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HIV-Positive Mothers' Disclosure of their Serostatus to their Young Children: A Review

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Abstract

One challenge faced by mothers living with HIV (MLWHs) is the decision about whether or not to disclose their HIV status to their young children, and how best to carry out the disclosure. Disclosure of their serostatus has emerged as one of the main concerns MLWHs have, and that decision can result in high levels of psychological distress. Concerns are exacerbated among MLWHs with younger children, due to the fact that they face additional worries, such as whether the child is old enough to understand, or will be able to keep the information confidential. A great deal of recent research—within approximately the past decade—has been conducted to investigate maternal disclosure of HIV, and the outcomes on children. This paper reviews the current state of the research literature, focusing on factors that appear to influence whether or not mothers chose to disclose; characteristics of children who have been made aware of their mothers' serostatus relative to children who remain unaware; factors that appear to influence children's reactions to maternal disclosure; and implications of this research as well as future research directions.

Keywords

Child Outcomes; HIV; Maternal Disclosure; Review Paper

Having entered the third decade of the AIDS epidemic, important shifts in its epidemiology are evident. Currently, close to half of the 37.2 million adults living with HIV worldwide are women (UNAIDS/WHO, 2004). Since the first reported case of AIDS in women in 1981 in the U.S., the percentage has continued to increase, accounting for an estimated 27% of new AIDS diagnoses in 2003 compared with only 7% in 1985 (Centers for Disease Control [CDC], 2004). From 1999 through 2003, the annual number of estimated AIDS diagnoses increased 15% among women and 1% among men (CDC, 2003). African American and Hispanic women together represent about 25% of all U.S. women, but account for 83% of AIDS diagnoses reported in 2003 (CDC, 2003; Spraggins, 2000). In fact, the first National Women and Girls HIV/AIDS Awareness day was announced this year (Fauci, 2006), in recognition of the increasing impact of HIV on women in the U.S. Thus, women are one of the groups now at the forefront of the disease, and are most often the primary caregivers in a family constellation (Bor & duPlessis, 1997; Wiener, Battles, & Heilman, 1998). As a result, growing numbers of children are living with an infected mother. An HIV diagnosis impacts not only mothers as individuals, but also affects how they care for their families (Schmidt & Goggin, 2002). While anyone diagnosed with HIV/AIDS faces the physical challenges of a chronic and thus far ultimately fatal disease, as well as the material and social impact of the stigma associated with this disease, mothers living with HIV (MLWHs) must also meet the demands of childrearing and mediate the negative impact of their illness upon their family (Black, 1993). These statistics

document the growing burden of HIV on women and their families, and their increasing need for supportive services.

Among the many challenges faced by MLWHs is the decision about whether and how to disclose their HIV+ serostatus to their children. In studies exploring the impact of HIV/AIDS on the ability of mothers to raise their children, disclosure of serostatus emerged as one of their main concerns (Donenberg & Pao, 2005; Faithful, 1997; Moneyham et al., 1996). The decision about disclosure can result in high levels of tension and stress for parents (Marks et al., 1992). These concerns may be exacerbated among parents who have younger children, due to the fact that they face additional worries, such as whether the child is old enough to understand, or if s/he will be able to keep the information confidential. This is of special concern among MLWHs who have school age children (Pilowsky, Wissow, & Hutton, 2000).

Many parents choose not to tell their young children about their HIV+ status due to worry that the children will not be able to handle the news (Black, 1993), or because they must also weigh the benefits of disclosure against the risk that sharing the information might make the family vulnerable through the child's disclosure to others (Murphy, Steers, & Dello Stritto, 2001). Evidence suggests, however, that among children to whom disclosure has not been made, many are nonetheless aware that something is wrong and experience confusion and anxiety as a result (Black, 1993; Murphy et al., 2001; Wiener & Septimus, 1990). Parents who defer disclosure also run other risks: that the decision will be taken from them when someone else discloses their HIV status; that their children may guess the secret; or that they may inadvertently reveal it in a moment of stress, depriving them of the opportunity to plan their disclosure to make its delivery as supportive as possible (Black, 1993; Vallerand, Hough, Pittiglio, & Marvicsin, 2005). Not disclosing can take both physical and psychological tolls on mothers. MLWHs report that they do not take their medications at times because they are afraid their children will observe them and suspect something is wrong, furthermore, mothers who have not disclosed often schedule medical appointments only when children are in school and are more likely to miss medical appointments (Hackl, Somlai, Kelly, & Kalichman, 1997; Mellins et al., 2002; Murphy et al., 2001). Clinicians often advise MLWHs to disclose because it is thought that both parents and children can benefit (Armistead & Forehand, 1995; Zayas & Romano, 1994). MLWHs who have disclosed report significantly lower levels of depression than mothers who have not disclosed (Wiener et al., 1998). Women who had discussed their HIV status with their immediate families reported stronger family cohesion than mothers who had not disclosed.

