# REASONS GIVEN FOR DISCLOSURE OF MATERNAL HIV STATUS TO CHILDREN

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**ABSTRACT** The purpose of this investigation was to ascertain the reasons given by mothers diagnosed with AIDS (acquired immunodeficiency syndrome) for disclosing or not disclosing their HIV (human immunodeficiency virus) status to their children, a dilemma faced by most HIV-infected parents and those who counsel them. We interviewed 29 mothers residing in one of two New York City facilities that provide housing and medical treatment for adults with AIDS. The majority of these mothers do not live with their children, but all had recent face-to-face contact with them. The two reasons most frequently considered important for disclosing to children were that disclosure was the "right thing to do" and the need to make arrangements for children's future in case of maternal death or incapacity. The reason most frequently considered important for not disclosing was maternal concern about discussing death and dying with children. These findings have significant implications for counseling of HIV-positive parents.

**KEY WORDS** Child welfare, Children, Disclosure, HIV, Mothers.

In this study, we examined the reasons given by mothers diagnosed with AIDS (acquired immunodeficiency syndrome) for disclosing or not disclosing their HIV (human immunodeficiency virus) status to their children. Although the literature about disclosure of HIV status has developed gradually in recent years, most of the research on disclosure has focused on disclosure by gay men, by counselors who provide HIV test results, and by infected health care profession-

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als, and on disclosure to HIV-infected children. Given the growing number of HIV-infected women of child-bearing age, it is surprising that there has been little empirically based research focusing on parental disclosure of HIV serostatus to children.[1,2]

The few studies that assessed the reasons parents disclose their HIV status to their children suggest that disclosure generally is related to their desire to protect their relationship with their children, to prepare children to face parental death, to provide accurate information to children who "knew that something was wrong" or who inadvertently found out from other sources, to avoid the stress and emotional pain often associated with hiding an illness, and because of parental opposition to family secrets.[3–6] These studies suggest that parents give multiple reasons for not disclosing to children, including their conviction that children are unable to grasp the meaning of the information, fear of harming children (because of the stress, stigma, or loss of custody), and reluctance to talk to children about the behaviors that exposed them to HIV infection (e.g., unprotected sex with multiple partners or injection drug use).[1,3,4–7] Nondisclosure to children might also allow mothers to avoid facing the consequences of their illness, including their own mortality.[8] However, much of this research precedes the use of protease inhibitors for treating HIV disease. Since the prognosis is improved greatly for patients who use protease inhibitors, the decision-making processes underlying disclosure might have changed. In addition, it is likely that a parent's decision to disclose to children is not influenced by just one factor, but by myriad factors. To understand the decision-making process of parents with HIV, it is useful to be aware of all the factors that might influence their decision. However, to counsel such parents successfully, it is also important to know which factors are considered most frequently by parents and which are deemed most important. Thus far, investigators have reported on reasons parents give for disclosure,[5,6,9,10] but few have ascertained which reasons are given more frequently or are considered more important by infected parents.

Thus, the current investigation aimed to fill a gap in the literature by ascertaining the frequency of reasons given for parental disclosure, and the importance attributed to each reason, using a semistructured interview with established reliability. In addition, we focused on inner-city mothers living in community residences for people with AIDS, a group that has received little attention from investigators. These are among the poorest and most disenfranchised AIDS-afflicted women.

While most of the women in these community residences do not live with their children, a few do; among the 29 mothers we surveyed, there were 6

coresident mothers, each living with one of their children. Of children in this sample, 8% (6 of 79) were living with their mothers. Typically, coresident mothers were living with the youngest of their children. Mothers who were not living with their children often remained in contact with them. Thus, we interviewed a series of mothers living in two such residences in New York City who lived with their children or had recent contact with them and asked these mothers to discuss their reasons for telling their children about their HIV infection or for not doing so.

## METHODS

### Subjects

Women who were living in one of two community residences for adults with AIDS were invited to participate in a reliability study of the Parent Disclosure Interview (PDI).[11] Eligibility criteria for that study were as follows: being a female resident of one of the two target facilities, having at least one child aged 4 years or older, and having had face-to-face contact with their child/children in the preceding month. At the two facilities, 32 eligible women were invited to participate in the study, and 29 (91%) women signed an informed consent form and completed the study. The present analysis is based on data collected for that reliability study.

