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Reasons for and against maternal HIV disclosure to children and perceived child reaction

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Abstract

This study explores the decision making of 66 HIV-positive women regarding disclosing their serostatus to their children and the child's perceived immediate and long-term reactions. Data came from a larger investigation of the disclosure process of HIV-infected women. Children included 27 boys and 39 girls between the ages 5 and 18 years. Forty-one children knew of their mother's diagnosis and 32 were disclosed to by their mother. Results suggest that women are interested in taking a leading role in disclosing to their children and make the decision based on the child's ability to handle the information and not be psychologically harmed.

Keywords

Children; disclosure; HIV; maternal; reactions

Introduction

The decision to disclose maternal serostatus to children is very complex. Reported rates of disclosure to children range from 30% (Armistead, Tannenbaum, Forehand, Morse, & