinical Care:** Although studies have been inconclusive, practitioners are confronted with disclosure issues daily. Even without evidenced based consensus on when the diagnosis of HIV should be disclosed to a child or on the psychological outcomes associated with disclosure, there does appear to be some clinical consensus on several issues related to working with families.[6,10,62,65–67] Unfortunately, most of these recommendations remain untested, although many of these guidelines are included in the Blasini et al. intervention.[51] In the hopes that future investigations can be devoted to evaluating these guidelines, recommendations from those clinical reports are provided here.

1. *Consider Child Abilities:* It is typically suggested that clinicians guide families with specific considerations for the child's ability to comprehend the information and cope with the knowledge that they are HIV-infected.[6,10,51]

2. *Assess caregivers abilities:* It is important to consider a caregivers' ability to cope with the stress of disclosure, ability to reach out for support when needed, and ability to discuss other stigmatized family secrets that might be related to disclosure of the child's HIV diagnosis[51]. If a child or guardian is concurrently experiencing significant unrelated stressors, it may not be the best time for disclosure to occur. Severely depressed or anxious caregivers may need to address their mental health needs before beginning the disclosure process. [8, 48]

3. *Rehearse and prepare for the actual disclosure:* Role-playing a disclosure scenario with a counseling professional and when medically appropriate, and being able to communicate a sense of hope and optimism for their child's prognosis and future have been found to be beneficial.[51, 74]

4. *Identify sources of support:* Both children and caregivers are likely to have more positive outcomes from disclosure if they have a strong support system to assist them. [6,51] While the healthcare team can provide some of this support, each family will need to turn to other significant people in their lives for ongoing support.

5. *Encourage ongoing open communication*: Finally, and most importantly, we need to move our understanding of disclosure from a single event to an individualized, dynamic, and gradual process of communicating information about health, illness, and living. [6,7,10,51, 74]

We undertook this review with the goal of synthesizing the literature and developing recommendations about whether to disclose and at what time. While the literature did not provide us with a consensus on the benefits, disadvantages, or proper timing for disclosure, it is our hope that the current review will inspire both new and seasoned researchers to investigate these provocative and potentially life preserving questions surrounding diagnostic disclosure.

## Acknowledgements

# References

1. Oleske J, Minnefor A, Cooper R, et al. Immune deficiency syndrome in children. JAMA 1983;249:2345–2349. [PubMed: 6834633]

2. Gortmaker SL, Hughes M, Cervia J, et al. Pediatric AIDS Clinical Trials Group Protocol 219 Team. N Engl J Med Nov 22;2001 345(21):1522–1528. [PubMed: 11794218]

3. Havens, JF.; Mellins, CA.; Hunter, J. Psychiatric Aspects of HIV/AIDS in childhood and adolescence. In: Rutter, M.; Taylor, E., editors. Child and Adolescent Psychiatry: Modern Approaches. 4. Oxford, UK: Blackwell; 2002. p. 828-841.

4. American Academy of Pediatrics Committee on Pediatrics AIDS. Disclosure of illness status to children and adolescents with HIV infection. Pediatrics Jan;1999 103(1):164–166. [PubMed: 9917458]

5. Walker, G. In the midst of winter. NewYork: Norton; 1993.

6. Lipson M. Disclosure of diagnosis to children with human immunodeficiency virus or acquired immunodeficiency syndrome. J Dev Behav Pediatr Jun;1994 15(3):S61–65. [PubMed: 8063922]

7. Funck-Brentano I. Informing a child about his illness in HIV infection: words and meaning. Psychiatr Enfant 1995;38(1):109–139. [PubMed: 8559848]

8. Wiener, L.; Septimus, A.; Grady, C. Psychosocial Support and Ethical Issues for the Child and Family. In: Pizzo, P.; Wilfert, K., editors. Pediatric AIDS: The challenge of HIV infection in infants, children, and adolescents. 3. Baltimore, MD: Williams and Wilkins; 1998. p. 703-727.

9. Mellins CA, Brackis-Cott E, Dolezal C, et al. Patterns of HIV Status Disclosure to Perinatally HIV-Infected Children and Subsequent Mental Health Outcomes. Clinical Child Psychology and Psychiatry 2002;7(1):101–114.