### Instruments

Subjects were interviewed by trained research interviewers using the PDI, a semistructured assessment designed for use with HIV-infected parents. A detailed description of the interview and reliability data have been reported elsewhere.[11] Briefly, the PDI was designed to inquire about disclosure to partners or spouses, adults in the community, relatives, and children aged 4 years and older. Separate questions address disclosure to adult children (i.e., those over the age of 18 years). Finally, there is a brief section dealing with plans for children's futures.

Mothers were asked to report whether they had disclosed their HIV status to any of their children aged 4 years and older. Mothers who reported they disclosed to any of their children were then asked a series of questions about their reasons for disclosure. Mothers who reported they chose not to disclose to any of their children were asked about their reasons for nondisclosure. Mothers who reported they disclosed to some, but not all, of their children were asked both series of questions.

Both series of questions started with an open-ended question ("Please tell

me your reasons for telling/not telling your child/children about your HIV infection"). Then, a list of reasons was provided, and mothers were asked to rate how important each reason was using a 4-point Likert scale format (very important, important, a little important, and not important).

### Data analysis

Data are presented as number and percentages of subjects who considered each reason for disclosure/nondisclosure important or very important. Two of the mothers who did not disclose their HIV status to any of their children failed to answer questions regarding the reasons for nondisclosure and therefore were excluded from that part of our analysis.

## RESULTS

### Description of the Sample

Table I shows the demographic characteristics of the 29 women in this sample, and their children. These women were predominantly single, African-American or Latina women, ranging in age from 24 to 47 years (mean = 36, SD = 5.8). All of the women were diagnosed with AIDS; most (N = 25, 86%) had learned about their HIV-positive status 2 or more years prior to the interview. The women varied with regard to their perceptions of their current health: 11 women (37.9%) reported excellent or very good health, 10 (34.5%) reported good health, and 8 (27.6%) reported fair or poor health. Disclosures of maternal HIV status according to the mothers' perception of their health status are shown in Table II. Of the 11 mothers who perceived their health as excellent or very good, 7 (63.6%) did not disclose their HIV status to any of their children; by contrast, among the 8 mothers who perceived their health status as fair or poor, 4 (50%) did not disclose their HIV status to any of their children. Participating mothers also varied on a more objective measure of current health status, the number of times hospitalized in the past year: 8 (27.6%) women were not hospitalized at all, 10 (34.5%) were hospitalized just once, and 11 (37.9%) were hospitalized two or more times in the past 12 months.

Each woman was the mother of between one and six children. There were a total of 79 children, 44 boys and 35 girls, whose ages ranged from 2 weeks to 17 years (mean age = 8.5 years, SD = 4.9). The total number of children aged 4 years and older was 64. All results reported below refer to these 64 children. Among these children, 2 (3.1%) lived with their mothers, 36 (56.3%) lived with relatives, 21 (32.8%) lived in foster care, and the remaining 5 (7.8%) lived elsewhere.

**TABLE I** Demographic Characteristics of Mothers (N = 29) with AIDS and Their Children, New York City, 1997

| | |
|---|---|
| Age range, years | |
| <35 | 13 (45%) |
| 35 and older | 16 (55%) |
| Ethnicity/race | |
| African-American | 21 (72%) |
| Latina | 7 (24%) |
| White | 1 (3%) |
| Marital status | |
| Single | 18 (62%) |
| Married | 1 (3%) |
| Widowed | 2 (7%) |
| Divorced/separated | 8 (28%) |
| Largest source of income | |
| SSI | 25 (86%) |
| Welfare | 1 (3%) |
| No legal source | 3 (10%) |
| Number of children in family | |
| 1 | 4 (14%) |
| 2 | 11 (38%) |
| 3–6 | 14 (48%) |
| Age range of children | |
| Infant: 2 weeks–3 years | 15 (19%) |
| Preschool: 4–5 years | 9 (11%) |
| School age: 6–11 years | 31 (39%) |
| Adolescent: 12–17 years | 24 (30%) |

**TABLE II** Disclosure of Maternal HIV Status According to Maternal Perception of Health Status, New York City, 1997 (N = 29 mothers)

| | Maternal Perception of Health Status* | | |
|---|---|---|---|
| Disclosure Status | Excellent/Very Good, N (%) | Good, N (%) | Fair/Poor, N (%) |
| Mothers who disclosed to all children (N = 5) | 2 (18.2) | 2 (20.0) | 1 (12.5) |
| Mothers who disclosed to some children (N = 7) | 2 (18.2) | 2 (20.0) | 3 (37.5) |
| Mothers who did not disclose to children (N = 17) | 7 (63.6) | 6 (60.0) | 4 (50) |

*Mothers' response to the following question: Please rate your health. Would you say your health is excellent, very good, good, fair, or poor?

