



Published in final edited form as:

*AIDS Care*. 2006 January ; 18(1): 60–65.

## The role of stigma in reasons for HIV disclosure and non-disclosure to children

R. A. OSTROM, J. M. SEROVICH, J. Y. LIM, and T. L. MASON

*Department of Human Development and Family Science, The Ohio State University, USA*

### Abstract

This study examined how stigma may impact HIV-positive women's disclosure to their children. Participants included HIV-infected women recruited from AIDS service organizations located in large midwestern cities. Using a questionnaire and guided interview, quantitative data were obtained regarding perceived HIV-related stigma and rates of maternal disclosure to children aged 5–18. According to the Kruskal-Wallis test, comparison between the disclosure groups showed non-significant differences in the total score of HIV stigma ( $\chi^2 = 0.518$  with  $df = 2$ ,  $p = 0.77$ ).

### Introduction

Given that approximately 80% of women with AIDS are within their reproductive years (Siegel & Schrimshaw, 2001), uncertainty about the future can include concern about who will take care of their children should they become incapacitated or die (Reyland et al., 2002). This additional stress can directly impact both the family and children, particularly when women must 'hide' their illness to protect their children. Relatedly, mothers with HIV infection may also face the realities of the stigma associated with HIV.

### Stigma, HIV and women

One characteristic unique to an HIV diagnosis is stigma. A person with a stigma is 'reduced in our minds from a whole and usual person to a tainted, discounted one' (Goffman, 1963). Stigma associated with HIV is thought to originate from the dislike of marginalized groups who were initially infected with HIV (Herek & Glunt, 1988). HIV bears the pre-existing stigma associated with sexual behaviors and illegal drug activity, as well as fatality and viewing individuals as transmitters of the virus (Herek & Glunt, 1988; Pryor et al., 1999). For women in particular, HIV-related stigma can cause them to be labeled as drug users, prostitutes (Bunting, 1996) or being sexually promiscuous.

### HIV disclosure and stigma

Based on preconceived notions regarding HIV-positive persons, stigmatization may have an impact on disclosure decisions. Researchers have suggested that the disclosure decision-making process theoretically results from people weighing the pros and cons associated with disclosure (Armistead et al., 2001; Black & Miles, 2002; Serovich, 2001). Contemplation of disclosure might include the possibility of garnering emotional or instrumental support; however, it may also subject them to rejection (Draimin, 1993). Disclosure to others also decreases the ability to control secondhand disclosure by others. Theoretically, then, mothers must consider that disclosure to children increases their vulnerability (Murphy et al., 2001).

Women are concerned that their children might be unable to keep the diagnosis secret resulting in stigmatization and isolation for them (Moneyham et al., 1996; Murphy et al., 2002).

There is limited empirical research regarding the impact of stigma on a mother's decision to disclose to her children. Studies regarding HIV-positive women and stigma have typically been conducted qualitatively or without a standardized measure of stigma (Ingram & Hutchinson, 1999; Letteney & La Porte, 2004; Murphy et al., 2002; Sowell et al., 1997). These studies are informative in understanding the mechanism of mothers' disclosure to children; however, they suffer from several limitations. First, scales utilized are typically not created for the purpose of gauging the perceived stigma of HIV-positive people and therefore were revised. In addition, studies artificially divide women into just two groups (i.e., disclosure group versus non-disclosure group) (Letteney & La Porte, 2004). However, mothers sometimes decide to disclose to some of their children but not all, making this grouping selection limiting. Thus, a more comprehensive assessment of a construct as complex as stigma is warranted and one examining the relationship between perceived HIV stigma and mothers' disclosure to children according to disclosure sub-groups may be more robust.

