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Disclosure of Parental HIV Infection to Children: A Systematic Review of Global Literature

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Abstract

This review examines the global empirical literature regarding disclosure of parental HIV infection to children. Thirty-eight articles published in English-language journals prior to 2011 were retrieved and reviewed regarding disclosure process, reasons for disclosure/nondisclosure and impacts of disclosure/non-disclosure. Disclosure rate was relatively low worldwide. The decision making of disclosure or non-disclosure was mainly affected by children's development level, stigma, consideration of children's benefits, and parenting practices. Unintentional and forced disclosures were common. Findings regarding the impacts of disclosure/non-disclosure were mixed but disclosure tended to have long-term positive impacts on the well-being of children, parents and family in general. This review underscores the importance of developing evidence-informed developmentally and culturally appropriate interventions to assist HIV-positive parents to disclose their HIV status to children, particularly in low--resource settings.

Keywords

Parental HIV infection; HIV disclosure; Children; Parental HIV disclosure; Literature review

Introduction

Successful therapies preventing perinatal transmission of HIV infection from mothers to infants have dramatically reduced the numbers of infected infants. New medical innovations and increasing availability of antiretroviral therapy (ART) have improved the health and longevity of HIV-positive parents, which means they are more likely to raise their children for many years after the initial diagnosis [1]. Disclosure of parental HIV infection to children (infected and/or uninfected) is an increasingly important issue in terms of parental mental health, children's health, parenting and custody plan, and family relationship [2–5].

Disclosure, or self-disclosure, is a process in which personal information is verbally communicated to another person [6–9]. A discloser needs to make decisions about what, when, to whom, and how much to disclose (e.g., scope of disclosure). The scope of disclosure varies, ranging from non-disclosure to partial disclosure to full disclosure [10]. A

disclosure episode often involves multiple reactions (cognitive, emotional, and behavioral) by both the discloser and the disclosure target [11].

Disclosing HIV infection is a challenging task because of potential stigma, blame, shame and fear associated with HIV infection [4]. Empirical studies report high rates of delayed disclosure or non-disclosure among HIV-positive persons [12]. Children appear to be disclosed to less often than parents, spouses, sexual partners, extended family and health care providers [13]. Disclosure to children is described as one of the main challenges for parents living with HIV [14], particularly for parents having younger children and school age children [15]. Parents living with HIV are often struggling with whether, when, and how to talk to their children about this topic [16]. Many of them do not disclose their HIV infection to children simply because they do not know how to do so [17].

Among studies investigating disclosure, the majority focused on the issue of maternal disclosure [18–21]. Hawk reviewed 30 articles on maternal disclosure published from 1995 to 2007 [22]. His review focused on predictors of disclosure, reasons for disclosure and nondisclosure, how disclosures were planned and executed, and the consequences of disclosure for both mothers and children. The review indicated differences between adolescents and younger children in terms of adjustment to maternal HIV disclosure [22]. Hawk suggested that further studies should examine age-related differences in post-disclosure adjustment among children, distinguish children's short- and long-term reactions to disclosure, and develop culturally appropriate interventions to support mothers and families in both the pre- and post-disclosure periods [22].

Murphy reviewed nine articles published from 1994 to 2006 focusing on maternal disclosure rates, factors affecting maternal decision to disclose, and short- and long-term child reactions to disclosure [23]. Her review also suggested children's cognitive development level, their coping skills, and maternal perception of stigma as main factors influencing their reactions to disclosure [23]. Murphy called for more studies to explore the process and impact of disclosure in the context of family, children's developmental level, and maternal access to and utilization of support services [23].

The reviews by Hawk and Murphy were informative in synthesizing existing research on maternal disclosure of HIV status to their children. However, their reviews only included studies based in the US. Disclosure practices and their impacts on families affected by HIV living in low-resource countries are likely to differ because of various cultural and social contexts. This systematic review aims to expand the previous two reviews by examining findings from the global literature regarding disclosure processes, reasons for disclosure/non-disclosure and impacts of disclosure/non-disclosure on the well-being of children, parents and family. The current review will cover more recent studies in both developed and developing countries and studies using both quantitative and qualitative methodologies.

Methods

Inclusion Criteria

A systematic literature search was conducted to identify studies that were: (1) peer-reviewed and published in English-language journals prior to 2011, (2) reporting experience or impacts of parental HIV disclosure to children, and (3) empirical studies using either qualitative or quantitative methodology.

Data Source

We conducted the literature search in April 2011 using the key words *disclosure HIV*, *disclosure HIV status children*, or *disclosure HIV children* in the MEDLINE, PubMed, PsycINFO, and Web of Science electronic databases. Thirty-three articles meeting inclusion criteria were initially identified. Four articles were excluded because of insufficient information on the measurement or description of parental disclosure to children. The reference lists of the remaining 29 articles and two previous reviews of maternal disclosure [22, 23] were then hand-searched, yielding ten more articles and resulting in 39 articles which were organized by research methodology (quantitative or qualitative method) in the current review. Two articles with both quantitative and qualitative components were presented separately by their methodologies [5,24]. The final literature set in the current review included 26 quantitative studies and 15 qualitative studies.

Data Abstraction

Data abstraction forms were developed and used to retrieve information on the study characteristics and main findings of the reviewed studies. The information on study characteristics included the sample description (i.e., sample size, participants' characteristics, age range), study location, and study design. The study findings were first organized using major themes such as disclosure rate, decision-making of disclosure, disclosure process, and disclosure outcomes. The themes were further expanded during the abstraction process to include additional topics. The final themes included disclosure rate, child awareness rate, timing of the disclosure, reasons for disclosure/non-disclosure, predictors of disclosure, disclosure approach, scope of disclosure, content of disclosure, professional support, reactions to disclosure, children outcomes, parents' outcomes, and family outcomes. For qualitative studies, key findings/messages were summarized; for quantitative studies, summary statistics (e.g., mean [standard deviation], proportion, range, odds ratio [95% confidence interval]) and relevant statistical significance (*P*-value) were recorded when they were available. Based on data abstraction, two tables were developed to summarize study characteristics and main findings of 26 quantitative studies (Table 1) and 15 qualitative studies (Table 2).

Results

Of the studies included in this review, three were published in the 1990s, 18 in the period from 2000 to 2004, and 19 since 2005; 28 studies (68%) were conducted in North America (26 in the US and two in Canada), five (12%) in Europe, four (10%) in Africa, and four (10%) in Asia.

Disclosure Rate

Twenty-three (88%) of the quantitative studies (Table 1) and seven (47%) of the qualitative studies (Table 2) in our review reported disclosure rate. Of these studies, 66% examined the proportion of HIV-positive parents disclosing to their children (parental disclosure rate) while the remaining studies reported the proportion of children who knew parental HIV status (children's awareness rate). The parental disclosure rate varied across locations. In a US-based qualitative study, all the parents living with HIV ($n = 33$) reported disclosure to their children [25]. However, disclosure rates reported by other studies in the US ranged from 20 to 67% with a median of 41%. The parental disclosure rates in other countries or regions were at a lower level, such as 50% in Uganda [26], 35% in Thailand [27], 31% in Canada [5], and 11% in European countries [4].

Children's awareness rates reported in the literature were typically higher than parental disclosure rates because some children might have guessed parental HIV status or learned it from others even though their parents did not tell them [3, 28]. Children might have learned of parental HIV infection themselves by observing signs of their parents' deteriorating health condition [25]. For instance, a study of 66 HIV-positive mothers and their children in the US suggested that 62% of children knew of maternal HIV infection, among whom only 48% were informed by their mothers [18]. A cross-sectional study in New York found that 97% of children were aware of maternal HIV infection [29]. However, the remaining studies in the US indicated that 34–68% of children of HIV-positive parents were not aware of parental HIV status [3, 16–18, 20, 30, 31]. The awareness rate among children was even lower in other countries including Belgium [24], Botswana [28], China [32], South Africa [33], and Sweden [34].

Timing of Disclosure

As shown in Table 1, 11 quantitative studies examined timing of disclosure with seven of them focusing on children's age at parental disclosure and the remaining focusing on the time interval between parental HIV diagnosis and disclosure to children. Five qualitative studies also reported children's age at parental disclosure and parental perception of appropriate age at which parents should tell children their HIV status (see Table 2).

The majority of the studies in the US indicated that increasing age of the children was associated with increasing parental disclosure [17, 21, 35, 36], but the age at which children were told by their parents about parental infection varied widely. According to a study of 58 HIVpositive mothers and their children, children were informed of parental HIV status at an average of 7 years old [29]. Another study with a smaller sample ($n = 17$) reported mean age of children being informed as 9.3 years [37]. A similar result was found in a longitudinal study of 99 HIVpositive mothers and their children with a mean children's age of 9.6 years at time of disclosure [31]. According to a qualitative study among HIV-positive mothers who disclosed their status to their children, the perceived appropriate age at which children should be informed ranged from 6 to 10 years [38].

Parents living with HIV in other countries generally disclosed to older age children. In European countries mean age of the children at disclosure was around 10 years, with a range

of 5–16 [4, 24, 34]. In developing countries, many parents waited until children reached early adolescence (12–14 years old) or even adulthood (e.g., 18 years old). In Uganda, the median age of the children at disclosure was 18 years [26]. In Thailand, children were told about their parents' HIV infection at an average of 13 years old [27]. In India, 15 years old was believed to be an appropriate age for the disclosure of parental HIV status [39].

Several studies examined the duration of time after parental diagnosis of HIV infection to disclosure of their status to their children [33, 35, 37, 40]. Two studies with small sample sizes indicated a mean duration of 2.5 years ($n = 17$) [37] and 5.4 years ($n = 23$) [40]. Another study with a larger sample ($n = 87$) suggested that parents disclosed their status to their children within an average of 13.6 months of their initial diagnosis [34]. A study in South Africa found that 14% of HIV-positive mothers informed their children within 1 month of their diagnosis, 50% did so within 1 year, and 70% within 2 years [33].

Scope and Content of Disclosure

When investigating the process of disclosure, some studies have described how much information parents share with their children about their health condition and HIV status (e.g., non-disclosure, partial disclosure, and full disclosure) [21, 29, 30, 41, 42]. Complete non-disclosure refers to no mention of HIV or of any illness. Partial disclosure indicates the situations in which children are given some but not all information about parental HIV infection. Partial disclosure often occurs in conjunction with deception about the nature or severity of the illness [43]. For example, children may be told that their parents are ill or chronically ill without learning that the “illness” is HIV infection or AIDS. When full disclosure occurs, children are told the name of the illness (HIV infection and/or AIDS), disease specific information (how it is transmitted, how to prevent, etc.) and anticipated clinical outcomes [10].

Based on the five quantitative studies (four studies in the US and one study in European countries) in our review (Table 1), over one half of the children being told of parental HIV status received full disclosure, while one-third of them received partial disclosure [21, 29, 30, 41, 42]. Most parents did not discuss the future course of their illness [44] or death [21, 30, 41]. The proportion of children being told that their parents might die from AIDS ranged from 5 to 13% [21, 30, 41], except in one study in the US 68% of children were informed that their parents might die from AIDS [29].

Both quantitative and qualitative studies in the global literature suggested that children's age was strongly related to how much information children were given and perceptions of how much should be presented [29,36,45]. A study in the US indicated that children older than 12 years were more likely to receive a full or more complete disclosure while younger children typically received a partial or deceived disclosure [41]. In families with more than one child, parents also tended to make non-disclosure or partial disclosure to the younger child and make full disclosure to the older child [21, 46]. Primary health care workers and villagers in Zimbabwe perceived that children should be partially disclosed about parental HIV infection when they reached 11 years of age while be fully disclosed at age 14 [47].

Studies in both the US [17, 25] and European countries [39] suggested that other individual characteristics of parents and children might be associated with the scope of the disclosure. Findings by Kirshenbaum and Nevid [29] suggested that HIV-positive mothers gave their daughters more detailed information. Mothers with higher household incomes, with a history of drug use, or with a psychiatric history tended to reveal more detailed information [29]. Older mothers were more likely to tell their children that they might die from AIDS [29]. Simoni and colleagues [21] reported that stage of mothers' illness and their ethnicity were not related to the scope of disclosure.

Qualitative studies in developing countries suggested the role of social and cultural contexts (such as stigmatization against people living with HIV) in affecting the scope or content of disclosure. In Asia and Africa, HIV-positive parents, particularly mothers, and their children have been suffering a severe HIV-related stigmatization and discrimination [33, 48–50]. The majority of HIV-positive parents did not disclose to children in order to protect them from stigma and even from being deprived of property rights [39]. A study in Thailand reported that all the HIV-positive mothers who disclosed their status to children requested them not to discuss maternal HIV infection at school to protect them from stigma [27]. In China, some caregivers would not like to tell AIDS orphans that their parents died from AIDS due to stigma [32]. In Botswana, HIV-positive parents did not talk about sexual topics related to HIV transmission and prevention when they disclosed their HIV status to children because it was viewed as inappropriate to discuss sexual matters with children [28].

Disclosure Approach

Existing studies showed that various approaches were used in practices of parental disclosure [18, 29, 33, 42, 46]. Children might be informed by parents (direct disclosure) or by other family member or non-family social network (indirect disclosure). They might be intentionally informed (intentional disclosure) or be accidentally disclosed (unintentional disclosure).

Seven quantitative studies (three in the US and four in other countries) and four qualitative studies (three in the US and one in Canada) in the current review examined the disclosure approaches. These studies showed similar findings, suggesting a high proportion of direct, but often unplanned, disclosure by HIV-positive parents. Based on the quantitative studies, over 60% of children being disclosed about maternal HIV infection were directly informed by their mothers [18, 29, 30, 33, 42], probably because the majority of HIV-positive mothers wanted their children to hear the diagnosis from themselves rather than others [18, 25, 37, 44, 51]. However, some children also learned about parental HIV infection from other family members or friends, or by overhearing their parents' conversations with others, or suspecting that their parents were HIV positive by noticing changes in their parents' health condition and medication [5].

In family-orientated societies where the family is viewed as a basic unit [52], family support is valued [53], and extended family members have significant responsibility and duty toward each other [54], family members may play a much more important role in the process of disclosure than in other societies [33]. For example, they might conduct indirect disclosure

to children or participate in direct disclosure by assisting parents to initiate conversations on topics about HIV [47].

Existing studies suggested that parental disclosure often happened in forced and unintentional ways [5, 25, 38, 51]. Parents could be forced to disclose to their children in some situations. For example, children might have already known or would know soon about their parents' HIV status [15]; children confronted their parents about their HIV or AIDS [25, 37]; the health status of HIV-positive parents declined or worsened [28, 51]; or the rest of the family members had already known about their HIV positive status [28]. Some disclosures were caused by arguments between family members [5, 51]. Unintentional disclosures might be accompanied by multiple disclosures in which children learned numerous "family secrets" simultaneously, such as more than one family member was infected, or parents' drug use and sexual histories [46].

Forced disclosure or unintentional disclosure was often a regrettable experience for parents and resulted in negative reactions from children [5, 51]. Parents having disclosed to children in an unplanned way advised other HIV-positive parents to have a well prepared plan regarding disclosure [25, 38]. Parents prepared themselves for adequate disclosure by talking with someone they trusted, waiting for their improved health status, praying, talking with professionals, and self-educating about HIV and AIDS [5, 38]. A study also found that women were more likely than men to prepare themselves by reading written materials (e.g., books, pamphlets) and ensuring the materials were accessible during the disclosure [5].

Parents with a plan for disclosure often made decisions as to where and when to disclose to children. One study in Canada found that 69% of disclosures occurred at home, and sometimes in the context of a special meal or favorite family activity [5]. HIV-positive mothers also thought it was appropriate to disclose in a moment free of other stressors or negative affect [38].

Reasons for Disclosure

Seventeen quantitative studies (14 in the US and three in other countries) explored reasons for parental disclosure/ non-disclosure to children, and/or the roles of individual characteristics of children and parents in predicting parental disclosure/non-disclosure. Eleven qualitative studies (three in the US and eight in other countries) explored reasons for parental disclosure/non-disclosure to children.

In general, the global literature suggested that reasons for parental disclosure included parental needs, parenting practices, and considerations of children's rights and benefits. Studies in both the US and other countries showed that some parents disclosed to children because of their own psychological and parenting needs [15,26,39]. HIV-positive parents were worried that children would learn about their HIV infection from other resources (e.g., family members, friends, and others) [27], and they had to devote considerable effort to guarding the secret while coping with the infection or the disease [55]. Some parents disclosed their infection when they could not bear to keep their illness a secret [15]. Some parents decided to tell children about their HIV status in order to obtain support from children. A study in India reported that 10% of the HIV-positive mothers thought HIV status

should be disclosed to children “so that they will support us and care for us” [39], while another study in Uganda indicated that HIV-positive parents generally agreed that disclosure could make it easier to ask for and receive support from their grown-up children [26].

The studies in the US indicated that some parents justified their disclosure to children because they believed that children had a right to know the facts [18, 37]. As parents, they thought that telling children the truth was the right thing to do [15] and they should be honest with their children if being asked about their HIV status [44]. A qualitative study in Canada suggested that different parenting practices might influence decision making of disclosure. Parenting practices focusing on protecting children’s innocence tended to shield children from knowing parental HIV infection, while parenting practices highlighting support for children’s individuality and autonomy, and perceiving family as a unit where parents and children should be equal members, encouraged disclosure to children [5].

Studies in both the US and other countries suggested that the consideration of children’s benefits played an important role in justifying parental disclosure. Some parents told their children they were HIV-positive in order to educate their children and protect them from HIV, because they felt that learning of parental HIV infection would warn their children about the dangers of drug use and unprotected sex [27, 28, 44, 51]. Disclosure of parental HIV status was viewed as an important step to make arrangements for children’s future in case of parental incapacity or death [15]. Disclosure was often executed with parental desire to prevent children from unexpected shock from illness or death [37]. One study in Uganda indicated that HIV-positive parents disclosed to children to ensure every family member knowing the real cause of death rather than suspecting malicious witchcraft [26].

Reasons for Non-Disclosure

Some parents did not tell children about their HIV status because of concerns about their children’s developmental level, their possible reactions to disclosure, and negative consequences of disclosure. Many studies indicated that parents who did not disclose to children believed their children were too young to understand the infection or the disease [24, 27, 28, 30, 37, 40, 44, 51]. When they were not sure as to the appropriate age at which to disclose, they elected to wait until they believed that their children were mature enough to handle the devastating news [26]. Some parents decided not to disclose to children in order to protect their carefree childhood or let them recover from a previous loss of a parent or other family member [18, 26, 37, 40].

Non-disclosure also resulted from their lack of confidence in managing the disclosure process. Many parents were unsure as to how to tell their children about their HIV positive status [17, 28, 30]. They were worried about discussing death with children or being asked about reasons of their infection [15]. They feared facing their children’s emotional reactions [17, 27, 30] and experiencing rejections as a result of the disclosure [37, 44].

Some parents hesitated to disclose to their children because of the perceived risks and/or negative consequences of the disclosure. Some were concerned about psychological harm to their children [27, 37], including emotional pain and burden [15, 24, 26, 28, 30, 33, 44], behavior problems [30, 33], development problems [33] and problems in school

performance [39]. Some were afraid that children might inadvertently tell others in schools or communities and thus experience stigmatization and discrimination [15, 17, 24, 28, 30, 33, 39, 40, 51]. Others feared that disclosure might damage the parent–child relationship. Some parents living with HIV were afraid of losing respect from their children [15,30].

Children's Reactions to Disclosure

Half of the qualitative studies described children's reactions to parental disclosure, with some reporting the reactions from the perspectives of both parents and their children (Table 2). Five (20%) of the quantitative studies examined children's reactions. Existing studies reported a variety of different reactions from children to the disclosure and the findings were similar between the studies in the US and other countries. One study suggested that approximately 40% of the children reacted negatively, while 30% of them reacted supportively to disclosure according to reports by their mothers [35]. In another study, 27% of children were perceived to react "maturely" [42]. Likewise, another study reported that some mothers observed that their children were acting more responsibly and independently after disclosure [44]. Several studies indicated a proportion of children showed no reactions to disclosure [5, 25, 35, 37], which might be attributed to the children's younger age. In a study involving children with an average age of 7 years, 51% of the children had no immediate reaction to their mother's HIV disclosure because of a limited understanding of HIV and its consequences [56].

Many studies suggested that for most children, knowledge of their parents' infection with HIV generated strong emotional reactions [25, 37, 44, 51]. Negative reactions were common after forced disclosure and unintentional disclosure [51]. Children were often shocked and upset following the disclosure [5, 33, 35]. Many cried [27], and some of them rejected this news [35]. The majority of children were scared by the uncertainty of their future. They feared losing their parent infected with HIV [25, 27, 33, 35, 37, 51], and feared additional opportunistic infections to their immune deficient parent [51]. Anxiety was common, with children expressing their concerns about parents' health [18, 27, 33, 42, 44], wanting more information about HIV [18, 37], or worrying about catching HIV themselves [17].

Impacts of Disclosure on Children

Seventeen of the 19 studies in this review that examined impacts of parental disclosure were quantitative studies; two [46, 57] were qualitative. As shown in Table 1, among the quantitative studies, 12 (71%) applied a cross-sectional design and five (29%) employed a longitudinal design.

Existing quantitative studies showed mixed results regarding the short-term effect of disclosure of parental HIV on children. Some cross-sectional studies indicated that disclosure was associated with lower emotional and social functioning [58], more externalizing symptoms [33], and higher depression score [3] among children. However, other cross-sectional surveys suggested that disclosure was not significantly related to children's psychological outcomes including externalizing problems [3, 35, 59], internalizing behaviors [3, 33, 35], anxiety [3], depression [59], adaptive functioning [29] or

school grades [59]. In one qualitative study, the majority of mothers reported no change in children's sleep patterns, their school performance, or behavior at home [44].

Some studies reported that HIV-positive parents often explicitly requested children not to tell others about parental HIV infection, in fear of stigma children might experience when others outside the families (e.g., peers and neighbors) knew their parental HIV status [29, 44, 57]. Children usually followed rules for disclosure set by their parents in order to protect their parents and families [57]. The pressure and stress to maintain the secrecy of parental HIV infection also created psychological problems for children [23]. Children who were required to keep the secret about parental HIV tended to have more externalizing behaviors [29, 40], and lower social competence [40]. Qualitative studies suggested that children often worried that their friends would find out and feared experiencing rejection from their peers as a result [57]. They generally had conflicting feelings about disclosure to others [46], desiring to tell others to get support, educate others, and normalize the illness, but worrying about stigma and rejection, and lacking confidence in deciding when and how to tell others [46].

As for long-term effects, some studies suggested that most children, particularly younger children, adjusted to parental HIV disclosure over time even after an initial emotional reaction. One study conducted in 10 Western European countries showed that 64% of parents felt that their children were coping better over time, with observed emotional reaction lasting for a limited period of time (e.g., 23% less than a month, 14% between a month and half a year, 11% between half a year and a year, and 12% longer than a year) [42]. A five-year longitudinal study found that problem behaviors decreased over time among disclosed children, while problem behaviors increased among non-disclosed children [36]. Another longitudinal study reported a consistent result, showing that negative mood score and total depression score decreased and household responsibilities increased for all children over one-year follow-up [60]. Compared to those who were not informed, children who were informed by parents exhibited a higher self-concept over time [61], although one study suggested an increase of children's externalizing behaviors over time based on mothers' reports [31].

Existing studies indicated that the majority of disclosed children were glad that they had been told about parental HIV status [20]. According to a qualitative study, children felt satisfied with being informed by their HIV-positive mothers so that they could better prepare for the future (93%), make decisions affecting themselves (86%), reduce mother's stress (79%), be closer to mothers (79%), talk openly (67%), and be less afraid (50%) [40].

There was some indication of poorer outcomes following disclosure to adolescents than to younger children. The needs to protect and assist their HIV-positive parents might result in a shifting of responsibilities from the parents to the adolescent children and speed up their childhood [25, 51]. Adolescent "parentification" might cause higher levels of distress, multiple sexual partners, and substance use [62]. Disclosed adolescents reported higher levels of depression and emotional distress compared to non-disclosed adolescents [36, 41, 60]. Some experienced higher rate of unprotected sexual behaviors and substance use [41, 42]. In a qualitative study that addressed changes among adolescents in terms of their

attitude, behavior and grades at school after parental disclosure, the majority of participants reported negative feelings about school, and increased truancy and failing grades [46].

Impacts of Disclosure on Parents and Family

Some studies reported that most HIV-positive mothers did not express regret about disclosing to their children [18, 38]. They felt satisfied with disclosure because it alleviated their stress around the need to hide their medical care and allowed their children to participate in future decision making [40]. Studies showed that disclosure to children was associated with better adherence to clinic appointments [3], lower anxiety and depression [13, 37], and higher social support for parents living with HIV [30]. However, a study with 188 HIV-positive mothers and their children in New York indicated that disclosure to children was not associated with mothers' psychological well-being or accessing to more social support resources [21]. Another study with a small sample ($n = 17$) suggested that 43% of parents felt overwhelmed and nervous after disclosure [37].

Parents generally described a closer and stronger relationship with children following disclosure, citing more closeness, more communication with children [27, 44, 51, 61]. Some HIV-positive mothers reported that their children comforted them after disclosure by hugging them and telling them that "it was going to be fine" [18]. In one US-based study, the family cohesion score was significantly higher among disclosers than non-disclosers [37]. In Uganda, the majority of parents reported obtaining support from their children after their disclosure [26]. In only one study did HIV-positive mothers perceive the quality of the mother-child relationship to decline after disclosure to their children, although the children did not report a similar feeling [31]. Murphy [23] hypothesized that the discrepancy might be associated with mother's negative misperceptions about disclosure from guilt for bringing HIV to the family or fear of children's negative reactions. In a study examining parental disclosure from the perspective of children, some children reported an increased sense of protectiveness of their HIV-positive mother, and a more open relationship with their mother [51].

The existing literature also suggested caution in interpreting closer family relationship following disclosure. Hawk pointed out that a closer relationship between parents and children after disclosure might also be indicative of psychological problems of children. For example, spending more time with parents and taking on more household responsibilities might suggest anxiety, hypervigilance, and overprotectiveness [16, 44, 63]. High family cohesion might not be positively associated with children's psychological well-being. A seven-year longitudinal study for HIV-positive mothers and their children indicated that higher family cohesion was associated with lower levels of self-concept and higher levels of depression for children [61].

Discussion

Disclosing parental HIV status to children was often a significant challenge and a dilemma for HIV-positive parents. Existing literature showed a low disclosure rate in both the US and other countries. The decision of disclosing parental HIV status to children appears to be influenced by individual characteristics of parents and children (e.g., gender, ethnicity, age,

income, etc.) and the health status of the parent, as well as children's cognitive developmental level, parenting practices, family relationship and social norms (e.g., HIV-related stigmatization and discrimination). These factors also shaped the practice of parental disclosure including the scope, content and approach of the disclosure.

Generally, disclosure of parental HIV status to children positively affected the well-being of children, parents, and family. Existing comparisons on impacts of disclosure and non-disclosure indicated that although disclosure involved risk of negative consequences, non-disclosure to children might generate problems rather than help family members toward better adjustment [64, 65]. However, findings about impacts of disclosure on children were generally mixed in the existing literature. There were several possible explanations about these mixed findings. First, the term of "disclosure" in different studies might not have the same meaning. As discussed by many authors [15, 25, 38, 51], a great number of HIV-positive parents disclosed their HIV status to their children unintentionally, poor-preparedly and even forcedly. These unplanned disclosures might actually result in negative reactions from children. The disclosure may not generate the desired benefit unless it is culturally and developmentally appropriate. Second, some of the mixed findings might result from variations in methodological issues including sampling and outcome measurement. Third, many studies failed to identify or control individual and contextual factors that could potentially mediate or moderate the impact of disclosure or nondisclosure.

Although future studies with vigorous research methodology, sufficient sample size and standard measurement instruments are needed to validate these speculations, the existing literature underlines the importance of looking at the issues of disclosure from a simple question of "whether or not disclose" to more insightful ones regarding when and how to disclose [10]. The existing literature also underscores the need for intervention efforts that can help HIV-positive parents to make culturally and developmentally appropriate disclosure to their children and to maximize the long-term benefits of the disclosure for the children and family.

There are some limitations in the current literature review. First, non-English-language articles or unpublished studies were not included in this review because of concerns regarding the accessibility to these studies. Second, this review lacked a guiding theoretical framework. The absence of such a guiding framework reflects the void of such a framework in the field of research on disclosure of parental HIV to children. Third, the current review was largely focusing on the issues of disclosure of parental HIV to uninfected children, although several studies did not clearly specify such a focus [5, 24, 27, 32, 39, 42].

Despite these limitations, the findings of current review have several important implications for future research and intervention. Future quantitative studies should employ a longitudinal study design whenever possible to establish a meaningful causal relationship in the consequences of disclosure and recruit a large enough sample size of respondents to ensure the power of analysis. The number of existing longitudinal studies was limited. In addition, half of the existing quantitative studies had no more than 100 respondents. Measurement of disclosure practice in some studies was very general without specifics regarding the scope or approach of disclosure, such as partial disclosure/ full disclosure, forced disclosure/planned

disclosure [4, 15, 17, 19, 24, 31, 35–37, 40, 61]. The lack of data on these different features of disclosure might make it hard to differentiate the effects of various types of disclosure. The lack of standard measurement also made it difficult to compare results across studies. For instance, some studies reported parental disclosure rate [4, 15, 19, 21, 30, 35–37, 40, 41, 59–61, 66], while some studies reported children's awareness rate [3, 17, 18, 20, 24, 28, 29, 31–34, 42]. In addition, future studies should collect data from both parents and children given the potentially unique perspectives from parents and children on disclosure issues.