A great deal of recent research—within approximately the past decade—has been conducted to investigate the issue of maternal disclosure, and the outcomes that such a disclosure has on the children in these families. This paper reviews the current state of the research literature conducted in the U.S. of maternal disclosure of HIV status to their young well children, focusing on factors that appear to influence whether or not mothers chose to disclose; characteristics of children who have been made aware of their mothers' serostatus relative to children who remain unaware; factors that appear to influence children's reactions to maternal disclosure; and implications of this research as well as future research directions. Literature searches for this paper were done using PscyINFO and PubMed. PscyINFO is a bibliographic database produced by the American Psychological Association that draws from over 2,150 journal titles of which 98% are peer reviewed, chapters from authored and edited books, and dissertations and other secondary publications. PubMed is a service of the U.S. National Library of Medicine and the National Institutes of Health that includes over 16 million citations of biomedical articles and draws primarily from the MEDLINE database that indexes articles from approximately 3,900 journals covering the fields of medicine, nursing, and preclinical sciences from 1966 to the present. No studies specific to child reactions to disclosure conducted

in countries outside the U.S. were included, since the focus was on maternal and child outcomes based on a U.S. population.

Characteristics of Women, and Mothers, with HIV/AIDS

In addition to facing the issue of disclosure, MLWHs face a number of other challenges. As it is critical to consider the context of the lives of these women in relation to their decision as to whether to disclose to their children, a brief review of the characteristics of women—especially mothers with HIV—will precede the discussion of disclosure.

Most HIV-infected women are of childbearing age. In the U.S., about 54% of women are African-American, 22% Latina, and approximately one-quarter White (Ellerbrock, Bush, Chamberland, & Oxtoby, 1991). These women fall in the lowest socioeconomic class and are faced with more barriers to health care (Ickovics & Rodin, 1992). Most live in large metropolitan areas, often in neighborhoods with high crime rates. An estimated one in five new HIV diagnoses among women is related to injection drug use (CDC, 2004), although more may be affected by substance abuse, such as being the partner of an IDU (Mellins, Kang, Leu, Havens, & Chesney, 2003). Similarly, mothers with HIV/AIDS tend to be minority, single, and poorly educated, with limited economic and social resources (Armistead, Morse, Forehand, Morse, & Clark, 1999; Catz, Gore-Felton, & McClure, 2002). Hough, Brumitt, Templin, Saltz, & Mood (2003) found that in one metropolitan area, mothers with HIV/AIDS were 86% African American, and over 96% were on public assistance--factors which put them at risk for emotional distress. HIV+ women have elevated depression scores compared with uninfected women (e.g., Catz et al., 2002), and those who are mothers are more depressed than women without children (Tompkins, Henker, Whalen, Axelrod, & Comer, 1999). Overall, HIV-infected women have higher rates of psychiatric disorders, including major depression and posttraumatic stress disorders (Lipsitz et al., 1994). Ill parents often express considerable anxiety about being less able to meet their children's needs (Altschuler & Dale, 1999), feel unprepared to struggle with these issues, and report they would welcome health professionals paying greater interest in their parenting. However, many MLWHs--despite parenting problems and depression, as well as high rates of mother-child separation--describe positive changes following diagnosis, and express optimism about their future (Tompkins et al., 1999).

Estimates of Young Children Aware of Parental HIV Status

Data from convenience samples estimate that anywhere from 34% to 82% (mean across studies is 59%) of HIV-infected parents have not disclosed to their children (e.g., Armistead, Klein, Forehand, & Wierson, 1997; Armistead et al., 1999; Armistead, Tannenbaum, Forehand, Morse, & Morse, 2001; Forsyth, Damour, Nagler, & Adnopolz, 1996; Murphy et al., 2001; Niebuhr, Hughes, & Pollard, 1994; Schrimshaw & Siegel, 2002; Shaffer, Jones, Kotchick, Forehand, & the Family Health Project Research Group, 2001). (See Table 1 for a summary of these studies.) The first study of nationally representative data (Corona et al., 2006) was conducted to examine child knowledge of parental HIV in a national probability sample. In-person interviews with parents and children (M age = 10.5 years), with adults receiving health care for HIV in the contiguous U.S., found that less than half (44%) of HIV-infected parents reported their children knew the parent had HIV, and 28% of parents with more than one child reported that some but not all of their children knew about their parental HIV status. However, even when mothers of young children have not disclosed, they plan to do so at some point in time. Similarly, Shaffer et al. (2001) found that 68% of children of HIV-infected mothers (age 6 – 11) were not aware of their mother's status, but most of the mothers planned to disclose eventually. However, as noted earlier, mothers find disclosure to their children to be the most

difficult disclosure, and the difficulties they anticipate may frequently be translated into low rates of disclosure to children (e.g., Tompkins et al., 1999).