## Purpose

Previous studies investigating stigma associated with HIV disclosure are few and each is limited in a number of ways. The purpose of this study was to use a standardized HIV stigma assessment with a sample from the midwest and to further explore and quantitatively assess what role stigma played in the reasons women gave regarding their choice to disclose or not to disclose their HIV status to their children. It is hypothesized that the level of perceived stigma will be positively associated with reasons for non-disclosure and negatively associated with reasons for disclosure. Furthermore, this study examined the degree to which stigma plays a role in women's decisions to disclose to children. It is hypothesized that perceived experience of HIV-related stigma will differ significantly between women who have disclosed their HIV status to none, some and all of their children.

## Methods

### Sample

Participants for this study were HIV-positive women participating in a larger, longitudinal study of HIV disclosure and mental health. All participation was voluntary and refusal to participate or dropping out of the study did not endanger or compromise participants' treatment at any of the sites. Participants were interviewed by trained doctoral students, who then conducted the assessments. All interviewers completed 4–6 hours of training by the PI or Post-Doctoral Fellow and were supervised weekly.

Eligibility requirements for this study were minimal. The participants were women who were HIV-positive or had AIDS and were 18 years old or older at the time of enrollment. The recruitment sites included large medical facilities associated with a large midwestern university medical center and nonprofit AIDS service organizations in the three largest metropolitan areas of the state (Cleveland, Columbus and Cincinnati). For this investigation, women were eligible if they had at least one biological child and had completed wave two of data collection where the stigma measure was administered. The final sample included 45 women and one randomly selected biological child for each woman. Ages of participants ranged from 22–49 and the mean age was 36.1 years. These women were primarily African-American (80%), with the remaining endorsing Caucasian (18%) and Hispanic/Latino (2%) as their race. The average monthly income was \$1,422, 51% of the women were married, partnered or dating and 33% of the women were single. The mean length of time since diagnosis was 8.3 years. The randomly selected biological children were composed of 17 boys (38%) and 28 girls (62%). These

children were aged between 5–18 years old and the mean age was 12.4. Twenty-eight children knew of their mother's diagnosis (62%), and 24 of those children had been disclosed to by their mother.

## Instruments

Disclosure was measured with a social network screening questionnaire that ascertained the extent of the available social network and the actual number of those in the social network to whom they had disclosed. An adaptation of Barreras' Arizona Social Support Interview Schedule (ASSIS; Barrera, 1981) was used for this purpose. After administration of the ASSIS, demographic information on each network member was obtained, including their gender, age, race, relationship with the participant, length of relationship, physical proximity, if this person knew they were HIV-positive and, if so, who disclosed to them.

After demographic information was collected, participants were asked about the reasons they might have considered before disclosing or deciding not to disclose to each particular person. Reasons for disclosure and non-disclosure to children were assessed with two scales adapted from Derlega et al. (2004). The scales included 16 statements designed to garner reasons for disclosure and 20 reasons for non-disclosure. Participants were asked to rate each reason for disclosure and non-disclosure on a five-point Likert-type scale for each child named in their social network. In this study Chronbach's alphas were acceptable (disclosure alpha = 0.77; non-disclosure alpha = 0.89)

Perceived stigma was measured with the HIV Stigma Scale (Berger et al., 2001). The instrument has 40 items measured on a four-point Likert-type response set. Reliability for the total scale is 0.96, and is 0.93 for the personalized stigma sub-scale, 0.93 for the disclosure sub-scale, 0.88 for the negative self-image scale, and 0.93 for the public attitudes. The assessment consists of four sub-scales: personalized stigma, disclosure, negative self-image and public attitudes.

## Data analysis

In order to investigate reasons for non-disclosure and disclosure and the relationships between these reasons and HIV-related stigma, descriptive statistics and correlation analyses were performed. To examine the association between HIV-related stigma and women's disclosure groups (i.e., none, some and all), the Kruskal-Wallis test for global comparison was performed. This non-parametric test was used because each group did not follow a normal distribution and had a relatively small sample size.

## Results

### Reasons for disclosure

The purpose of this study was to further explore and quantitatively assess the role stigma plays in women's decisions to disclose or not to disclose their HIV status to their children. To begin, descriptive statistics were performed for reasons women endorsed for disclosure to children. The most strongly endorsed reasons for disclosure to children included wanting the child to hear the diagnosis from the mother, that the child had a right to know, wanting the child to know what was wrong with the mother and wanting the child to prepare for what might happen. Overall (95%), women did not regret telling their children (see Table I).

In order to investigate the degree to which stigma is related to reasons for disclosure, correlations were performed between the four stigma sub-scales and each reason. Results revealed a statistically significant correlation between only two of the 16 reasons for disclosure and stigma sub-scale scores. A mother's decision to disclose to reassure her child was correlated

with negative self-image ( $r = -0.43$ ). That is, mothers who experienced less stigma also reported wanting to disclose as a means of reassuring their child. Maternal impromptu disclosure was correlated with public attitudes sub-scales ( $r = -0.49$ ) and the negative self-image sub-scale ( $r = -0.46$ ). That is, mothers who experienced lower levels of stigma reported disclosure of their status to children without any specific reason or concern.

### Reasons for non-disclosure

The most strongly endorsed reasons for non-disclosure included thinking the child deserves to have as carefree a childhood as possible, not wanting to scare the child, not wanting the child to worry about the mother and not wanting the child to be hurt by the reactions of others (see Table II). Correlation analysis revealed a statistically significant correlation between five of the 20 reasons for non-disclosure and the stigma sub-scale scores. A mother not disclosing because her diagnosis is personal was correlated with the public attitudes sub-scales ( $r = 0.45$ ). Also, a mother not disclosing because of the stress associated with telling a child was correlated with personalized stigma ( $r = 0.46$ ). Mothers who experienced stigma also thought that their diagnosis was personal and reported not disclosing because of the disclosing stress. A mother not disclosing due to fear that the child may tell others was correlated with the personalized stigma sub-scale ( $r = 0.45$ ) and negative self-image ( $r = 0.49$ ). That is, mothers who experienced stigma also reported not disclosing to their children because of fear that the child may tell others. Finally, a mother not disclosing because she does not want her child to be burdened or would like to keep this information from the child was correlated with negative self-image ( $r = 0.46$ ;  $r = 0.46$ ). That is, a mother who has a negative self-image is not disclosing because of concern about her children. Although neither of these reasons was among the top four most endorsed reasons, their mean scores demonstrated that they were a factor in the women's decision not to disclose.

### HIV perceived stigma

To examine the degree to which stigma played a role in women's decisions to disclose to children, the women were split into 'all' ( $n = 18$ ), 'some' ( $n = 9$ ) and 'none' ( $n = 18$ ) categories for disclosure group. Women who told none, some or all of their children were not statistically different in terms of demographics.

To test the main hypothesis that perceived experience of HIV-related stigma will differ significantly among women who have disclosed their HIV status to none, some and all of their children, the Kruskal-Wallis test was performed. According to the test, comparison between the disclosure groups showed non-significant differences in the total score of HIV stigma ( $\chi^2 = 0.518$  with  $df = 2$ ,  $p = 0.77$ ). To ensure that there were no differences in terms of types of stigma, four additional Kruskal-Wallis tests were performed. Results suggested there was no difference among women who tell none, some or all of their children to the degree to which they experienced personalized stigma ( $\chi^2 = 0.51$ ,  $p = 0.78$ ), stigma related to disclosure ( $\chi^2 = 3.57$ ,  $p = 0.17$ ), negative self-image ( $\chi^2 = 1.09$ ,  $p = 0.58$ ) or public attitudes ( $\chi^2 = 0.73$ ,  $p = 0.70$ ). See Table III for means and standard deviations of sub-scale scores.