10. Ng, WYK.; Mellins, CA.; Ryan, S. The mental health treatment of children and adolescents perinatally infected with HIV. In: Abrams, E., editor. Topic of the month. 2004.

11. Harris NS, Thompson SJ, Ball R, Hussey J, Sy F. Zidovudine and Perinatal Human Immunodeficiency Virus Type 1 Transmission: A Population-Based Approach. PEDIATRICS 2002;109(4):e60. [PubMed: 11927733]

12. 2004 Report on the Global AIDS Epidemic. UNAIDS Web site. 2004 [Accessed (11/14/2005)]. Available at: http://www.unaids.org/bangkok2004/report.html

13. Katz ER, Jay SM. Psychological aspects of cancer in children, adolescents, and their families. Clinical Psychology Review 1984;4:525–542.

14. Spinetta, JJ. Disease-related communication: how to tell. In: Kellerman, J., editor. Psychological aspects of childhood cancer. Springfield, IL: Charles C. Thomas; 1980. p. 257-269.

15. Gaylin, W.; Macklin, R., editors. Who speaks for the child? The problems of Proxy Consent. New York, NY: Plenum Press; 1982.

16. Bibace R, Walsh ME. Development of children's concepts of illness. Pediatrics Dec;1980 66(6):912–917. [PubMed: 7454481]

17. Spinetta J, Maloney J. Death anxiety in the outpatient leukemic child. Pediatrics 1975;56:1034–1037.

18. Waechter E. Children's awareness of fatal illness. American Journal of Nursing 1973;71:1168–1172.

19. Spinetta JJML. Death anxiety in the outpatient leukemic child. Pediatrics 1975;56:1034–1037.

20. Claflin CJ, Barbarin OA. Does telling lies protect more? Relationships among age, information disclosure, and what children with cancer see and feel. Journal of Pediatric Psychiatry 1991;16:169–191.

21. Chesler MA, Paris J, Barbarin OA. "Telling" the child with cancer: parental choices to share information with ill children. J Pediatr Psychol Dec;1986 11(4):497–516. [PubMed: 3559843]

22. Slavin LA, O'Malley JE, Koocher GP, Foster DJ. Communication of the cancer diagnosis to pediatric patients: impact on long-term adjustment. Am J Psychiatry Feb;1982 139(2):179–183. [PubMed: 7055287]

23. Spinetta JJ, Maloney LJ. The child with cancer: patterns of communication and denial. J Consult Clin Psychol Dec;1978 46(6):1540–1541. [PubMed: 730918]

24. Perrin EC, Gerrity PS. There's a demon in your belly: children's understanding of illness. Pediatrics 1981;67:841–849. [PubMed: 7232049]

25. Lester P, Chesney M, Cooke M, et al. 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 Syndrome 2002;31:309–317.

26. Nagler, SF.; Adnopoz, J.; Forsyth, BWC. Uncertainty, stigma and secrecy: psychological aspects of AIDS for children and adolescents. In: Geballe, S.; Gruendel, J.; Andiman, W., editors. Forgotten children of the AIDS epidemic. New Haven: Yale University Press; 1995. p. 71-82.

27. Havens, JF.; Mellins, CA.; Ryan, S. Child psychiatry: Psychiatric sequelae of HIV and AIDS. In: Sadock, B.; Sadock, V., editors. Kaplan & Sadock's Comprehensive Textbook of Psychiatry. 8. Baltimore, MD: Williams & Wilkins; 2005. p. 3434-3440.

28. Forsyth BW. Psychological aspects of HIV infection in children. Child Adolesc Psychiatr Clin N Am Jul;2003 12(3):423–437. [PubMed: 12910816]

29. Grubman S, Gross E, Lerner-Weiss N, et al. Older children and adolescents living with perinatally acquired human immunodeficiency virus infection. Pediatrics May;1995 95(5):657–663. [PubMed: 7724299]

30. Courville, T. Disclosure versus non-disclosure of HIV/AIDS Diagnosis to children with transfusion associated HIV-1 infection. Paper presented at: International Conference on AIDS; 1992; 19–24 July;

31. Ledlie SW. Diagnosis disclosure by family caregivers to children who have perinatally acquired HIV disease: when the time comes. Nurs Res May–Jun;1999 48(3):141–149. [PubMed: 10337845]

32. Wolters, PL.; Brouwers, P. Neurobehavioral function and assessment of children and adolescents with HIV-1 infection. In: Zeichner, SL.; Read, JS., editors. Textbook of Pediatric Care. Cambridge: Cambridge University Press; 2005.