The age at which children are told by a mother that she is HIV-positive has varied widely, with some studies not reporting age. Kirshenbaum and Nevid (2002) found that on average, children were first disclosed information at age 7. Murphy, Roberts, & Hoffman (2006) also found that among mothers who could recall the exact age their child had been disclosed to, in one sample the mean age of the children at disclosure was 7.25 (median of 8), with a range of approximately 4 – 14; $N = 82$); in a second, smaller, separate sample the mean age of disclosure was 10 (range 5 – 14). In calculations conducted for this review paper, it was determined that in a sample of 90 families, by age 12 – 13, 84% of the children had been informed of their mothers' serostatus.

Findings Related To Disclosure of Parental Illness (non-HIV/AIDS)

Until recently, little was known about family adaptation to maternal illness, especially the impact on school-age children and the parent-child relationship (Issel, Ersek, & Lewis, 1990; Lewis, Hammond, & Woods, 1993). The primary research emphasis has typically been on the patients' adjustment to illness, rather than child or family adjustment (Kotchick, Forehand, Wierson, Armistead, & Klein, 1996; Lewis, 1986). Furthermore, studies prior to 1996 typically obtained children's reports of functioning months or years after the parent's illness diagnosis (Compas, Worsham, Ey, & Howell, 1996), with Compas et al. providing some of the first data on children's functioning near the time of parental illness, linking child efforts to avoid thoughts about parental cancer with greater symptoms of anxiety/depression. In a review of the limited research on children's coping with parental illness (Worsham, Compas, & Ey, 1997), one finding that emerged is that parental illness is associated with psychological distress in children; however, there is considerable variation in adjustment among children, with adolescents reporting higher levels of maladjustment than younger children. In families where a parent has terminal cancer, Siegel et al. (1992) found diminished self-esteem among children. Rait and Lederberg (1989) found increased incidences of psychological symptoms, acting out behaviors, and low self-esteem among children whose parents had cancer, although children who had information about their parent's illness exhibited less anxiety than children who lacked such information. In another sample, children informed that a parent had terminal cancer had significantly lower levels of anxiety than children not informed (Rosenheim & Reicher, 1985). Even within the same family, anxiety of informed children tended to be lower than that of their uninformed siblings. Developmental differences in levels of anxiety were found among uninformed children: pre-adolescents (ages 10 – 12) had higher anxiety than did latency age children (ages 6 – 9). In summary, findings from the cancer literature would suggest that psychological distress may occur among children in these families, although this may be more significant among older children and among children not informed.

Findings Specific to Maternal HIV/AIDS Disclosure

Factors Affecting Maternal Decisions to Disclose

Maternal Illness—Some research indicates that among HIV-positive mothers, maternal health may determine the amount of information disclosed to children, if not the actual disclosure itself. Vallerand et al. (2005) reported that mothers' decision to disclose was dependent on the degree of the mother's illness. Similarly, Lee and Rotheram-Borus (2002) found that disclosure was significantly more common among parents with poor health, although it did not vary according to ethnicity, socioeconomic status, or mental health symptoms. While maternal T-cell count was not related to level of disclosure in one study, it was related to the amount of detailed information conveyed, with a broader range of information disclosed to children among mothers with higher counts (Kirshenbaum & Nevid, 2002), and mothers who reported psychiatric histories generally disclosed more details about

their health condition than those without such histories, as did mothers using drugs. The authors noted that while those mothers may have more experience disclosing personal problems, and being open and honest may reflect philosophies learned in drug treatment and recovery programs, it may also be the case that these mothers may have greater difficulty regulating information or are less able to maintain boundaries. Maternal psychological health influences the impact of maternal illness on children, and child behavioral problems are significantly related to maternal psychological distress (Bauman, Camacho, Silver, Hudis, & Draimin, 2002). Thus, it appears that parental skills, preparedness, and ability to set an appropriate emotional tone in the context of disclosure are especially critical maternal skills among HIV-positive mothers who plan to disclose.

Mothers who are in ill health may also need children to assist them, and disclosure is one way to explain to the child why they need to assist more in the household. However, Murphy et al. (2001) found that among young children household responsibilities increased across time for all children—regardless of whether they were aware of maternal serostatus. It is therefore likely that this was related to normal developmental factors, and not “parentification” of the children due to disclosure and maternal illness.