More studies are needed in developing or transitional countries. The geographic distribution of existing studies did not appropriately reflect the actual HIV epidemics and the global needs of parental disclosure. The number of studies in African and Asian countries remained limited. Only eight (20%) of the reviewed articles were from African and Asian countries. In addition, we could not locate any study from Eastern European countries, which have experienced a dramatic increase in new infections among injecting drug users [67]. In low-resource settings, where HIV-positive parents and their children are living in specific culture contexts with different traditions from developed countries, the Western disclosure model and experience may be challenged and inappropriate. Although there was some report on culturally adapted strategies in developing countries to support parental disclosure to children, such as “memory books” in Uganda, which assisted HIV-positive parents to disclose to their children by encouraging parents to write their life histories [68], the available resources for training health providers in disclosure intervention were largely based on the Western experience [69, 70]. The lack of data about disclosure practice and published disclosure research in developing countries indicates the need for investigation of disclosure issues in these countries.

Intervention studies are needed to support families as they struggle with issues associated with disclosure. Existing studies suggest a high desire from parents living with HIV to obtain professional guidance and support during the disclosure process due to complexity of parental HIV disclosure to children [42], intervention studies related to parental HIV disclosure to children were limited worldwide. Only two disclosure-related intervention studies (i.e., employing disclosure as either one of the intervention components or one of the key outcomes) were identified during the current review [66, 71]. The first one was a two-year randomized controlled trial among 307 parents living with AIDS and 412 adolescent children in New York [71]. Parents-focused intervention was designed to help them improve their coping skills with illness and disclosure, reduce risk behaviors and create positive family routines. Adolescents-focused intervention aimed to help them adjust to parental illness, improve family relationship and reduce youths' risk acts. The intervention significantly reduced emotional distress, multiple problem behaviors among both parents and adolescents, and improved adolescents' self-esteem. However, no difference was found between the intervention and control groups in terms of parent's coping style or scopes of disclosure [71]. The second intervention study was a nine-month randomized controlled trial among 80 HIV-positive mothers and their children in Los Angeles [66]. This mother-focused intervention included three sessions to assist mothers to well prepare for disclosure by understanding children's typical development, improving mother–child communication, and taking role-play exercise for disclosure. This intervention successfully increased disclosure rate, disclosure self-efficacy, promoted mother–child communication, and improved

maternal emotional functioning. The intervention also showed initial efficacy in reducing depression and anxiety and increasing happiness feelings among young children 6–12 years of age [66].

Future research and interventions regarding parental HIV disclosure to children should consider children's cognitive development level. Psychological studies indicated that understanding of illness, health and death evolved with age [72, 73]. By age 9, children were able to understand finality of death, and typically define illness as a set of symptoms. By age 12 or 13, they had a broader conception and were able to understand multiple causes of illness and various body responses to illness [74]. Understanding AIDS might follow a similar developmental progression [75]. Future research and intervention efforts therefore need to consider children's cognitive development level, emotional maturity, and their ability of understanding HIV in order to help parents to make disclosure in developmentally appropriate ways, and provide psychological support to both parents and children following the disclosure [29, 35]. HIV guidelines issued by WHO and many national organizations [76–79] recommended developmentally appropriate disclosure to children. A developmentally appropriate disclosure of parental HIV status to children might be a process starting with partial disclosure, extending to full disclosure, and finally reaching the full preparation for potential parental death.

Future research and interventions also need to consider influence of family and community factors on the disclosure and its consequence. For example, open, honest communication and close relationships between parents and children were viewed as positive factors for appropriate disclosure [15, 51]. Stigma and discrimination from neighborhood, schools and even health care institutes was one of main barriers for HIV-positive parents to disclose HIV status to their children. Therefore, the intervention for disclosure to children should be comprehensive with efforts to create a positive family context (such as improving parenting skills, increasing parent–child communication, promoting quality of parent–child relationship, decreasing interparental conflicts, etc.) and to reduce HIV-related stigma in communities.

In summary, disclosure of parental HIV status to children is a significant challenge for HIV-positive parents. Parents need professional support in making a decision about disclosure and managing age-appropriate disclosure to their children. However, there are significant knowledge gaps regarding culturally and developmentally appropriate psychological intervention and services for HIV-positive parents and their children, especially in developing countries and other resource-poor settings. Future studies need to be guided by solid theoretical frameworks, with appropriate study design and standardized measurement, and with efforts to examine impacts of different types of disclosure on parents, children and their families. It is urgent to develop evidence-informed interventions to assist HIV-positive parents to disclose their HIV status to children and assist their children to cope with parental HIV infection and AIDS in a culturally and developmentally appropriate manner.

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References

1. Enger C, Graham N, Peng Y, Chmiel JS, Kingsley LA, Detels R, et al. Survival from early, intermediate, and late stages of HIV infection. *JAMA*. 1996;275(17):1329–34. [PubMed: 8614118]
2. Marks G, Bundek NI, Richardson JL, Ruiz MS, Maldonado N, Mason HR. Self-disclosure of HIV infection: preliminary results from a sample of Hispanic men. *Health Psychol*. 1992;11(5):300–6. [PubMed: 1425547]
3. Mellins CA, Brackis-Cott E, Dolezal C, Leu CS, Valentin C, Meyer-Bahlburg HF. Mental health of early adolescents from high-risk neighborhoods: the role of maternal HIV and other contextual, self-regulation, and family factors. *J Pediatr Psychol*. 2008;33(10):1065–75. Epub 2008/02/06. [PubMed: 18250092]
4. Thorne C, Newell ML, Peckham CS. Disclosure of diagnosis and planning for the future in HIV-affected families in Europe. *Child Care Health Dev*. 2000;26(1):29–40. Epub 2000/03/04. [PubMed: 10696516]
5. Dematteo D, Harrison C, Arneson C, Goldie RS, Lefebvre A, Read SE, et al. Disclosing HIV/AIDS to children: the paths families take to truth-telling. *Psychol Health Med*. 2002;7(3): 339–56.
6. Chelune GJ. Measuring openness in interpersonal communication In: Chelune GJ, editor. *Origins, patterns and implications of openness in interpersonal relationships* San Francisco: Jossey-Bass; 1979 p. 1–27.
7. Cozby PC. Self-disclosure: a literature review. *Psychol Bull*. 1973;79:73–91. [PubMed: 4567729]
8. Jourard SM. A study of self-disclosure. *Sci Am*. 1958;198(5): 77–82.
9. Jourard JM. *The transparent self*. New York: Van Nostrand; 1964.
10. Wiener L, Mellins CA, Marhefka S, Battles HB. Disclosure of an HIV diagnosis to children: history, current research, and future directions. *J Dev Behav Pediatr*. 2007;28(2):155–66. [PubMed: 17435473]
11. Greene K, Derlega VJ, Mathews A. Self-disclosure in personal relationship In: Vangelisti A, Perlman D, editors. *Cambridge handbook of personal relationships*. Cambridge, England: Cambridge University Press; 2006 p. 409–427.
12. Skogmar S, Shakely D, Lans M, Danell J, Andersson R, Tshandu N, et al. Effect of antiretroviral treatment and counselling on disclosure of HIV-serostatus in Johannesburg, South Africa. *AIDS Care*. 2006;18(7):725–30. Epub 2006/09/15. [PubMed: 16971281]
13. Armistead L, Morse E, Forehand R, Morse P, Clark L. African-American women and self-disclosure of HIV infection: rates, predictors and relationship to depressive symptomatology. *AIDS Behav*. 1999;3(3):195–204.
14. Faithfull J. HIV-positive and AIDS-infected women: challenges and difficulties of mothering. *Am J Orthopsychiatr*. 1997;67(1): 144–51.
15. Pilowsky DJ, Sohler N, Susser E. Reasons given for disclosure of maternal HIV status to children. *J Urban Health*. 2000;77(4): 723–34. Epub 2001/02/24. [PubMed: 11194312]
16. Tompkins TL, Henker B, Whalen CK, Axelrod J, Comer LK. Motherhood in the context of HIV infection: reading between the numbers. *Cult Diversit Ethn Minority Psychol*. 1999;5(3): 197–208.
17. Corona R, Beckett MK, Cowgill BO, Elliott MN, Murphy DA, Zhou AJ, et al. Do children know their parent's HIV status? Parental reports of child awareness in a nationally representative sample. *Ambul Pediatr*. 2006;6(3):138–44. Epub 2006/05/23. [PubMed: 16713931]
18. Delaney RO, Serovich JM, Lim JY. Reasons for and against maternal HIV disclosure to children and perceived child reaction. *AIDS Care*. 2008;20(7):876–80. Epub 2008/07/09. [PubMed: 18608085]
19. Letteney S, LaPorte HH. Deconstructing stigma: perceptions of HIV-seropositive mothers and their disclosure to children. *Soc Work Health Care*. 2004;38(3):105–23. Epub 2004/05/20. [PubMed: 15149914]

20. Murphy DA, Austin EL, Greenwell L. Correlates of HIV-related stigma among HIV-positive mothers and their uninfected adolescent children. *Women Health*. 2006;44(3):19–42. Epub 2007/01/27. [PubMed: 17255064]
21. Simoni JM, Davis ML, Drossman JA, Weinberg BA. Mothers with HIV/AIDS and their children: disclosure and guardianship issues. *Women Health*. 2000;31(1):39–54. [PubMed: 11005219]
22. Hawk ST. Disclosures of maternal HIV infection to seronegative children: a literature review. *J Soc Pers Relatsh*. 2007;24(5): 657–73.
23. Murphy DA. HIV-positive mothers' disclosure of their serostatus to their young children: a review. *Clin Child Psychol Psychiatry*. 2008;13(1):105–22. Epub 2008/04/17. [PubMed: 18411869]
24. Nostlinger C, Jonckheer T, DeBelder E, VanWijngaerden E, Wylock C, Pelgrom J, et al. Families affected by HIV: parents' and children's characteristics and disclosure to the children. *AIDS Care*. 2004;16(5):641–708. Epub 2004/06/30. [PubMed: 15223533]
25. Kennedy DP, Cowgill BO, Bogart LM, Corona R, Ryan GW, Murphy DA, et al. Parents' disclosure of their HIV infection to their children in the context of the family. *AIDS Behav*. 2010;14(5): 1095–105. Epub 2010/05/29. [PubMed: 20509046]
26. Rwemisisi J, Wolff B, Coutinho A, Grosskurth H, Whitworth J. 'What if they ask how I got it?' Dilemmas of disclosing parental HIV status and testing children for HIV in Uganda. *Health Policy Plan*. 2008;23(1):36–42. Epub 2007/12/25. [PubMed: 18156633]
27. Dane B. Disclosure: the voices of Thai women living with HIV/ AIDS. *Intern Soc Work*. 2002;45(2):185–204.
28. Nam SL, Fielding K, Avalos A, Gaolathe T, Dickinson D, Geissler PW. Discussing matters of sexual health with children: what issues relating to disclosure of parental HIV status reveal. *AIDS Care*. 2009;21(3):389–95. Epub 2009/03/13. [PubMed: 19280415]
29. Kirshenbaum SB, Nevid JS. The specificity of maternal disclosure of HIV/AIDS in relation to children's adjustment. *AIDS Educ Prev*. 2002;14(1):1–16. Epub 2002/03/20.
30. Murphy DA, Steers WN, DelloStritto ME. Maternal disclosure of mothers' HIV serostatus to their young children. *J Fam Psychol*. 2001;15(3):441–50. Epub 2001/10/05. [PubMed: 11584794]
31. Shaffer A, Jones DJ, Kotchick BA, Forehand R, Armistead L, Morse E, et al. Telling the children: disclosure of maternal HIV infection and its effects on child psychosocial adjustment. *J Child Fam Stud*. 2001;10(3):301–13.
32. Xu T, Yan Z, Rou K, Wang C, Ye R, Duan S, et al. Disclosure of parental HIV/AIDS to children in rural China. *Vulnerable Child Youth Stud*. 2007;2(2):100–5.
33. Palin FL, Armistead L, Clayton A, Ketchen B, Lindner G, Kokot-Louw P, et al. Disclosure of maternal HIV-infection in South Africa: description and relationship to child functioning. *AIDS Behav*. 2009;13(6):1241–52. Epub 2008/09/05. [PubMed: 18770026]
34. Asander AS, Bjorkman A, Belfrage E, Faxelid E. HIV-infected African parents living in Stockholm, Sweden: disclosure and planning for their children's future. *Health Soc Work*. 2009; 34(2):107–15. Epub 2009/05/12. [PubMed: 19425340]
35. Armistead L, Tannenbaum L, Forehand R, Morse E, Morse P. Disclosing HIV status: are mothers telling their children? *J Pediatr Psychol*. 2001;26(1):11–20. Epub 2001/01/06. [PubMed: 11145728]
36. Lee MB, Rotheram-Borus MJ. Parents' disclosure of HIV to their children. *AIDS*. 2002;16(16): 2201–7. Epub 2002/11/01. [PubMed: 12409742]
37. Wiener LS, Battles HB, Heilman NE. Factors associated with parents' decision to disclose their HIV diagnosis to their children. *Child Welf*. 1998;77(2):115–35. Epub 1998/03/26.
38. Murphy DA, Roberts KJ, Hoffman D. Regrets and advice from mothers who have disclosed their HIV + serostatus to their young children. *J Child Fam Stud*. 2003;12(3):307–18.
39. Thomas B, Nyamathi A, Swaminathan S. Impact of HIV/AIDS on mothers in Southern India: a qualitative study. *AIDS Behav*. 2009;13(5):989–96. [PubMed: 18941883]
40. Tompkins TL. Disclosure of maternal HIV status to children: to tell or not to tell...that is the question. *J Child Fam Stud*. 2007; 16(6):773–88.
41. Rotheram-Borus MJ, Draimin BH, Reid HM, Murphy DA. The impact of illness disclosure and custody plans on adolescents whose parents live with AIDS. *AIDS*. 1997;11(9):1159–64. Epub 1997/07/15. [PubMed: 9233464]

42. Nöstlinger C, Bartoli G, Gordillo V, Roberfroid D, Colebunders R. Children and adolescents living with HIV positive parents: emotional and behavioural problems. *Vulnerable Child Youth Stud.* 2006;1(1):29–43.
43. Funck-Brentano I [Informing a child about his illness in HIV infection: words and meaning]. *Psychiatr Infant* 1995;38(1): 109–139. Epub 1995/01/01. L'information de l'enfant sur sa maladie dans un cas d'infection a VIH: parole et sens. [PubMed: 8559848]
44. Schrimshaw EW, Siegel K. HIV-infected mothers' disclosure to their uninfected children: rates, reasons, and reactions. *J Soc Pers Relatsh.* 2002;Special Issue: personal and social relationships of individuals living with HIV and/or AIDS 19(1):19–44.
45. De Baets AJ, Sifovo S, Parsons R, Pazvakavambwa IE. HIV disclosure and discussions about grief with Shona children: a comparison between health care workers and community members in Eastern Zimbabwe. *Soc Sci Med.* 2008;66(2):479–91. Epub 2007/10/12. [PubMed: 17928117]
46. Woodring LA, Cancelli AA, Ponterotto JG, Keitel MA. A qualitative investigation of adolescents' experiences with parental HIV/AIDS. *Am J Orthopsychiatr.* 2005;75(4):658–75. Epub 2005/11/03.
47. DeBaets AJ, Sifovo S, Parsons R, Pazvakavambwa IE. HIV disclosure and discussions about grief with Shona children: a comparison between health care workers and community members in Eastern Zimbabwe. *Soc Sci Med.* 2008;66(2):479–91. Epub 2007/10/12. [PubMed: 17928117]
48. Black BP, Miles MS. Calculating the risks and benefits of disclosure in African American women who have HIV. *J Obstet Gynecol Neonatal Nurs.* 2002;31(6):688–97. Epub 2002/12/06.
49. Mawar N, Saha S, Pandit A, Mahajan U. The third phase of HIV pandemic: social consequences of HIV/AIDS stigma & discrimination & future needs. *Indian J Med Res.* 2005;122(6):471–84. Epub 2006/03/07. [PubMed: 16517997]
50. Nelson KE, Suriyanon V, Taylor E, Wongchak T, Kingkeow C, Srirak N, et al. The incidence of HIV-1 infections in village populations of Northern Thailand. *AIDS.* 1994;8(7):951–1005. Epub 1994/07/01. [PubMed: 7946105]
51. Vallerand AH, Hough E, Pittiglio L, Marvicsin D. The process of disclosing HIV serostatus between HIV-positive mothers and their HIV-negative children. *AIDS Patient Care STDS.* 2005; 19(2):100–9. Epub 2005/02/18. [PubMed: 15716641]
52. Schweder RA, Bourne EJ. Does the concept of the person vary cross-culturally? In: Schweder RA, LeVine RA, editors. *Culture theory: essays on mind, self, and emotion.* Cambridge: England Cambridge University Press 1984 p. 158–199.
53. Molwau N. *Handbook of social services for Asian and Pacific Islanders.* Westport, CT: Greenwood Press 1991.
54. Foster G. The capacity of the external family safety net for orphans in Africa. *Psychol Health Med.* 2000;5(1):55–9.
55. LCS Associates. Report on the lives of Chicago women and children living with HIV infection Chicago, IL department of children and family services 1994.
56. Murphy DA, Roberts KJ, Hoffman D. Young children's reactions to mothers' disclosure of maternal HIV + serostatus. *J Child Fam Stud.* 2006;15(1):39–56.
57. Murphy DA, Roberts KJ, Hoffman D. Stigma and ostracism associated with HIV/AIDS: children carrying the secret of their mothers' HIV + serostatus. *J Child Fam Stud.* 2002;11(2): 191–202.
58. Xu T, Wu Z, Rou K, Duan S, Wang H. Quality of life of children living in HIV/AIDS-affected families in rural areas in Yunnan, China. *AIDS Care.* 2010;22(3):390–406. Epub 2010/04/15. [PubMed: 20390520]
59. Armistead L, Klein K, Forehand R, Wierson M. Disclosure of parental HIV infection to children in the families of men with hemophilia: description, outcomes, and the role of family processes. *J Fam Psychol.* 1997;11(1):49–61.
60. Murphy DA, Marelich WD, Hoffman D. A longitudinal study of the impact on young children of maternal HIV serostatus disclosure. *Clin Child Psychol Psychiatry.* 2002;7(1):55–70.
61. Murphy DA, Marelich WD, Amaro H. Maternal HIV/AIDS and adolescent depression: a covariance structure analysis of the “parents and adolescents coping together” (PACT) model. *Vulnerable Child Youth Stud.* 2009;4(1):67–82. Epub 2010/03/09. [PubMed: 20209025]
62. Stein JA, Riedel M, Rotheram-Borus MJ. Parentification and its impact on adolescent children of parents with AIDS. *Fam Process.* 1999;38(2):193–208. Epub 1999/07/17. [PubMed: 10407720]

63. Ingram D, Hutchinson SA. Double binds and the reproductive and mothering experiences of HIV-positive women. *Qual Health Res.* 2000;10(1):117–32. Epub 2000/03/21. [PubMed: 10724748]
64. Cooklin AI, Gorrell Barnes G. Taboos and social order: new encounters for family and therapist In: Imber-Black E, editor. *Secrets in families and family therapy.* New York: Norton 1993.
65. Cottle TJ. *Children's secrets.* Reading: Addison-Wesley; 1980.
66. Murphy DA, Armistead L, Marelich WD, Payne DL, Herbeck DM. Pilot trial of a disclosure intervention for HIV + mothers: the TRACK program. *J Consult Clin Psychol.* 2011;79(2): 203–14. Epub 2011/03/02. [PubMed: 21355637]
67. UNAIDS. Report on the global AIDS epidemic. 2010.
68. Witter S. Breaking the silence: memory books and succession planning: The experience of NACWOLA and save the children UK in Uganda London, England save the children UK, 2004.
69. African network for the care of children affected by AIDS (ANECCA). *Handbook on paediatric AIDS in Africa* 2004.
70. Abrams E, EI-Sadr W, Rabkin M. *The ICAP pediatric clinical manual.* Columbia University: New York International Center for AIDS-programs; 2005.
71. Rotheram-Borus MJ, Lee MB, Gwadz M, Draimin B. An intervention for parents with AIDS and their adolescent children. *Am J Public Health.* 2001;91(8):1294–302. [PubMed: 11499122]
72. Lansdown R, Benjamin G. The development of the concept of death in children aged 5–9 years. *Child Care Health Dev.* 1985;11(1):13–20. Epub 1985/01/01. [PubMed: 3995689]
73. Natapoff JN. A developmental analysis of children's ideas of health. *Health Educ Q.* 1982;9(2–3): 130–41. Epub 1982/01/01. [PubMed: 7169323]
74. Perrin EC, Gerrity PS. There's a demon in your belly: children's understanding of illness. *Pediatrics.* 1981;67(6):841–9. Epub 1981/06/01. [PubMed: 7232049]
75. Osborne ML, Kistner JA, Helgemo B. Developmental progression in children's knowledge of AIDS: implications for education and attitudinal change. *J Pediatr Psychol.* 1993;18(2):177–92. Epub 1993/04/01. [PubMed: 8492272]
76. Department of Health Republic of South Africa. Guidelines for the management of HIV in children. In: Department of Health Republic of South Africa, editor. 2010.
77. Uganda Ministry of Health. National ARV treatment and care guidelines for adults and children. In: Uganda Ministry of Health, editor. 2003.
78. Zambia Ministry of Health, UNICEF. *Zambian guidelines for antiretroviral therapy of HIV infection in infants and children: towards universal access.* In: Zambia Ministry of Health, UNICEF, editors. 2007.
79. HIV/AIDS prevention and control office Ethiopia Ministry of Health. Guidelines for paediatric HIV/AIDS care and treatment in Ethiopia. In: Ethiopia Ministry of Health, editor. 2008.

Table 1

Summaries of quantitative studies

Study	Ref #	Sample description ^a	Location	Study design	Main findings ^b
Murphy et al. (2011)	[65]	80 HIV+ mothers, 80 children Children age: 6–12	Los Angeles, US	Longitudinal experimental design, 9 months time span	<i>Disclosure rate</i> Overall 20% (16/80), 33.3% in the intervention group (13/39), 7.3% in the control group (3/41)
Xu et al. (2010)	[57]	116 children from HIV-affected families, 109 from unaffected ones in rural areas Children age: 8–17	Yunnan, China	Cross sectional survey	<i>Disclosure rate</i> N/A <i>Children outcomes</i> Disclosure was associated with lower PedsQL scores: emotional functioning ($P < 0.05$), social functioning ($P < 0.05$)
Murphy et al. (2009)	[60]	135 HIV+ mothers, 135 children Children age: 6–11	Los Angeles, US	Sequential longitudinal design, 7 years time span	<i>Disclosure rate</i> 36% at baseline <i>Children outcomes</i> Disclosure was associated with higher self-concept ($P < 0.01$) <i>Family outcomes</i> Disclosure was associated with higher family cohesion ($P < 0.05$).
Palin (2009)	[33]	103 HIV+ mothers Children age: 11–16	Pretoria, South Africa	Cross sectional survey	<i>Children awareness rate</i> 44% <i>Timing of disclosure</i> Time since diagnosis (14% within 1 month, 50% within 1 year, 70% within 2 years) <i>Disclosure approach</i> 96% informed by mothers, 2% by grandparents, 2% by non-related person <i>Predictors of disclosure</i> Being married or widows <i>Reasons for non-disclosure</i> Concerns about children's internalizing problems (70%), development problems (37%), negative feelings about the future (16%), and their ability of keeping secret (9%) <i>Reactions</i> Sadness (60%), worry (47%), fear (22%), rejection (16%) <i>Children outcomes</i> Disclosure was associated with more externalizing symptoms ($P < 0.05$), but <i>not</i> with internalizing behaviors
Mellins et al. (2008)	[3]	220 adolescents, 220 mothers, half of whom were HIV+ Children age: 10–14	New York, US	Cross sectional survey	<i>Children awareness rate</i> 66% <i>Children outcomes</i> Disclosure was associated with higher CDI depression score (7.0 vs. 5.1, $P < 0.05$), <i>not</i> with STAI-C anxiety score, or CBCL scores
Delaney et al. (2008)	[18]	66 HIV+ mothers, 66 children Children age: 5–18	Midwest, US	Cross sectional survey	<i>Children awareness rate</i> 62% (41/66) 90% of mothers did not regret disclosure <i>Disclosure approach</i> 78% were informed by mothers <i>Reasons for disclosure</i> Wanted children to hear the diagnosis from mothers (Mean = 4.69 in a 5-point scale), children had a right to know (M = 4.5), wanted to reassure the children (M = 4.41) <i>Reasons for non-disclosure</i> Children deserved a carefree childhood (M = 4.38), children might be worried (M = 4.37) or scared (M = 4.19) <i>Reactions</i> Comforted mothers (M = 3.69), showed concern (M = 3.77) and wanted more information (M = 3.68) <i>Children outcomes</i> Comforted mothers (M = 3.89), remained worried (M = 3.65)
DeBaets et al. (2008)	[45]	64 primary health care workers, 131 community members Children age: N/A	Rural Eastern Zimbabwe	Cross sectional survey	<i>Disclosure rate</i> N/A <i>Timing of disclosure</i> (preferred children's age) Partial disclosure (10.8 ± 4.2), full disclosure (14.4 ± 4.5)

Study	Ref #	Sample description ^a	Location	Study design	Main findings ^b
Tompkins (2007)	[40]	23 HIV+ mothers, 23 non-infected children Children age: 9–16	Los Angeles, US	Cross sectional survey	<i>Disclosure approach</i> (preferred) Combinations discloses: involving a health care worker (56%), family member (52%), Preferred family members: father's sister (37%), grandmother (40%), partner (15%) <i>Disclosure rate</i> 61% <i>Timing of disclosure</i> Time since diagnosis (Mean = 5.4 years, SD = 4.31) <i>Reasons for satisfaction in disclosure</i> (For mothers) Children could participate in decision affecting them (100%), mothers felt less stress (86%), improved maternal health (71%), easier health seeking (64%), talked with children more (57%), children felt less stress and worry (57%) (For children) Better prepared for the future (93%), made decisions affecting them (86%), reduced mother's stress (79%), were closer to mothers (79%), talked openly (67%), were less worried (50%) <i>Reasons for non-disclosure</i> Protected children, feared stigma, children were not in an appropriate developmental level <i>Predictors of disclosure</i> Single-parent (83% vs. 36%, $P < 0.05$), no association with income, education, ethnicity or mother's age <i>Children outcomes</i> Disclosure was not associated with child functioning. Children asked to keep disclosure secret had lower social competence and more externalizing problems ($P < 0.05$). Children knew more than their mothers had disclosed had higher level of externalizing problems ($P < 0.01$) and lower level of behavioral competence ($P < 0.05$).
Corona et al. (2006)	[17]	274 HIV+ parents, 453 children ^c Children age: 5–17	US	Cross sectional survey	<i>Children awareness rate</i> 44% <i>Predictors of non-disclosure</i> Higher income, being in an HIV risk groups of heterosexual intercourse, higher CD4 #, greater social isolation, younger children <i>Reasons for non-disclosure</i> Children might emotionally react (67%), children might tell others (36%), did not know how to tell (28%) <i>Children outcomes</i> 11% were worried about catching HIV from parents
Nostlinger et al. (2006)	[42]	718 HIV+ parents, 1136 children from 15 European HIV treatment centers Children age: 18	10 Western European countries	Cross sectional survey	<i>Children awareness rate</i> 21% <i>Timing of disclosure</i> Children's age (to the elder child in one family) (Median = 11, Mean = 10.7, SD = 4.8) <i>Scope of disclosure</i> 78% informed about HIV, 22% chronic disease <i>Disclosure approach</i> 62% informed by parents, 11% with professional support <i>Reactions</i> Depressive (39%), mature (27%), anxious (11%) <i>Reaction lasting time</i> 1 month (23%), 1–6 months (14%), 6–12 months (11%), over 12 months (12%)
Murphy et al. (2006)	[20]	118 HIV+ mothers, 118 children Children age: 10–17	Los Angeles, US	Cross sectional survey	<i>Children awareness rate</i> 37% <i>Predictors of non-disclosure</i> Disclosure-related stigma ($P < 0.01$) <i>Children outcomes</i> Children disclosed had lower CDI (4.44 vs. 7.37, $P < 0.01$), higher Piers-Harries Children's self-concept: physical appearance and attributes ($P = 0.008$), popularity ($P = 0.026$), happiness and satisfaction ($P = 0.01$), were more likely to value school's performance.
Letteney and LaPorte (2004)	[19]	88 HIV+ mothers Children age: 5–18	New York, US	Cross sectional survey	<i>Disclosure rate</i> 67% <i>Predictors of non-disclosure</i> Using secrecy as a stigma management tool ($P = 0.01$), perceiving devaluation and discrimination ($P = 0.01$)
Nostlinger et al. (2004)	[24]	168 HIV+ parents, 279 children ^d Children age: 17	Belgium	Cross sectional survey	<i>Children awareness rate</i> 26% <i>Timing of the disclosure</i> Children's age (Median = 16) <i>Predictors of disclosure</i> Older children ($P < 0.000$), families from developing countries ($P < 0.0005$)