33. Wiener, L.; Martin, S. Psychosocial aspects of neurologic impairment in children with AIDS. In: Gendelman, H., et al., editors. The Neurology of AIDS. 2. Oxford University Press; 2003.

34. Armstrong, DWE.; Jacqueline Levy, J.; Briery, B., et al. Merging of Neuroscience, Psychosocial Functioning, and Bioethics in Pediatric HIV. Paper presented at: 110th Annual American Psychological Association; Chicago, Illinois. 2002.

35. Melvin D. Psychological Issues, challenges and achievements. Journal of HIV Therapy 1999;4(3): 77–81.

36. Bachanas PJ, Kullgren KA, Suzman Schwartz K, et al. Predictors of psychological adjustment in school-age children infected with HIV. J Pediatr Psychol 2001;26:343–352. [PubMed: 11490035]

37. Cohen J, Reddington C, Jacobs D, et al. School-related issues among HIV-infected children. Pediatrics 1997;100:e8. [PubMed: 9200382]

38. Flanagan-Klygis E, Ross LF, Lantos J, et al. Disclosing the diagnosis of HIV in pediatrics. J Clin Ethics Summer;2001 12(2):150–157. [PubMed: 11642067]

39. Hammami N, Nostlinger C, Hoeree T, et al. Integrating adherence to highly active antiretroviral therapy into children's daily lives: A qualitative study. Pediatrics 2004;114:591–597.

40. Hardy MS, Armstrong FD, Routh DK, et al. Coping and communication among parents and children with human immunodeficiency virus and cancer. J Dev Behav Pediatr Jun;1994 15(3):S49–53. [PubMed: 8063919]

41. Instone SL. Perceptions of children with HIV infection when not told for so long: Implications for diagnosis disclosure. J Pediatr Health Care 2000;14:235–243. [PubMed: 11005886]

42. Lester P, Chesney M, Cooke M, et al. Diagnostic disclosure to HIV-Infected children: How parents decide when and what to tell. Clinical Child Psychology and Psychiatry 2002;7(1):85–99.

43. Mellins CA, Ehrhardt AA. Families affected by pediatric acquired immunodeficiency syndrome: sources of stress and coping. J Dev Behav Pediatr Jun;1994 15(3):S54–60. [PubMed: 8063921]

44. Mettler, MA.; Borden, K.; Lopez, E., et al. Racial and Ethnic Patterns of Disclosure to Children with HIV. Paper presented at the American Psychological Association's Annual Conference; August 1997; Chicago, IL.

45. Mialky E, Vagnoni J, Rutstein R. School-age children with perinatally acquired HIV infection: Medical and psychosocial issues in a Philadelphia cohort. AIDS Pt Care STDs 2001;15:575–579.

46. Thorne C, Newell M-L, Peckham CS. Disclosure of diagnosis and planning for the future in HIV-affected families in Europe. Child: Care, Health, and Development 2000;26:29–40.

47. Wiener L, Battles H, Heilman N, et al. Factors Associated with Disclosure of Diagnosis to Children with HIV/AIDS. Pediatric AIDS and HIV Infection 1996;7(5):310–324. [PubMed: 11361489]

48. Waugh S. Parental views on disclosure of diagnosis to their HIV-positive children. AIDS Care 2003;15:169–176. [PubMed: 12856338]

49. Havens JF, Mellins CA, Pilowski D. Mental health issues in HIV-affected women and children. International Review of Psychiatry 1996;8:217–225.

50. Mellins CA, Kang E, Leu CS, et al. Longitudinal study of mental health and psychosocial predictors of medical treatment adherence in mothers living with HIV disease. AIDS Patient Care STDS Aug; 2003 17(8):407–416. [PubMed: 13678542]

51. Blasini I, Chantry C, Cruz C, et al. Disclosure model for pediatric patients living with HIV in Puerto Rico. Journal of Developmental and Behavioral Pediatrics 2004;25(3):181–189. [PubMed: 15194903]

52. Hardy MS, Routh DK, Armstrong FD, et al. Interpersonal distance and coping in children with HIV and cancer. Child Health Care Spring;1995 24(2):119–131. [PubMed: 10143002]

53. New, M.; Lee, S.; Pao, M. Prevalence of mental health in pediatric HIV: a family perspective. Presented at the NIMH Conference on the Role of Families in Preventing and Adapting to HIV/AIDS; Washington, DC. 2003.