Child Queries—Mothers may also be influenced by child curiosity and questions asked by the child about the mother's health. The **P**arents **A**nd children **C**oping **T**ogether (PACT) study was designed to longitudinally assess MLWHs and their young, well children (N = 135) age 6 – 11 years of age to investigate child outcomes for children living with a chronically ill mother with a stigmatized disease (e.g., Murphy et al., 2001; Murphy et al., 2006). The study has been conducted over the past nine years, and the children are now transitioning to early and middle adolescence, with the majority of families continuing to be followed (**P**arents and **A**dolescents **C**oping **T**ogether [PACT 2]). In addition, Murphy a qualitative study with mothers in the PACT study who had disclosed and with their children (N = 47) was conducted in which in-depth, open-ended interviews assessed--from both the mother and the child perspective--the content, process, and outcomes of maternal disclosure. At PACT baseline, 34% of the children had been told their mothers were HIV-positive (Murphy et al., 2001). In the majority of disclosures (83%) mothers had personally disclosed to the children. In 17% of cases, children found out from someone else. Regardless of whether mothers had disclosed their illness status, the children were often aware that their mothers were taking medications, and sometimes asked questions about their mothers' health: 92% of the mothers reported that their children were aware they were taking medications. Of those, 39% reported that their children were concerned, worried or anxious about this. About a quarter of the mothers reported their children had asked questions almost every week or more about their health; another quarter reported occasional questions (once a month or more). Mothers who had disclosed reported higher levels of social support in their lives than non-disclosing mothers. Children of disclosing mothers displayed lower levels of aggressiveness (by mother's report), and lower negative self-esteem (by child report), compared to children of non-disclosing mothers. Disclosure was related to both mothers' and children's assessments of closeness to each other at the PACT baseline (Murphy, Greenwell, Mouttapa, Brecht, & Schuster, 2006).

Child Age and Gender—Two findings have been fairly consistent: mothers are less likely to disclose to younger children; and mothers are more likely to disclose to female children (Armistead et al., 1997; Murphy, 1995; Tompkins et al., 1999). For example, in a sample of 301 parents living with their 395 children age 12 to 17 years, results showed that parents were more likely to disclose to older than to younger children, with mothers more likely to disclose earlier than fathers and mothers disclosing more often to their daughters than to their sons (Lee & Rotheram-Borus, 2002). The issue of age at the time of disclosure is interesting, as there is a perception that parental disclosure of HIV serostatus will result in negative outcomes for younger children. However, research indicates this may not be a valid assumption. There

may be poorer outcomes of disclosure for older children: adolescents informed have reported significantly higher levels of depression and emotional distress compared to uninformed adolescents, and higher sexual risk behavior (Armistead et al., 1997; Lee & Rotheram-Borus, 2002; Rotheram-Borus, Draimin, Reid, & Murphy, 1997). Moreover, the negative impact of disclosure on both parents and their adolescent children may persist for a considerable period of time (Lee & Rotheram-Borus, 2002). In younger children, Schrimshaw and Siegel (2002) found that although adverse reactions were reported for some children, most mothers reported that, while emotional at first, children did not experience lasting negative impact, and many reported their relationship with the children became better following disclosure. This is consistent with findings by Murphy et al. (2006), investigating young children's short-term and long-term reactions to maternal disclosure in the PACT study (described earlier). Overall, 51% of the children had no immediate reaction to their mother's HIV disclosure; the average age of children in this group was 7. Some children simply had a limited understanding (e.g., "I knew it was a disease, but I didn't know what it [really] was ..."). Some children understood what HIV/AIDS was, but still did not consider the disclosure to be traumatic (e.g., "I just took it all normal. [I didn't] freak out, 'Oh, mom's dying'"; "[I felt] the same. It could be like asthma, just because you have asthma don't mean you gotta die"). The other 49% of the children expressed an emotional reaction (mean age of this group was 8). These children had a better understanding of HIV/AIDS.

Maternal Fears About Disclosure Outcomes—Mothers who chose not to disclose to their children have been found to be significantly more likely than disclosers to use secrecy as a stigma management tool, and to feel devalued and discriminated against (Letteney & LaPorte, 2004). They may also have negative misperceptions about disclosure. In one sample, mothers reported a significant increase in child behavior problems and a decrease in mother-child relationship quality from pre- to post-disclosure; however, children reported an increase in their understanding of HIV/AIDS, and no significant behavioral changes (Shaffer et al., 2001). It has been suggested this misperception may stem from guilt for bringing HIV into the family, or fear that these reactions will occur. Similarly, in a longitudinal analysis of the relationship of the psychological well being of the children to HIV-positive mothers' disease severity and maternal disclosure (Murphy, Marelich, & Hoffman, 2002a) found that child and maternal reports did not always match. When mothers served as an informant for the child, those who had disclosed reported poorer scores on three child depression subscales than non-disclosing mothers. However, only children who had not been disclosed to reported total depression scores higher than standard means of general samples. It may be that mothers who disclosed initially perceived the children having some psychological distress, but that this was relatively short-lived and had disappeared by the time the children were assessed, but it was salient to MLWHs, who remembered and reported it. Another possibility for the discrepant child and mother reports is that mothers may not be accurately aware of their children's internal moods. Mothers who have not disclosed may assume that their children are doing well, as they believe the children are unaware of any problem. However, previous literature indicates that such children may indeed be aware of a problem, even if they do not know the exact nature of the problem (e.g., Forsyth et al., 1996; Nagler, Adnopo, & Forsyth, 1995; Rosenheim & Reicher, 1985; Wiener & Septimus, 1990). For example, they may be aware through observation that their mother is ill and taking medications.