### Disclosure

Of the 29 mothers, 17 did not tell any of their children; 5 mothers told all of their children; and 7 mothers told some, but not all, of their children about their HIV status. Three mothers reported that although they did not disclose to their children, their children had found out about their HIV status.

We inquired about disclosure among children aged 4 years and older. Among these children, the youngest target of maternal disclosure was a 6-year-old child. As shown in Table III, disclosure was more frequent when children were older. None of the 9 children of preschool age (4–5 years) were told; 5 (31.2%) of the school-aged children (6–11 years) and 11 (68.8%) adolescents (12–17 years) were told.

There was an association between disclosure and plans for children's future. All 5 mothers who disclosed their HIV status to all their children reported they had asked somebody to make a commitment to take care of their children in case of death or incapacity. Among the mothers who disclosed to some and to none of their children, 71% (5 of 7) and 65% (11 of 17), respectively, reported having made such plans (data not shown).

### Reasons for Disclosure

As mentioned above, 5 mothers told all of their children, and 7 mothers told some, but not all, of their children about their HIV status. Thus, 12 mothers disclosed to at least 1 child. These 12 mothers were given a list of reasons for disclosing their HIV status to their children and were asked how important each reason was. The two reasons most frequently considered important or very important were that disclosure was "the right thing to do" and that disclosure

**TABLE III** Disclosure of Maternal HIV Status to Children Aged 4 Years and Older According to Children's Ages, New York City, 1997 (N = 64 children)

| Children's Age, Years | Children Not Told,* N (%) | Children Told,† N (%) |
|---|---|---|
| 4–5 | 9 (18.8) | 0 |
| 6–11 | 26 (54.2) | 5 (31.2) |
| 12–17 | 13 (27.1) | 11 (68.8) |

*N = 48; there were 48 children aged 4 years and older who were not told about their mothers' HIV status.

†N = 16; there were 16 children aged 4 years and older who were told about their mothers' HIV status.

was a preliminary step toward making arrangements for the child's future in case of maternal incapacity or death (see Table IV).

We also asked an open-ended question about mothers' reasons for revealing their HIV status to their children. The most common reason, given by 6 women in response to this question, was that the child "needs to know," "should know," or "has the right to know" about the parent's illness. Three women stated that their declining health or physical appearance fueled the disclosure. Three other reasons were each mentioned by 1 or 2 parents. These reasons were that children would benefit from this knowledge, to help children understand what the parent is going through, and to prepare children for an eventual change in their living situation.

#### Reasons for Nondisclosure

As mentioned above, 17 mothers refrained from disclosing their HIV status to any of their children, and 7 mothers told some, but not all, of their children. Thus, 24 mothers refrained from disclosing to at least 1 child. These 24 mothers were given a list of reasons for not disclosing their HIV status to their children and were asked how important each reason was. The three reasons most frequently considered important or very important were maternal concern regarding talking to children about death and dying; indications that children may not understand what they are told; and a desire to protect children from painful worries (see Table V).

We also asked an open-ended question about mothers' reasons for not revealing their HIV status to their children. The most common response, given by 12 women, to this question was that the child was too young to understand or deal with the information. Three mothers stated that they did not disclose because

**TABLE IV** Reasons Given by Mothers for Telling Child (Children) About Their HIV Status, New York City, 1997 (N = 12)*

| Reason Given | Number of Mothers Who Stated that Reason Was "Important" or "Very Important," N (%) |
|---|---|
| Right thing to do | 12 (100%) |
| To make arrangements for child's future in case of maternal incapacity or death | 11 (92%) |
| Child already found out | 9 (75%) |
| Child will find out sooner or later | 9 (75%) |
| Mother can't bear to keep secrets | 7 (58%) |

*These are the 12 mothers who told at least one child about their HIV status.