54. Riekert KA, Wiener L, Battles HB. Prediction of psychological distress in school-age children with HIV. Children's Health Care 1999;28:201–220.

55. Wiener L, Battles H. Untangling the Web: A Close Look at Diagnosis Disclosure among HIV-infected Adolescents. Journal of Adolescent Health. in press

56. Brackis-Cott E, Mellins CA, Abrams E, et al. Pediatric HIV medication adherence: the views of medical providers from two primary care programs. J Pediatr HealthCare Sep–Oct;2003 17(5):252–260.

57. Marhefka SL, Tepper VT, Brown JL, et al. Caregiver psychosocial characteristics and children's adherence to antiretroviral therapy. AIDS Pt Care STDs. in press

58. Mellins CA, Brackis-Cott E, Dolezal C, et al. The role of psychosocial and family factors in adherence to antiretroviral treatment in human immunodeficiency virus-infected children. Pediatr Infect Dis J 2004;23(11):1035–41. [PubMed: 15545859]

59. Johnson, SB. Managing insulin-dependent diabetes mellitus in adolescence: A developmental perspective. In: Wallander, JL.; Siegel, LJ., editors. Adolescent health problems: Behavioral perspectives. xii. New York, NY, US: Guilford Press; 1995. p. 314p. 265-288.

60. Cooklin, ABG. Taboos and social order: new encounters for family and therapist. In: EI-B, editor. Secrets in families and family therapy. New York: WW Norton; 1993. p. 292-328.

61. Murphy LM, Koranyi K, Crim L, et al. Disclosure, stress, and psychological adjustment among mothers affected by HIV. AIDS Patient Care STDS Feb;1999 13(2):111–118. [PubMed: 11362099]

62. Wright LS, Wrigt NB, Stimmel DT. Childhood unhappiness and family stressors recalled by adult children of substance abusers. Alcohol Treatment 1991;8:67–80.

63. Lipson M. What do you say to a child with AIDS? Hastings Cent Rep Mar–Apr;1993 23(2):6–12. [PubMed: 8463092]

64. Epstein BJ, Little SJ, Richman DD. Drug-resistance among patients recently infected with HIV. New England Journal of Medicine 2000;347:1889–90. [PubMed: 12466517]

65. Gard LH. Patient disclosure of HIV status to parents: Clinical considerations. Prof Psychol Res Pract 1990;21:252–256.

66. Tasker, M. How can I tell you?. Bethesda, MD: Association for the Care of Children's Health; 1992.

67. Wiener, L.; Figueroa, V. Children Speaking With Children and Families About HIV Infection. In: Pizzo, P.; Wilfert, K., editors. Pediatric AIDS: The Challenge of HIV Infection in Infants, Children, and Adolescents. 3. Baltimore: Williams and Wilkins; 1998. p. 729-758.

68. Brackis-Cott E, Mellins CA, Abrams E, et al. Pediatric HIV medication adherence: the views of medical providers from two primary care programs. J Pediatr Health Care 2003 Sep–Oct;17(5):252–60. [PubMed: 14576630]

69. Frederick T, Thomas P, Mascola L, et al. Human immunodeficiency virus-infected adolescents: a descriptive study of older children in New York City, Los Angeles County, Massachusetts and Washington, DC. Pediatr Infect Dis J 2000;19:551–555. [PubMed: 10877172]

70. D'Angelo LJ, Abdalian SE, Sarr M, et al. The Adolescent Medicine HIV/AIDS Research Network. Disclosure of Serostatus by HIV Infected Youth: The Experience of the REACH Study. Journal of Adolescent Health 2001;29S:72–79.