Maternal Regrets and Advice Regarding Disclosure—Among MLWHs who had disclosed to their young children (Murphy, Roberts, & Hoffman, 2003), the majority of MLWHs (68%) had no regrets about disclosing. However, some mother did have regrets about disclosing and had advice for other MLWHs planning to disclose. The main regret was that they had not planned for the event, but during an emotional time had just blurted out the news to their children. They deemed it crucial to have a plan for what to say in disclosing. In addition,

all forms of education to prepare them (e.g., educating themselves, speaking with health care professionals, and attending conferences) were seen by participants as methods to empower mothers so they felt better able to share appropriately with their children, indicating a need for assistance at this critical time. Most mothers strongly believed that it should be the mother, rather than someone else, who communicates the news, even if they decide to have someone else present at the time of disclosure. Some wished they had known better how (i.e., what language to use) to make sure their child understood and wasn't afraid. Many MLWHs felt having support available for children if necessary was important.

Characteristics of Children Aware and Unaware of Maternal HIV/AIDS status

Short and Long-term Child Reactions to Disclosure—Armistead and colleagues (2001) found that mothers perceived children as demonstrating a variety of reactions to disclosure, with approximately half reacting in a positive manner, and about 40% reacting negatively. However, Armistead and Forehand (1995) noted that a child may have short-term reactions of depression, anxiety, or anger in response to disclosure, but that long-term effects could be different. This is consistent with findings by Murphy et al. (2006) in a qualitative study conducted with mothers in the PACT study (described earlier) who had disclosed and with their children. Most commonly, children were upset immediately following the disclosure, evidenced by psychological distress. For example, many cried (e.g., “I looked at the frown on her face and then all of a sudden I see these tears coming”: “Suddenly I hear a sobbing noise ... he was in pain”). Anxiety seemed to be the main reaction, with children expressing concern about their MLWH's health and how long she would live (e.g., “She ... said ‘Oh-oh, is that the same thing daddy had? Are you going to die like daddy?’”). And some children tried to reassure their mother (“Mommy, you are going to live a long time. You are going to see us get bigger. You are going to see your grandchildren.”) Approximately one-third of the children (34%) brought up the subject of their MLWH's death. About two-thirds (63%) of the children were surprised at the news, but 32% reported they guessed something was wrong (e.g., “She was always feeling sick, like tired.”; “I already knew ... I could tell by the meetings that she go to.”).

For long-term reactions, approximately half the children were not worried over time. However, 49% continued to express some worry longitudinally, typically expressed as concern about whether their mother feels o.k. and worry when she is ill. In families where the mothers enjoyed good health, children worried less often. Over one-third also reported fear of “catching” HIV. A few children ($n = 7$) showed acting out behavior, which ranged from mild to more severe, from arguing with their mothers to getting into trouble at school. The most maladaptive responses exhibited were regressive-type behaviors (e.g., wanting to sleep with mom all the time after a long period of having slept on their own, starting to wet the bed again), occurring among a few children. It is possible that some negative reactions may be due to inappropriate disclosure, as some of the MLWHs admitted that they handled the disclosure poorly (see Murphy et al., 2003).

All of the published PACT disclosure papers of quantitative data were primarily based on retrospective data (i.e., many MLWHs had disclosed prior to baseline, so there was no data on many children prior to the disclosure occurring). However, a number of children were disclosed to during the course of the study. For this review paper, an analysis of depression and anxiety scores for PACT children, before, during, and after disclosure for those who were unaware of their MLWHs' serostatus at baseline and who were disclosed to at any of the follow-up points thus far ($N = 37$) was conducted. Children showed significant improvement on the mental health variables at the assessment following disclosure (which gave them time to adjust potentially, if they were immediately distressed by the disclosure). Children had significantly lower total Child Depression Inventory scores ($p = .03$), including trends or significant

differences for the negative mood ($p = .08$), Interpersonal Problems ($p = .04$), and Anhedonia ($p = .02$) subscales. They also showed trends for lower anxiety (Reynolds physical anxiety subscale $p = .07$, and worry/oversensitivity subscale $p = .08$).

From these studies, it is apparent that the most of children adjusted over time, but a small percentage did have maladaptive reactions that were sustained. When the children were asked if they wished their mother had not disclosed to them (Murphy et al., 2006), the majority responded negatively—they were glad they were told. Contrary to previous speculation, these mothers did not report high rates of acting out behavior among the children, and among those who did, few attributed it to their disclosure. Since the children are going through normal childhood development stages (e.g., increasing association with peers and influence by peer norms, individuation from their parents) the mothers may be correct that these behaviors are not related to disclosure. However, clinical implications from this study indicate that some families may need follow-up referrals following disclosure. In summary, while children of MLWHs can be distressed by disclosure, the majority of young children adjust well at the time of disclosure, or later over time following the disclosure. Children who react negatively may in part be responding to the fact that their MLWH handled the disclosure poorly (e.g., did not plan, did not know what to say, were over-emotional [angry or upset]), according to MLWH report. MLWHs wanted more preparation for this important family process. In addition, a small number of children react maladaptively, and this reaction is sustained. These children may need support following disclosure, ranging from MLWH's being able to help provide basic coping strategies, to referral for professional support in some cases.