### Discussion

Using a quantitative HIV stigma scale (Berger et al., 2001), this study assessed the role that stigma played in women's decisions to disclose their HIV status to all, some or none of their children, as well as how stigma impacted the reasons women provided for their decision. Previous research has concluded that stigma plays a large part in women's decision to disclose their HIV status (Forsyth et al., 1996; Ingram & Hutchinson, 1999; Moneyham et al., 1996; Murphy et al., 2002; Sowell et al., 1997); however, this claim was not supported in this study. Stigma only played a minimal role in the reasons for disclosure and non-disclosure and was

not experienced differentially by women in this sample who disclosed to all, some or none of their children. The results of this study suggest that women are interested in taking the lead role in disclosing to their children and make the decision based on the child's ability to cope with the information, thereby reducing psychological harm. Thus, women are protective of their children and most likely gauge disclosure decisions based on perceived child maturity and emotional stability.

There are several plausible explanations for these findings. The relationship between a mother and each of her children is a very special and unique relationship. Each child's life circumstances are different and this uniqueness may be a driving force behind disclosure decisions. Women may indeed weigh the pros and cons involved with sharing their diagnosis with each of their children (Armistead et al., 2001; Black & Miles, 2002; Serovich, 2001). Then, based on their individual characteristics, the mother decides if disclosure is appropriate regardless of any stigma she experiences. Women may be more concerned about a child's wellbeing rather than the response or possible devaluation and exclusion of others. For example, women may not want their diagnosis shared with others and, therefore, secrecy is the barrier to disclosure rather than concern about being stigmatized by their children (Letteney & La Porte, 2004). These factors, rather than stigma, may also explain why mothers have told some of their children but not all.

There may be other more pressing societal or personal issues women experience (e.g., depression) that may impact disclosure to children. For example, many women in our study were infected by their husbands or committed partners who had been having extramarital affairs, sexual relationships with men or engaging in intravenous drug use. Explaining to children the mode of infection, especially in these situations, can be extremely difficult. In an effort to avoid such situations, mothers may decide not to disclose. Therefore, it is plausible that personal issues experienced by women may impact disclosure and this notion is worthy of further investigation.

Another plausible explanation resides in the fact that this study included a midwestern sample. Most studies researching disclosure have been conducted in larger more coastal cities such as New York City (Kirshenbaum & Nevid, 2002; Letteney & La Porte, 2004), New Orleans, Louisiana (Armistead et al., 2001) or in the southeastern USA (Black & Miles, 2002; Sowell et al., 1997). Women living in smaller, non-coastal, midwestern areas may experience the social ramifications of HIV infection differently. That is, it is plausible that these women experience closer ties with family that might mitigate experiences of stigma.

In addition, interpretative caution may be required because of the cross-sectional, retrospective nature of this data. Due to an inherent time delay and not being able to collect data immediately post disclosure, women may respond differently than when they actually disclosed their status to their children. If this is so, the relationship between stigma and disclosure may be underestimated. Clearly, a better test of this relationship would be to interview women immediately post disclosure to ascertain their reasons and assess the level of stigma experienced. These studies, however, are difficult and costly to conduct.

As others have noted (Letteney & La Porte, 2004; Reyland et al., 2002; Sowell et al., 1997), there remains inconsistency in the explanations surrounding why women choose to or choose not to disclose to their children and there is still no definitive answer as to whether women should disclose. The theoretical models available have not explicitly been applied to disclosure to children; hence a void in the literature remains. While no one theory may be able to completely explain women's decision-making regarding children, a lack of understanding leaves intervention efforts crippled. Given that new advances in medication result in women having opportunities to live rather healthy lives, women have the ability to conceal their

diagnosis for longer periods of time if they so choose. Therefore, the disclosure decisions may be a concern for many years meaning more research, explicitly focused on children and longitudinal in nature, needs to be conducted. What motivating factors are in operation when women face this task and from where do they seek guidance and support? It is especially curious how women manage informational boundaries between children when only some are informed. Helping professionals involved in their care should be sensitive to the unique relationship that a mother has with her children and should assist women in coping with the various forms of perceived stigma as well as the complex and difficult process of deciding whether to disclose to one's children.