**TABLE V** Reasons Given by Mothers for Not Telling Child (Children) About Their HIV Status, New York City, 1997 (N = 22)*

| Reasons Given | Number of Mothers Who Stated that Reason Was "Important" or "Very Important," N (%) |
|---|---|
| Concerned regarding talking to child/children about death and dying | 17 (77%) |
| Child may not understand | 16 (73%) |
| Don't want child to worry | 17 (77%) |
| Child may ask how mother got infected | 10 (45%) |
| Child may tell others | 9 (41%) |
| Child won't care about mother any more | 8 (36%) |

*These data are available for 22 of the 24 mothers who did not tell at least one child about their HIV status.

they were not living with their children. Three mothers wanted to spare the child from being worried or scared. Three mothers felt it was not the "right time" for disclosure. Each of the two remaining reasons were given by 1 or 2 parents. These reasons were not knowing how to tell the children and feeling "scared" to do it.

## DISCUSSION

More than half (17; 59%) of the mothers had not revealed to any of their children aged 4 years and older that they were HIV positive. Studies focusing on adolescents have reported higher rates (74%) of parental disclosure.[2] A study that included younger children, between 3 and 18 years of age, revealed a lower disclosure rate (45%).[1] Thus, given the ages of the children in our study, and considering that most children were not living with their mothers, the disclosure rate is consistent with other reports.

We were not able to ascertain whether coresidence (children living with their mothers) influenced disclosure. In this sample, mothers only disclosed to their children over the age of 6 years, and the majority of the children who lived with their mothers were under the age of 6 years (4 of 6 coresident children).

Clearly, mothers' perception of their own health status and the age of their children had an impact on the decision to disclose. Mothers seem to have made disclosure decisions implicitly or explicitly in the context of the child's developmental stage. They did not disclose to any preschoolers and disclosed to some school-aged children and to most adolescents. A similar pattern has been described in other populations of HIV-infected parents.[1,2] In response to both the open-ended and the structured questions regarding reasons for not disclosing

their HIV status to their children, mothers frequently mentioned that the child was too young to understand or deal with the information. For example, a mother said, "(Initially) didn't think he would understand. When he was older, it didn't enter my mind."

In response to both the open-ended and the structured questions, the most common reason mothers gave for disclosing their HIV status to their children was that children have the right to know or need to know. A sense of duty, based on ethical concerns, sometimes blended with pragmatism (e.g., one women added "besides I couldn't hide it") was the prevailing reason given for disclosure to children. For example, a mother said, "She noticed I was changing and I thought she had the right to know." Another said, "They needed to know what was going on. I wanted to be the one to tell them."

A concern that was deemed important or very important by most mothers in response to a structured question (i.e., talking to one's child/children about death and dying) was mentioned only by a single mother in response to the pertinent open-ended question. However, it is likely that this concern may have been too painful to verbalize, even though it was a significant concern; when women were asked to rate the importance of this concern in their decision-making process, most acknowledged its importance. This issue was highly relevant to women in this sample as their illness was advanced in most cases, and they could have learned only recently about the success of treatments that use protease inhibitors in combination with other antiviral drugs. Initially, the new and hope-enhancing medication discoveries might have left these women bewildered. After being told that their life was likely to end soon, they learned that it might not be the case. In addition, not living with one's children might render such discussions even more painful as a result of the shame and guilt related to having placed their children or having had them removed from their care. Most mothers were not living with their children because they had been removed from their care following allegations of child neglect. Anecdotal information suggests that these allegations surfaced when these mothers were using illicit drugs.

A third common concern was the desire not to cause worry or scare one's children. For example, a mother said, "(My children) have enough in their minds. I don't want to give them more worries." Similarly, in the above-mentioned study of disclosure to HIV-infected children,[12] fear of worrying children and a belief that children will not understand what they are told were the two most common reasons for nondisclosure.

Even though detailed descriptions of the many reasons given for disclosure and nondisclosure of parental HIV status to children are found in the litera-

ture,[5,7,9,13] to the best of our knowledge no published studies have provided data regarding which reasons are given more frequently or considered most important by HIV-infected parents. However, Wiener et al.[12] provided data, based on interviews with 17 families, regarding reasons most frequently given by parents for disclosure/nondisclosure of the child's HIV status to HIV-infected children. They showed that opposition to family secrets and the child's "right to know" were the two most common reasons for disclosure. The belief that disclosure of parental HIV status is the right thing to do, as we report in the current study, parallels the belief that the child has the right to know his/her own diagnosis. The children in the study of Wiener et al. were predominantly Caucasian. Thus, some essential beliefs regarding what children are entitled to know might be shared among families of varied ethnic origins in the US.

This study has several limitations. First, the sample was limited to 29 mothers from a specific population of disadvantaged mothers with AIDS, most of whom did not live with their children. This group has received limited attention from researchers, even though there is an increasing number of children of impoverished, AIDS-diagnosed, predominantly African-American and Latino women living in foster care or relative placement.[14] Nevertheless, we mention it as a study limitation because it limits the generalizability of our findings to this specific population. In addition, we did not attempt to include HIV-infected fathers in this study. Thus, until replications are available, we will not know whether the results reported here apply to populations of women with a higher level of social integration, to HIV-afflicted mothers who do not yet have AIDS, to women with AIDS who live with their children, and to fathers. Finally, information about the wishes of the children's current guardians and their impact on disclosure decisions is lacking.

Future research needs to address disclosure issues in the context of the complex interaction among AIDS-diagnosed mothers who do not live with their children, the children's guardians, and the developmental stage of the children. Such research may generate policy guidelines that child welfare professionals sorely need.

## CLINICAL AND PUBLIC HEALTH IMPLICATIONS

The results reported here have important implications for counseling of HIV-positive parents in this population. The need to make arrangements for the child's future was cited often by mothers as a reason for telling children about their HIV status. Nevertheless, only 66% (data not shown) reported having made arrangements, and only 24% reported having legally formalized them. These

data may indicate that parents gave a socially desirable response to this question. Alternatively, it may indicate that they experience the need to make appropriate arrangements, but find it difficult to do them. They seem to be in need of emotional and legal assistance if formal arrangements are to be made.

Concern about discussing death and dying and about children's ability to understand an AIDS diagnosis were frequently cited reasons for nondisclosure. Helping severely ill AIDS-diagnosed parents discuss death and dying, as well as assisting them in describing and explaining their illness to their children, may be helpful to both parents and children. Specifically, parents may benefit from guidance regarding the cognitive, emotional, and developmental considerations that impinge on children's ability to understand and cope with disclosure of parental illness. A consideration of the potential benefits and risks involved in disclosing to children and to adolescents is also relevant.[2]

Given the frequent concern about children's ability to "understand" information that is imparted to them, clinicians may help parents by educating them regarding children's cognitive development and their understanding of illness, causality, and prognosis at different developmental stages. Also, symptomatic parents who do not want to "worry" their children may benefit from understanding that it may be more anxiety provoking for a child to witness a parent's declining health while receiving evasive answers to their questions than learning about the parent's illness. Finally, it is important for clinicians to understand that disclosure to children is often a process, rather than an event. This process may start with an acknowledgement of parental illness, followed by references to "a virus," leading to full disclosure. The timing of this process should be determined by parents, with input from their families, counselors, and therapists. Parents who perceive respect for their own timetable are better able to establish rapport with professionals than those who do not.

As new treatments have become available, HIV-related illnesses have become chronic illnesses; thus, parents are living with their illness for many years and with varying degrees of health deterioration. Those concerned with prevention of children's difficulties need to consider that HIV-positive mothers, as well as fathers and other caregivers, have needs that vary according to their illness stage. HIV-seropositive asymptomatic parents may need little assistance in dealing with their children, except as it relates to frequent concurrent social problems and, when applicable, to parental drug dependence. Symptomatic parents, as their illness progresses, often need supportive services (e.g., home attendants) and after-school programs for their children. Finally, when parents become severely ill, they need assistance in planning for their children's future, and some

may benefit from counseling focused on disclosure to children. Parents who became infected with the HIV virus as a direct or indirect result of their drug involvement are often reluctant to seek help for their children. This reluctance is based on fear of having their children removed from their care. Programs that aim at helping children of AIDS-afflicted drug-involved parents need to be sensitive to these fears. Separating enforcement of child abuse laws from providing family support services would go a long way toward addressing these fears.

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