Factors Influencing Children's Reactions to Maternal Disclosure

Cognitive Development

A number of factors may influence children's reactions to maternal disclosure. One of the most important is that young children's reactions are influenced by their understanding of HIV/AIDS, which in turn may partially reflect their level of cognitive development. Understanding of illness, health, and death varies with age (Perrin & Gerrity, 1981; Natapoff, 1982; Lansdown & Benjamin, 1985). Kindergarten age children see illness as stemming from a concrete action that was or was not done, and define illness only when s/he is told or sees external signs (e.g., "You have to stay in bed"); however, children can discuss concepts (for example, of death, even though they do not fully understand its meaning and finality). By approximately age 9, a developmental shift occurs and children can differentiate internal and external phenomena; they can also understand finality of death. At this age, children typically define illness as a set of symptoms, and believe it is important to take medication and follow the doctor's orders. Finally, by age 12 or 13, children have a broader conception, and can comprehend multiple causes of illness, and that bodies respond variably. Understanding of AIDS follows a similar developmental progression (Osborne, Kistner, & Helgemo, 1993). Children as young as 6 are aware of AIDS (Sly, Eberstein, Quadagno, & Kistner, 1992), and in grades 1 through 6 express fear and misconceptions related to transmission (Fassler, McQueen, Duncan, & Copeland, 1990; Osborne et al., 1993). By grades 4 and 5, children recognize that they cannot contract HIV simply by being near someone infected (Osborne et al.). Since developmental factors may influence how children respond, it is key that mothers have some awareness of their children's understanding of illness and health behaviors, and that the disclosure be developmentally appropriate for the age the child in terms of the wording and level of information provided. It also follows that basic transmission information, such as the fact that casual contact does not transmit HIV, would need to be given at the time of disclosure.

Perceived Stigma

Stigma and how it impacts children affected by AIDS has begun to be investigated. The relationship of maternal perception of stigma and rates of maternal disclosure to children age 5 to 18 years was investigated, with level of perceived stigma not found to influence disclosure (Ostrom, Serovich, Lim, & Mason, 2006). Bauman et al. (2002) found that child behavior problems among children affected by maternal HIV/AIDS were not related to stigma. Perhaps the most important issue related to stigma for a disclosure intervention is that children told to keep a parental HIV diagnosis a secret exhibit more behavior problems than those children who are not told to keep it a secret (Kirshenbaum & Nevid, 2002). Murphy, Roberts, & Hoffman (2002) conducted in-depth, qualitative interviews with HIV-positive mothers and with their well children age 6–11 to whom their mothers had disclosed her serostatus, in order to ascertain their perceived stigma levels. The majority of the PACT mothers (77%) who disclosed explicitly told their child not to tell other people. Only 23% of the MLWHs identified “safe people” with whom their child could talk. The majority of children respected their mothers' wishes; only four children disclosed to someone after being told not to do so. Surprisingly, even children this young were very aware of the stigma by association that may occur, and were concerned about other people finding out for two reasons: self-protection (i.e., worry that their own identity would be tainted if others found out); and because they wanted to protect their mother (fear people would think badly of her). Many children thought their friends would assume they were also infected if they were to find out. The burden of keeping the disclosure a secret may cause stress to children. Moreover, some children who said they were worried a lot since the disclosure did not want to talk with their mother about their concerns. The clinical implications from this study are that mothers may want to help the child with a list of safe people in whom they can confide when they have concerns or questions. If there are few support people in the family's life, MLWHs may need assistance in exploring the idea of accessing professional support, and assistance in identifying such resources.

Finally, perceived stigma directed at the mother may be detrimental for children. Murphy, Austin, & Greenwell (in press) found that early and middle adolescent age children who perceived high levels such stigma were more likely to participate in delinquent behavior, compared to those reporting low HIV-related stigma.

Flannery and Rotheram-Borus (2006) have identified three pathways that organize the personal choices made by mothers living with HIV: to tell no one, to tell some and not others, or to tell everyone. The mother's choice of a major pathway significantly impacts the type of challenge that the children experience. For example, children in families in which the mother is very public about their status are more likely to experience stigma than children whose HIV connection is unknown. When parents have told some of their friends and family, but not their children, the parent risks the child finding out from other sources.

Child Coping and Problem-solving Skills

There is substantial empirical evidence that problem solving, coping, and self-valuing are important for child adjustment (Spivack, Platt & Shure, 1976; Shure & Spivack, 1987; Shure, 1988). Older children are more likely to use cognitive strategies (Spirito, Stark, Grace, & Stamoulis, 1991), and female youth report using social support more frequently than males (Stark, Spirito, Williams, & Guevremont, 1989). Avoidant coping is associated with poorer adjustment (Kotchick et al., 1996). Compas et al. (1996) found children's avoidance of thoughts about parental cancer was related to greater symptoms of anxiety-depression. Very little work has been conducted thus far in the area of interventions to assist young children's coping with maternal disclosure of HIV-serostatus, although some of the studies reviewed thus far would indicate that some children do need such strategies.

