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-
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.\textsuperscript{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.\textsuperscript{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).\textsuperscript{1,3-7} Nondisclosure to children might also allow mothers to avoid facing the consequences of their illness, including their own mortality.\textsuperscript{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,\textsuperscript{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-affected 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