71. Sherman BF, Bonanno GA, Wiener LS, Battles HB. When Children Tell Their Friends They Have AIDS: Possible Consequences for Psychological Well-Being and Disease Progression. Psychosomatic Medicine 2000;62:238–247. [PubMed: 10772404]

72. The American Counseling Association, Code of Ethics 2005. Virginia. 2005. www.counseling.org

73. Wiener, L.; Lyons, M. HIV Disclosure: Who Knows? Who needs to know? Clinical and Ethical Considerations. In: Lyons, M.; D'Angelo, LJ., editors. Teenagers, HIV and AIDS. Westport, CT: Praeger Press; 2006.

74. Wiener, L. Helping a parents with HIV tell his or her children. In: Aronstein, DM.; Thompson, BJ., editors. HIV and Social Work: a Practitioner's Guide. Binghamton, NY: Haworth Press; 1998. p. 327-338.

**Table 1**

Disclosure of HIV Diagnosis to Perinatally HIV-Infected Youth

| Study | Sample Description | % Disclosed and/or Mean Age Disclosed | Instruments & Design | Disclosure Findings | Study Limitations |
|---|---|---|---|---|---|
| Bachanas et al., 2001[36] | 36 HIV+ children ages 6–16 years ($M$ age = 9.6 years) and their caregivers & 32 healthy controls | 64% disclosed | Brief Symptom Inventory (caregiver adjustment), Child Behavior Checklist (Caregiver Report) and Behavior Assessment System for Children, Children's Health Locus of Control, Coping Strategies Inventory (Child Report) Design: Cross-sectional | Withholding diagnosis associated with increased internalizing behavior problems and psychological adjustment problems in children and increased caregiver psychological distress. | Small sample size, cross-sectional design, disclosure not primary focus of paper, did not control for timing of disclosure |
| Blasini et al., 2004[51] | 40 HIV+ youth ($M$ age = 13.8 years,) 39 caregivers, 16 health care professionals | 100% disclosed. | Semi-structured interview Pre-Post Intervention, with no disclosure-related pre-data from child report. Design: Quasi-experimental | 42% sad immediately post-disclosure. 22% worried and cried one week post-disclosure. Caregivers reported children were inquisitive (38%), crying (20%), angry (13%), anxious (10%) depressed (3%). 70% of children reported feeling normal after 6 months. 85% considered disclosure a positive event. 58% self-reported greater adherence. | Small sample size, lack of comparison group, did not use standardized measures of psychological functioning |
| Cohen et al., 1997[37] | 92 HIV+ school-aged children who were enrolled in school in Massachusetts 1993–1994; ($M$ age= 8.5 years) | 42% disclosed. $M$ age at disclosure = 8 years | Surveys designed by the authors and completed by nurses based on medical record review Design: Cross-sectional with medical record review | Disclosure not associated with CDC clinical category or relationship to caregiver. | Retrospective medical record reviewed, disclosure not focus of study, no measures of psychological functioning |
| Grubman et al., 1995[29] | 42 HIV+ children ages 9–16, years, ($M$ age = 11.4 years) | 57% disclosed. | Study based on medical record data of clinical, immunologic, and psychosocial parameters | 70% of youth with asymptomatic illness were not disclosed to. One third of the caregivers disclosed the children's diagnosis to schools | Based only on a retrospective review of medical records |
| Flanagan-Klygis, et al., 2001[38] | 65 Caregivers of HIV+ children (primarily ages 4–12 years) and 75 physicians | 35% disclosed. $M$ age = 7.8 years at disclosure. | Caregiver and physician-completed questionnaires designed by the authors. Design: Cross-sectional | For children over 8, caregivers were primarily reasons for nondisclosure. Concern disclosure would be a burden, would lead to depression and fear about questions regarding vertical transmission. | Cross-sectional, lack of child-report data, actual age range not reported |
| Funck-Bretano, 1997[7] | 35 HIV+ children, ages 5–10 ($M$ age=7.5 years), and their caregivers | 23% nondisclose d, 20% deceived, 40% partially disclosed; 17% fully disclosed. | Semi-structured interviews with children and caregivers and 3 projective drawings (per child). Design: Cross-sectional | Study described disclosure patterns. Most children (74%) reported HIV-related stressors regardless of disclosure status. | Small sample size, cross-sectional, no statistical analysis |
| Hammami et al., 2004[39] | 11 caregivers of HIV+ children, ages 0–19 years, prescribed antiretroviral therapy | Not reported | Semi-structured interviews Design: Cross-sectional | The majority of caregivers reported that children became more cooperative with medication-taking following disclosure. Of those who were adherent, the majority of caregivers reported that disclosure helped adherence. Of those who were nonadherent, the majority of caregivers report that disclosure hindered adherence. | Small sample size, no statistical comparisons made, disclosure not primary focus of study. |
| Hardy et al., 1994, 1995[40], [52] | 20 HIV+ children, 20 children with cancer, 20 controls, and caregivers. Children ranged from ages 4–7 ($M$ age = 5.25 years) | 25% of HIV+ disclosed versus 95% of children with cancer. | Demographic Interview, Coping Strategies Inventory Observation of doll placement in model medical exam room Design: Cross-sectional | Children with HIV significantly less likely to be told diagnosis compared to children with cancer. Disclosure not related to parent or child coping. | Sample size, cross-sectional, different demographic variables between each group |