Disclosure as a Process & Final Summary

There are potential risks and benefits associated with disclosure. As noted by DeMatteo et al. (2002), disclosure to children takes place within historical and social contexts that include current knowledge of HIV, belief systems, parent-child relationships, family dynamics, and interactions with health care systems. Disclosure is a dynamic process. Explanations about what is happening around physical symptoms and general education about HIV and AIDS can be the first steps, and are likely to be just as important as full disclosure of status. Additionally, children's informational needs are likely to change relative to their developmental stage. Although disclosure of parental HIV status is an ongoing family process, this process does not always include the level of parental preparation or anxiety that researchers may anticipate, with some disclosures being spontaneous, unplanned, or pressured (DeMatteo et al., 2002). Murphy et al., (2003) has found that mothers often regret these types of unprepared disclosures.

Positive aspects of disclosure from mother child dyads have been found to include open, honest communication, and closer relationships between mothers and their children (Vallerand et al., 2005). Pilowsky et al. (2000) recommended that disclosure is an area in which a proactive stance may prevent serious problems, but that a plan needs to be developed with the family, driven by the family's comfort level, child inquiries, and anticipation of situations in which child knowledge of maternal serostatus would be important. Appropriate disclosure may enable children to deal positively with maternal illness. Simoni, Davis, Drossman, and Weinberg (2000) suggest that although maternal disclosure involves some risk of negative consequences, ultimately it may lead to improved child outcomes. Open discussions about HIV illness have been shown in some studies to lead to more fulfilling family relationships (e.g., Brown & Powell-Cope, 1993), and child confusion or misperceptions about their mother's health are likely to continue if such discussions do not occur (Siegel & Gorey, 1994).

Moreover, nondisclosure is no guarantee of positive outcomes for children. Among families in which mothers have chosen not to disclose to their younger children, previous research indicates that psychological distress may be apparent in the child due to guilt they feel for a disordered family environment whose source they cannot identify (Wiener & Septimus, 1990), and they may show elevated levels of anxiety (Forsyth et al., 1996; Murphy, Kaufman, & Swendeman, 1998; Siegel et al., 1992). Children who found out their mothers' HIV serostatus, but had not previously been told, frequently report they knew something was wrong but felt unable to ask about the cause (Nagler et al., 1995).

Research by Murphy et al (2001; 2002a) indicates that children aware of their mother's HIV status are for the most part doing well compared to children unaware of their mothers' status. Noted throughout this review paper, research has been presented that indicate support and safety of disclosure to young school-age children: (1) clinicians advising parents to disclose (Armistead & Forehand, 1995; Zayas & Romano, 1994); (2) MLWHs who have disclosed reporting significantly lower levels of depression (Wiener et al., 1998), and having stronger family cohesion following disclosure; and (3) MLWHs reporting that their children are emotional at first, but exhibiting no lasting negative impact, and disclosure resulting in improved parent-child relationships (Schrimshaw & Seigel, 2002). Findings earlier from the cancer literature support these findings: (1) younger children disclosed to had lower levels of maladjustment than adolescents (Worsham et al., 1997); and (2) lower levels of anxiety were found among children informed by their parents (Rosenheim & Reicher, 1985) than uninformed children. However, findings from these and other evaluations of disclosure outcomes are complex, and sometimes counter-intuitive, such as indications that older children may experience more ill effects of disclosure than younger children. In addition, even among younger children, a small number may evidence sustained, maladaptive responses to maternal disclosure, indicating a need for professional referral for therapy (Murphy et al., 2006),

although the majority of children seem to adjust well over time. However, it should be noted that we know little if anything about whether child reactions to disclosure differ if fathers disclose their serostatus. Women are most often the caregivers in these families (Bor & duPlessis, 1997; Wiener et al., 1998) and thus almost all of the information available comes from families in this type of constellation.