### Acknowledgements

This work was funded by a grant awarded to Julianne M. Serovich from the National Institutes of Mental Health (R01MH62293).

### References

- Armistead L, Tannenbaum L, Forehand R, Morse E, Morse P. Disclosing HIV status: Are mothers telling their children? *Journal of Pediatric Psychology* 2001;26(1):11–20. [PubMed: 11145728]
- Barrera, M., Jr. (1981). Social support in the adjustment of pregnant adolescents: Assessment issues. In B.H. Gottlieb (Ed.), *Social networks and social support* (pp. 69–96). Beverly Hills, CA: Sage.
- Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing and Health* 2001;24:518–529. [PubMed: 11746080]
- Black B, Miles MS. Calculating the risks and benefits of disclosure in African American women who have HIV. *Journal of Obstetric, Gynecologic and Neonatal Nursing* 2002;31(6):688–697.
- Bunting SM. Sources of stigma associated with women with HIV. *Advances in Nursing Science* 1996;19(2):64–73. [PubMed: 8939289]
- Derlega VJ, Winstead BA, Greene K, Serovich J, Elwood WN. Reasons for HIV disclosure/non-disclosure to relationship partners: A contextual analysis. *Journal of Social and Clinical Psychology* 2004;23:747–767.
- Drainin, B.H. (1993). *Coping when a parent has AIDS* New York: Rosen Publishing Group.
- Forsyth BW, Damour L, Nagler S, Adnopo J. The psychological effects of parental human immunodeficiency virus infection on uninfected children. *Archives of Pediatrics and Adolescent Medicine* 1996;150:1015–1020. [PubMed: 8859131]
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity* Englewood Cliffs, NJ: Prentice Hall.
- Herek GM, Glunt EK. An epidemic of stigma: Public reactions to AIDS. *American Psychologist* 1988;43(11):886–891. [PubMed: 3063145]
- Ingram D, Hutchinson SA. HIV-positive mothers and stigma. *Health Care for Women International* 1999;20:93–103. [PubMed: 10335159]
- Kirshenbaum SB, Nevid JS. The specificity of maternal disclosure of HIV/AIDS in relation to children's adjustment. *AIDS Education and Prevention* 2002;14(1):1–16. [PubMed: 11900106]
- Letteney SL, La Porte HH. Deconstructing stigma: Perceptions of HIV-seropositive mothers and their disclosure to children. *Social Work in Health Care* 2004;38(3):105–123. [PubMed: 15149914]
- Moneyham L, Seals B, Demi A, Sowell R, Cohen L, Guillory J. Experiences of disclosure in women infected with HIV. *Health Care Women International* 1996;17:209–221.
- Murphy DA, Roberts KJ, Hoffman D. Stigma and ostracism associated with HIV/AIDS: Children carrying the secret of their mothers' HIV-positive serostatus. *Journal of Child and Family Studies* 2002;11(2):191–202.
- Murphy DA, Steers WN, Dello Stritto ME. Maternal disclosure of mothers' HIV serostatus to their young children. *Journal of Family Psychology* 2001;15(3):441–450. [PubMed: 11584794]
- Pryor JB, Reeder GD, Landau S. A social-psychological analysis of HIV-related stigma: A two-factor theory. *American Behavioral Scientist* 1999;42(7):1193–1211.



- Reyland SA, Higgins-D'Alessandro A, McMahon TJ. Tell them you love them because you never know when things could change: Voices of adolescents living with HIV-positive mothers. *AIDS Care* 2002;14(2):285–294. [PubMed: 11940285]
- Serovich JM. A test of two HIV disclosure theories. *AIDS Education and Prevention* 2001;13(4):355–364. [PubMed: 11565594]
- Siegel K, Schrimshaw EW. Reasons and justifications for considering pregnancy among women living with HIV/AIDS. *Psychology of Women Quarterly* 2001;25:112–123.
- Sowell RL, Lowenstein A, Moneyham L, Demi A, Mizuno Y, Seals BF. Resources, stigma and patterns of disclosure in rural women with HIV infection. *Public Health Nursing* 1997;14(5):302–312. [PubMed: 9342922]

Table 1

Mean and standard deviation for measures of reasons for disclosure.