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| Study | Sample Description | % Disclosed and/or Mean Age Disclosed | Instruments & Design | Disclosure Findings | Study Limitations |
|---|---|---|---|---|---|
| Instone, 2000[41] | 12 HIV+ children, ages 6–12 years, and their caregivers (n=13) | 66% disclosed. | Projective drawings and discussion with children, qualitative interviews with caregivers Design: Cross-sectional | Drawings indicated emotional distress, including themes of threat, illness, and loss, regardless of disclosure status. | Sample size, projective drawings subject to differences in interpretation, distress suggested by all drawings so no clear findings for disclosure |
| Lester et al., 2002(a) & 2002 (b)[25, 42] | 51 HIV+ children (ages > 4 years) | 43% disclosed. | Brief disclosure interview (medical provider report), Demographic questionnaire (caregiver report), Moos Family Relationship Index, Parent Diagnostic Disclosure interview, Weschler Preschool and Primary or Children's Scale of Intelligence-R, Child Diagnostic Disclosure interview Design: Cross-sectional | Child's older age, higher IQ and family expressiveness, living in urban area, and greater # life events increase probability of earlier disclosure. No association between disclosure and any disease related variables. Higher parent-rated child anxiety among disclosed group. | Cross-sectional design, did not control for timing of disclosure, actual age range not specified. |
| Marhefka et al., in press[57] | 54 caregivers of HIV+ children, ages1–13 years (M age = 7 years) | Not reported. | Demographic Questionnaire, Pharmacy Refill Records Design: Cross-sectional | Children who knew their status were less likely to be adherent. | Cross-sectional design, disclosure not primary focus of study, did not control for timing of disclosure |
| Mellins & Ehrhardt, 1994[43] | 52 participants from 25 families affected by pediatric HIV; 14 were children ages 4–14 years. | 29% disclosed. | Open-ended qualitative interview Design: Cross-sectional | Caregivers of non-disclosed children reported fear that disclosure would lead to questions about transmission, traumatize child, or lead to child telling others. Caregivers requested help with disclosure. | Small sample size, disclosure not primary focus of study |
| Mellins et al., 2002[9] | 77 perinatally-infected children, ages 3–13 (M age = 8 years), and their caregivers | 30% disclosed M age = 7 years. | Structured interview including measures on disclosure, Beck Depression Inventory, Children's Depression Inventory, Child Behavior Checklist, State–Trait Anxiety Inventory (Youth and Adult forms) Design: Cross-sectional | Child's older age and higher SES associated with disclosure. Post-disclosure 46% sad, 39% scared, 39% angry, 39% confused, 54% shocked. Trend for less depression in disclosed children | Cross-sectional design |
| Mellins et al., 2004[58] | 75 perinatally HIV-infected children, ages 3–13 years (M age = 8 years). | Not reported in this paper (see Mellins et al., 2002). | Caregiver-reported disclosure status and 2-day recall of missed medication doses Design: Cross-sectional | Children who knew their HIV Status were less likely to be adherent | Cross-sectional, disclosure not primary focus of study |
| Mettler et al., 1997[44] | 27 HIV+ school age children, ages 5–12 years (M age =8 years), and their caregivers (n=25) | 37% disclosed; age range 2 to 12 years; M age=6 years. | Semi-structured audiotaped interviews in English or Spanish Design: Cross-sectional | Hispanic caregivers were least likely to disclose HIV status to their child and likely to feel negative or neutral about their disclosure/non disclosure compared to African American and Caucasian caregivers | Small sample size, cross-sectional, age not controlled for. |
| Mialky, Vagnoni, & Rutstein, 2001[45] | 54 caregiver-child dyads (M age= 10 years). | 43% disclosed M age = 9 years; 69% of children aged > 10 years disclosed; 100% of children aged> 12 years disclosed.; | Child and caregiver Interviews, Design: Cross-sectional with medical record review | Interviews focused on school related issues. School employees had been told the child's diagnosis in 23% of the cases. | Disclosure not primary focus of study, cross-sectional. |