Maternal factors also seem to influence disclosure, and these have been covered in this review paper. Moreover, it is clear that it is a difficult process for mothers, resulting in anxiety in planning for the disclosure, and in some trauma, which may be avoided or lessened by assisting MLWHs through this process. Few interventions, other than for prevention or medication adherence, are available for women living with HIV. There is a need to develop, test, and evaluate interventions that would assist HIV-positive mothers deal with this serious family issue. Two projects that are currently just now beginning may address some of these issues. One new program, "The Aunties," is a self-directed disclosure intervention for African-American women living with HIV. Based on an adaptation of a family, evidence-based intervention (e.g., Rotheram-Borus et al., 2001; 2004, 2006), the program adopts the perspective that women choose a disclosure pathway to tell everyone, some people, or no one. Through role model stories presented on a DVD, African-American women are encouraged to make personal choices regarding their pathway and to develop skills to proactively cope with situations that offer the opportunity for disclosure. It is self-directed in that a work-book, a planner with inspirational readings, a children's book, and a DVD version of the workbook are available to support the woman's disclosure pathway (Flannery, personal communication). The results of a randomized controlled trial should be available in the next year. A second new project is also being developed. Murphy is beginning a newly NIH-funded study of a brief, individual, cognitive-behavioral intervention to assist HIV-positive mothers disclose to their well, young children. The three-session individual intervention will assist mothers living with HIV/AIDS to: (1) explore concerns about and barriers to disclosure to their children, including whether the child is developmentally ready and if the mother is ready; (2) prepare them for disclosure by teaching about strengthening family routines and parent-child communication; (3) provide them with advice from HIV-positive mothers who have disclosed; (4) prepare them for the questions the children are likely to have when the disclosure occurs; (5) prepare them to discuss the disclosure at a developmentally appropriate level for the age of their child; and (6) provide them with behavioral practice for the disclosure. Hopefully, these projects and others will result in efficacious interventions that will be disseminated for widespread use. More needs to be known about the interaction of characteristics and circumstances of the mother and child, and the impact of disclosure needs to be evaluated in the context of developmental level, degrees of disclosure, and access to and utilization of support services.

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Table 1
Studies on Estimates of Maternal HIV-status Disclosure to Young Children

Source	Sample Location Setting Sample Size	% Fathers Ethnicity	Inclusion Criteria	% Not Disclosed
Armistead et al., 1997	United States	100% Fathers	Families in which the father has a hemophilia diagnosis and HIV infection; married or had lived with female partner for at least 2 years; at least 1 biological child between 3 and 18 years of age.	55%
	Hemophilia Treatment Centers (17) N = 67 families	11% AA N/R LAT 81% WH		
Armistead et al., 1999	New Orleans, Louisiana	0% Fathers	Women between 18 to 50 years old; had at least one biological child between the ages of 6 and 11 who was not HIV-infected; did not report having used intravenous drugs within the 6 months prior to the first assessment; at least one CD4 count under 600.	72%
	HIV Clinic & private physician offices N = 100	100% AA 0% LAT 0% WH		
Armistead et al., 2001	New Orleans, Louisiana	0% Fathers	Women with at least one biological child between the ages of 6 and 11 at the first assessment who was not HIV-infected; reported no intravenous drugs within the 6 months prior to the first assessment; at least one CD4 count under 600.	82%
	HIV Clinic & private physician offices N = 87	100% AA 0% LAT 0% WH		
Forsyth et al., 1996	Yale-New Haven Hospital, Connecticut	3% Fathers	HIV-infected parents with a child between 6 and 16 years of age.	54%
	HIV clinics and primary care centers N = 26	N/R AA N/R LAT N/R WH		
Murphy et al., 2001	Los Angeles County, California	0% Fathers	Women with AIDS diagnosis or HIV-symptomatic status; well child age 6–11; English or Spanish speaking.	70%
	Primary care sites & AIDS service organizations N = 135	39% AA 26 LAT 21% WH		
Niebuhr et al., 1994	Galveston, Texas	59% Fathers	HIV-infected parents with at least one child age < 1 – 48; registered patient of a University HIV/AIDS clinic.	34%
	University HIV/AIDS clinic N = 77	18% AA 5% LAT 76% WHI		
Schrimshaw et al., 2002	New York, NY	0% Fathers	Women who had tested seropositive for HIV antibodies or diagnosed with AIDS with at least one child age < 1 – 25; resided in the New York City metropolitan region; 20–45 years of age; if Hispanic, were Puerto Rican and had resided on the U.S. mainland for at least 4 years, or if African American or White, were U.S. born and non-Hispanic; had completed eighth grade; had not injected drugs in the past six months.	34%

Source	Sample Location Setting Sample Size	% Fathers Ethnicity	Inclusion Criteria	% Not Disclosed
	AIDS service organizations N = 45	33% AA 33% LAT 33% WHI		
Shaffer et al., 2001	New Orleans, Louisiana	0% Fathers	Women between 18–45 years old; reside with target child who was 6 –11 years old at time of recruitment; confirmed medical diagnosis of HIV with T-cell counts of 600 or less; no intravenous drug use within the past year.	68%
	HIV/AIDS public health clinic N = 99	100% AA 0% LAT 0% WHI		
Corona et al, 2006	United States	71% Fathers	HIV-infected person 18 years old or older; at least one visit to a nonmilitary, nonprison medical provider other than an emergency department in the contiguous United States during the first 2 months of 1996; custody of at least one child at follow-up.	66%
	HCSUS Study Participant N = 274	51% AA 19% LAT 30% WHI		

Note. AA = African-American. LAT = Latino/Hispanic. WHI = White.