Study	Ref #	Sample description ^a	Location	Study design	Main findings ^b
Murphy et al. (2002)	[59]	81 children living with HIV+ mothers Children age: 6–11	Los Angeles, US	Longitudinal study, 1 year time span	<i>Disclosure rate</i> 40% (32/81) <i>Children outcomes</i> Disclosure was associated with higher children's CDI negative self-esteem (1.2 vs. 0.48, $P < 0.05$) (between-group main effects), higher CDI interpersonal problems scores (1.14 vs. 0.67, $P < 0.05$) (at baseline), <i>not</i> with CBCL or household responsibilities scale. CDI negative mood, CDI total score decreased and household responsibilities increased for all children over time.
Lee and Rotheram-Borus (2002)	[36]	301 HIV+ parents, 395 adolescent children Children age: 11–18	New York, US	Longitudinal study, 5 year time span	<i>Disclosure rate</i> 30% within 1 month, 6% within 2–3 months, 11% 4–12 months, 16% 1–3 year, 21% over 3 years, 12% non-disclosure till death <i>Predictors of disclosure</i> Being mothers, (HR = 2.02, 95% CI 1.25–3.26), being daughters (for maternal disclosure) (HR = 1.33, 95% CI 1.09–1.62), being elder children, higher # stressful life events, more severe diagnosis, more stigma children experienced (OR = 2.81, 95% CI 1.07–7.35), larger social networks <i>Children outcomes</i> Children disclosed: higher problem behaviors, decreased over time (slope = -0.002), more negative family events, decreased (slope = -0.01) Non-disclosed: increasing problem behaviors (slope = 0.003), disclosure was <i>not</i> associated with emotional distress, self-esteem, or parental bonding
Kirshenbaum and Nevid (2002)	[29]	58 HIV+ mothers, 58 children Children age: 4–18	New York, US	Cross sectional survey	<i>Children awareness rate</i> 97% <i>Timing of disclosure</i> Children's age (Mean = 7) <i>Disclosure approach</i> 75% were informed by mothers <i>Scope of disclosure</i> 68% were informed about potential death, 57% about maternal HIV/AIDS, 43% about illness <i>Content of disclosure</i> 34% were asked to keep disclosure secret <i>Children outcomes</i> Children requested to keep disclosure secret tended to have higher CBCL problem behavior score ($P < 0.05$). Disclosure was <i>not</i> associated with children's adaptive functioning
Demattero et al. (2002)	[5]	51 adults, 54 children from 44 HIV affected families from multi-sites Children age: (over 83%) 5–19	Canada	Cross sectional survey	<i>Disclosure rate</i> N/A <i>Reactions</i> Emotional reaction (47%), no emotional reaction (43%) (parents' report); sad or upset (87%) (children's report) <i>Disclosure approach</i> Disclosing at home (69%); disclosing all at once (47%), gradually (44%); topic could be initiated by children/children's questions (86%) Preparation before disclosure: Talking with people trusted (78%), waiting for improved health of infected parent (71%), prayer (50%), talking with professionals (49%)
Shaffer et al. (2001)	[31]	99 HIV+ inner city African American mothers, 99 children Children age: 6–11	New Orleans, US	Longitudinal study, 30–34 months time span	<i>Children awareness rate</i> 32% <i>Timing of disclosure</i> Children's age (Mean = 9.59, SD = 2.46) <i>Predictors of disclosure</i> Older children <i>Children outcomes</i> Disclosure was associated with increased externalizing behaviors ($P < 0.01$, mothers reported), increased knowledge of HIV/AIDS ($P < 0.05$, children reported). <i>Family outcomes</i> Disclosure was associated with declined mother-child relationship quality ($P < 0.05$, mothers reported).
Murphy et al. (2001)	[30]	135 HIV+ mothers, 135 children Children age: 6–11	Los Angeles, US	Cross sectional survey	<i>Disclosure rate</i> 30% <i>Children awareness rate</i> 51% <i>Disclosure approach</i> 83% informed by mothers, 7% by others <i>Scope of the disclosure</i> 13% informed about potential death of AIDS, 16% AIDS, 38% HIV+, 4% chronically ill, 29% ill

Study	Ref #	Sample description ^a	Location	Study design	Main findings ^b
Armistead et al. (2001)	[35]	87 HIV+ African American mothers, 87 children Children age: 6–11	New Orleans, US	Cross sectional survey	<p><i>Reasons for non-disclosure</i> Children were too young to understand (85%), children might tell others (42%), did not know how to tell (40%), children might have problem behaviors (21%), children might be angry and withdraw (18%), children might be afraid of parents (17%), and children might lose respect for parents (9%)</p> <p><i>Parents outcomes</i> Disclosure was associated with higher scores on personal/private feelings (in social support scale) ($P = 0.008$).</p> <p><i>Children outcomes</i> Disclosure was associated with lower levels of aggressiveness ($P = 0.03$), negative self-esteem ($P = 0.04$)</p> <p><i>Disclosure rate</i> 30%</p> <p><i>Timing of disclosure</i> Time since diagnosis (Mean = 13.63 months, SD = 19.39)</p> <p><i>Predictors of disclosure</i> Lower income, being more bothered by physical symptoms, being older children, being girls</p> <p><i>Reactions</i> Supportive (30.4%), accepted (17.4%), fearful (17.4%), disappointed (8.7%), angry (8.7%), rejected (4.3%), no emotional reaction (13.5%)</p> <p><i>Children outcomes</i> Disclosure was <i>not</i> associated with internalizing or externalizing behaviors.</p>
Pilowsky et al. (2000)	[15]	29 HIV+ mothers Children age: 4–17	New York, US	Cross sectional survey	<p><i>Disclosure rate</i> 41%</p> <p><i>Reasons for disclosure</i> Right thing to do (100%), made arrangements for children's future (92%), children already found out (75%), children would find out sooner (75%), could not bear to keep secrets (58%)</p> <p><i>Reasons for non-disclosure</i> Concerns about talking to children about death (77%), children might not understand (73%), children might be worried (77%), children might ask reasons of infection (45%), children might tell others (41%), and concerns about losing respect from children (36%)</p>
Thome et al. (2000)	[4]	121 parents, (92% HIV?), 50 alternative caregivers, 226 children (62% HIV?) from ten pediatric centers Children age: 19, with 55% 6	7 European countries (German, Italy, The Netherlands, Portugal, Spain, Switzerland, and the UK)	Cross sectional survey	<p><i>Disclosure rate</i> 11%</p> <p><i>Timing of disclosure</i> Children's age (Mean = 10, Range = 5–12)</p> <p><i>Predictors of disclosure</i> Older children ($P < 0.02$), longer time since diagnosis (7.0 vs. 6.1 years, P-value was not reported)</p>
Simoni et al. (2000)	[21]	188 HIV+ mothers, 267 children Children age: 1–19	New York, US	Cross sectional survey	<p><i>Disclosure rate</i> 50%</p> <p><i>Scope of disclosure</i> Disclosing HIV/AIDS (50%), potential death (6%), illness (6%), something else (1%)</p> <p><i>Predictors of disclosure</i> Older children, <i>no association</i> with ethnicity, stage of illness</p> <p><i>Parents outcomes</i> Disclosure was <i>not</i> associated with psychological well-being or obtaining more social support resources.</p>
Wiener et al. (1998)	[37]	17 HIV+ parents, 17 children recruited in National Cancer Institute Children age: 5–18	US	Cross sectional survey	<p><i>Disclosure rate</i> 41%</p> <p><i>Timing of disclosure</i> Children's age (Mean = 9.3), Time since diagnosis (Mean = 2.5 years)</p> <p><i>Reasons for disclosure</i> In case of children's hearing from others, being prepared for maternal death, opposing to family secrets, children's asking about HIV/AIDS</p> <p><i>Reasons for non-disclosure</i> Psychological harms to children, children might not understand, preserved childhood, feared children's rejection</p> <p><i>Reactions</i> Started asking questions, scared, or no emotional reaction</p> <p><i>Parents outcomes</i> 57% (4/7) relieved, 29% (2/7) overwhelmed, 14% (1/7) nervous after disclosure, disclosure was associated with lower parental depression ($P = 0.12$)</p>

Study	Ref #	Sample description ^a	Location	Study design	Main findings ^b
Rotheram-Borus et al. (1997)	[41]	151 HIV+ parents, 171 children Children age: 12–18	New York, US	Longitudinal study, 3–6 months time span	<i>Family outcomes</i> Disclosure was associated with higher family cohesion score ($P = 0.08$), <i>not</i> with social support satisfaction, or children's self-perceived competence. <i>Disclosure rate</i> 44% <i>Scope of disclosure</i> 5% informed about potential death, <5% AIDS, 74% informed HIV+, <10% ill <i>Predictors of disclosure</i> Older children ($P < 0.001$) <i>Children outcomes</i> Children disclosed: less likely to be sexually abstinent (48.5% vs. 67.6%, $P = 0.039$), more unprotected sexual risk acts (baseline, $P < 0.03$), more likely to smoke (baseline, $P < 0.005$; follow-up, $P = 0.016$), higher weighted substance use index (baseline, $P = 0.003$; follow-up, $P = 0.004$), more symptoms of emotional distress (follow-up, $P = 0.01$), higher level of distress (follow-up, $P = 0.005$) <i>Disclosure rate</i> 45% <i>Predictors of disclosure</i> Older children, Caucasian families, in the symptomatic-AIDS stage of father <i>Children outcomes</i> Disclosure was <i>not</i> associated with child depression, externalizing problems or lower GPA.
Armistead et al. (1997)	[58]	67 HIV+ fathers, 67 mothers, 67 children from 17 hemophilia treatment centers Children age: 3–17	US	Cross sectional survey	