| Study | Sample Description | % Disclosed and/or Mean Age Disclosed | Instruments & Design | Disclosure Findings | Study Limitations |
|---|---|---|---|---|---|
| New, Lee & Pao, 2003[53] | 57 HIV+children children, ages 6.2 –12.7 years (M age= 9.9 years) and their caregivers | 44% disclosed. | Child Behavior Checklist (parent report), Teacher Report Form, Brief Symptom Inventory, Computerized Diagnostic Interview for Children, Structured Clinical Interview for DSM-IV-Screen. Design: Cross-sectional | Children who knew their diagnosis scored higher on total and internalizing scales of CBCL, but neither group scored in clinical range. | Cross-sectional |
| Riekert et al., 1999[54] | 61 HIV+ children, (ages 6 – 11 years M age = 8.9 years) and their caregivers | 74% disclosed. | Child Behavior Checklist, Speilberger State-Trait Anxiety Inventory, Beck Depression Inventory, Family Environment Scale, Health Status Questionnaire, The Children's Depression Inventory, Speilberger State-Trait Anxiety Inventory for Children, The Dominic | Children who knew their diagnosis reported significantly lower scores on depression and anxiety measures than children who did not know their diagnosis. | Focus of study was on child's psychological distress. Non-representative sample. |
| Thorne, Newell, & Peckham, 2000[46] | 182 European caregivers of 140 HIV+children, ages 2–19 years, (disclosure information available for 125), 56 uninfected children and 30 children with unknown/indeterminate status | 18% disclosed; median age 10 years for disclosed vs. 6 years for non-disclosed. | Caregiver-completed questionnaires designed by the authors. Design: Cross-sectional | Child's older age, non-biological caregiver, and previous disclosure of parent's diagnosis associated with disclosure. | Lack of child-report, cross-sectional |
| Waugh, 2003[48] | 13 families with 15 perinatally infected children, child age 5–9 years (M age=7.3 years) | 0% fully disclosed; 92% partially disclosed | Parental interview (open-ended) and Understanding Illness and HIV Scale. Scale devised by the authors Design: Cross-sectional | Parents waiting until child was 'ready.' Fear of accidental disclosure most frequently given reason for nondisclosure. | Small sample size, qualitative, did not include families who chose to disclose. Cross-sectional |
| Wiener et al., 1996[47] | 99 HIV+ children(ages 5–19, M age=10.5) and their caregivers) | 75% disclosed; M age = 7.5 years. | Caregivers completed Parent Diagnostic Disclosure Interview, Beck Depression Inventory, Family Environment Scale, Arizona Social Support Interview Schedule, and a Demographic Questionnaire. Children who were aware of their diagnosis completed a Diagnostic Disclosure Interview Design: Cross-sectional | Univariate: older age of child and better immune functioning and caregiver HIV-, female, and not depressed associated with disclosure. Sixty- five percent felt that they were told at the right time and 86% by the right person. Thirty percent of these children reported that their life had gotten worse since they learned their diagnosis. | Cross-sectional, no report of child psychosocial functioning. |
| Wiener and Battles, in press[55] | 40 HIV infected adolescents/young adults. (M age = 18.3 years) | 100% Disclosed, M age = 7.5 years. | Impact of Events Scale, Self Perception Profile for Adolescents, Brief Symptom Inventory, Demographic questionnaire | No association between age of learning diagnosis and posttraumatic stress or psychological distress; those who learned diagnosis younger had disclosed to more people in their own networks. | Small sample size, focus of study was youth's disclosure to others. |