	<i>M</i>	<i>SD</i>
I wanted him/her to hear the information from me	4.73	0.52
This child had a right to know	4.55	0.60
I wanted this child to know what was wrong with me	4.55	0.67
I wanted to prepare this child for what might happen	4.50	0.96
I did not want to keep secrets from this child	4.50	0.67
This child could handle the truth	4.32	0.78
I wanted to reassure this child	4.31	0.89
I thought this child was mature enough to know	4.23	1.02
This child needed to know how sick I was or could become	4.14	1.17
I wanted to get this child to get the support he/she needed	4.14	1.25
I rely on this child for practical support (e.g., help around the house)	3.64	1.43
I felt like I could not hide it anymore	3.59	1.37
I rely on this child for emotional support	3.27	1.35
I was worried that this child might overhear information about my diagnosis	3.09	1.60
This child kept asking me questions about my being sick	2.91	1.38
I did not think about telling him/her; I just blurted it out	2.46	1.63

*Note.* Reasons for disclosure were assessed on a five-point scale (1 = not at all a factor, 5 = very much a factor).



Table II

Mean and standard deviation for measures of reasons for non-disclosure.

	M	SD
This child deserves to have as carefree a childhood as possible	4.53	1.06
I do not want to scare this child	4.40	1.24
I do not want this child to worry about me	4.20	1.32
I do not want this child to be hurt by the reactions of others	4.20	1.32
I fear this child might tell others of my HIV status	4.06	1.62
This child does not need to be burdened	3.93	1.33
I want to protect this child so others will not hurt him/her because of my status	3.93	1.67
This child is not old enough to know	3.80	1.57
I want to keep this information from this child for as long as possible	3.73	1.58
This child is not mature enough to know	3.67	1.63
It would be too stressful for me to tell this child	3.60	1.64
This child cannot handle the truth right now	3.60	1.76
My diagnosis is personal	3.20	1.47
This child does not have any reason to know	3.13	1.51
This child does not need to know how sick I am or could become	3.00	1.65
I am afraid this child will ask questions that I am not prepared to answer	2.60	1.76
I am afraid this child will ask too many questions	2.33	1.63
I am afraid that I will have to tell this child how I contracted HIV	2.20	1.37
I am afraid this child will be angry with me	2.20	1.42
I am afraid this child will lose respect for me	2.13	1.60

Note. Reasons for non-disclosure were assessed on a five-point scale (1 = not at all a factor, 5 = very much a factor).

Table III

Means of HIV stigma scores by sub-scales and disclosure groups (mean±SD).

Group	None (n = 18)	Some (n = 9)	All (n = 18)	P
Stigma sub-scales				
Disclosure				
Public	3.21±.65 <sup>a</sup>	2.80±.83 <sup>a</sup>	2.97±.58 <sup>a</sup>	0.168
Negative self-image	2.78±.55 <sup>b</sup>	2.56±.69 <sup>ac</sup>	2.82±.57 <sup>a</sup>	0.696
Personalized	2.70±.74 <sup>b</sup>	2.40±.75 <sup>bc</sup>	2.50±.67 <sup>b</sup>	0.580
P	2.43±.54 <sup>c</sup>	2.33±.66 <sup>b</sup>	2.56±.60 <sup>b</sup>	0.776
Total	<0.001 2.73±0.55	0.008 2.55±0.67	<0.001 2.77±.54	0.772

Note. Stigma was assessed on a four-point scale (1 = *strongly disagree*, 4 = *strongly agree*). Means in the same column that do not share subscripts differ at  $p < 0.05$ .