^aNot all the studies used independent samples

^bMain findings include disclosure rate, timing of the disclosure, approach, scope and content of disclosure, reasons for disclosure/non-disclosure, predictors of disclosure, reactions to disclosure, and outcomes of disclosure on children, parents and family (e.g., psychological well-being, family relationship). Available data regarding these findings from each study were presented in the column

^cThis study used a sub-sample from a larger national representative sample of the HIV Cost and Services Utilization Study (HCSUS). The main variables were drawn from follow-up survey (1997–1998), but some demographic variables were collected from baseline (1996–1997)

^dThis study was a part of a comprehensive study combining quantitative and qualitative methods. The quantitative data is presented in this table

Table 2

Summaries of qualitative studies

Study	Ref #	Sample description and study design	Location	Main findings
Kennedy et al. (2010)	[25]	Semi-structured interviews in 33 HIV+ parents, 27 minor children, 19 adult children, 15 caregivers ^a Children age: (minor children) 9–17, adult children (18)	US	<i>Disclosure rate N/A</i> (Only children who had known parental HIV serostatus were recruited in the study) <i>Disclosure approach</i> Unplanned disclosure was common. Children questioned parental health and medication. They guessed or indirectly learned of parental HIV infection. <i>Reactions</i> Many families described positive results of disclosure (emotional support).
Nam et al. (2009)	[28]	In-depth interviews in 21 HIV+ parents in ART care centers Children age: 5–18	Botswana	<i>Children awareness rate</i> 29% were told, 33% thought to have guessed <i>The content of disclosure</i> Parents did not talk about HIV-related sexual and reproductive health topics to children. <i>Reasons for disclosure</i> Children were HIV-positive, the rest of the family had already knew, parents were sick <i>Reasons for non-disclosure</i> Children were too young, didnot know how to tell, children might feel pain, others might know, children might experience stigma <i>Professional support</i> Parents required support in managing age-appropriate disclosure to children.
Thomas et al. (2009)	[39]	In-depth interviews in 60 HIV+ mothers Children age: (over 40%) 10	Chennai, India	<i>Disclosure rate N/A</i> <i>Disclosure timing</i> 15 years old should be an appropriate age for parental HIV disclosure. <i>Reasons for disclosure</i> Getting support from children <i>Reasons for non-disclosure</i> Children might experience discrimination, children might tell others, possible negative effects on admission to schools and school performance
Asander et al. (2009)	[34]	Semi-structured interviews in 47 HIV+ African immigrant parents from 41 families, 87 children Children age: 18	Stockholm, Sweden	<i>Disclosure rate</i> 12% (5/41) <i>Children awareness rate</i> 9% (8/87) <i>Timing of the disclosure</i> Children's age (Median = 11, Range = 8–16) <i>Predictors of disclosure</i> Only mothers disclosed to children, most were single, had no relatives in Sweden. Disclosure was not associated with age, clinical status, ARV, religion, education or knowledge of HIV.
Rwemisisi et al. (2007)	[26]	In-depth interviews in ten HIV+ parents, directors and key informants interviews in two counselors from each of five NGO Children age: (minor children) 4–17, (adult children) 18–36	Uganda	<i>Disclosure rate</i> 50% <i>Timing of the disclosure</i> Children's age (Median age = 18, Range = 14–22) <i>Reasons for disclosure</i> Getting support from children <i>Reasons for non-disclosure</i> Uncertainty about appropriate age for disclosure, lack of perceived benefits for child, emotional pain <i>Professional support</i> Counselors confirmed lack of policy and training guidelines on parent–child disclosure, and inconsistent advice.
Xu et al. (2007)	[32]	Semi-structured interviews in 16 children, 16 caregivers and five key informants in community Children age: 8–17	Yunnan, China	<i>Children's awareness rate</i> 18.8% (3/16) <i>Reasons for disclosure</i> Children heard from gossip and kept asking for the truth; children had guessed it by observing parental medication <i>The content of disclosure</i> Some grandparents would rather tell children their parents died from drug overdose than AIDS. <i>Reasons for non-disclosure</i> Children were too young to understand, parents did not know how to explain HIV or answer questions about HIV, children might tell others, protected children from unpleasant events and avoid psychological distress <i>Reactions</i> Children were concerned about parental health and kept parents from any heavy work. <i>Children outcomes</i> No obvious psychological distress
Murphy (2006)	[55]	In-depth interviews in 47 HIV+ mothers who disclosed to children ^b	Los Angeles, US	<i>Disclosure rate N/A</i> <i>Reactions</i> Anxiety about maternal health, fear of maternal death and worry about stigma Anxiety decreased over time among the majority of children, and they appeared to adjust well to disclosure

Study	Ref #	Sample description and study design	Location	Main findings
Woodring et al. (2005)	[46]	Children age: 6–11 Semi-structured interviews in nine adolescents Children age: 11–17	New York, US	<i>Disclosure rate N/A</i> <i>Disclosure approach</i> Unplanned disclosure was accompanied by multiple disclosures. It was common that parents disclosed to youngest child last. <i>Children outcomes</i> Many struggled with desire to disclose to others (to get support, educate others, normalize the illness) and fear of disclosure to friends and at school (stigma, rejection, secondary disclosure) and how and when to disclose.
Vallerand et al. (2005)	[50]	Semi-structured interviews in 35 HIV+ mothers, 19 children Children age: 10–18	Detroit, US	<i>Disclosure rate N/A</i> <i>Reasons for disclosure</i> Children were developmentally ready, protected children from HIV/AIDS, feared forced disclosure, health status declined <i>Reasons for non-disclosure</i> Children might not be able to understand, feared stigma <i>Reactions</i> Mothers often described disclosure event in a positive way, while children recalled shock and fear. 52% of mothers reported positive (closer and stronger) relationship with their children after disclosure, while some mothers and children reported negative impacts (emotional reactions, fears about uncertainty, negative behaviors, and forced secrecy). Negative reactions were common for forced disclosure.
Nostlinger et al. (2004)	[24]	Qualitative study in 13 African caregivers ^c Children age: 17	Belgium	<i>Disclosure rate N/A</i> <i>Reasons for non-disclosure</i> Emotionally disturbing for children (67%), stigma (59%), children being too young (41%) <i>Professional support</i> 69% (9/13) of parents required professional support.
Murphy et al. (2003)	[38]	In-depth interviews in 47 HIV+ mothers who disclosed to children ^b Children age: 6–11	Los Angeles, US	<i>Disclosure rate N/A</i> <i>Timing of the disclosure</i> Preferred children's age (Range = 6–10) <i>Disclosure approach</i> The majority of mothers (68%) did not regret disclosing. They recommended self-preparation with well-planned disclosure approach and content before disclosure and emotion control during disclosure. It was also important to answer children's questions, provide emotional support, and introduce children to other healthy HIV+ mothers.
Murphy et al. (2002)	[56]	In-depth interviews in 47 HIV+ mothers who disclosed to children, 47 children ^b Children age: 6–11	Los Angeles, US	<i>Disclosure rate N/A</i> <i>The content of disclosure</i> Most mothers explicitly requested children not to tell others because they feared stigma. <i>Reaction</i> The majority of children did not disclose to others or want others to know because they hoped to protect mothers. <i>Children outcomes</i> Children expressed concerns about their friends finding out, and fears of stigma, but the burden of keeping the secret was not a stressor for some of them.
Schrimshaw and Siegel (2002)	[44]	In-depth interviews in 45 HIV+ mothers ^d Children age: 25	New York, US	<i>Disclosure rate</i> 66% <i>Reasons for disclosure</i> Educate children about HIV (40%), children should be disclosed directly by mothers (20%), children should be disclosed before mother's poor health status (20%), parents should be honest with children (33%) <i>Reasons for non-disclosure</i> Children were too young (50%), children might have emotional burden (27%), feared rejection (20%), children might fear losing mother (20%), wanting children to recover from previous losses (17%) <i>The content of disclosure</i> Most mothers did not discuss the future course of illness, only a few gave explicit instruction about who to tell and who not to tell about the disease. <i>Reactions</i> Sadness, concern, disbelief, but reactions did not last long Most mothers reported no change in children's school performance, behavior at home or sleep patterns. Some reported children's acting more responsibly, independently, and closer mother-child (particularly daughter) relationship.

Study	Ref #	Sample description and study design	Location	Main findings
Demattero et al. (2002)	[5]	Qualitative study in 51 adults, 54 children from 44 HIV-affected families from multi-sites Children age: (over 83%) 5–19	Canada	<i>Disclosure rate</i> 31% <i>Timing of the disclosure</i> Age at which children really understood HIV (children's report) was 11 year old. <i>Disclosure approach</i> Sometimes disclosures were planned in the context of a special meal or favorite family activity. Sometimes disclosures occurred in the context of family argument and after a parent had been drinking. <i>Reasons for non-disclosure</i> Protected children's normal childhood, children might not be able to understand HIV
Dane (2002)	[27]	Semi-structures interview in 26 HIV+ women Children age: 3–19	Thailand	<i>Disclosure rate</i> 35% (9/26) <i>Timing of the disclosure</i> Children's age (Mean = 13.3, Preferred = 10) <i>The content of disclosure</i> All the mothers requested children not to discuss maternal HIV infection at school to protect them from stigma. <i>Reasons for disclosure</i> Protected children from HIV/AIDS <i>Reasons for non-disclosure</i> Children were too young, mothers feared the consequences of disclosure, disclosure would hurt children <i>Reactions</i> Worried, concerned, confused, scared and tearful, closer mother-child relationship

^aThis study used a sub-sample from a larger national representative sample of the HCSUS. The baseline of HCSUS was conducted in 1996–1997, but this study collected qualitative data in 2004–2005

^bThese studies used the same data, but presented as independent studies due to different research topics

^cThis study was a part of a comprehensive study combining quantitative and qualitative methods. The qualitative data is presented in this table

^dThis study used a sub-sample from a larger study about HIV+ mothers in New York City (N = 146)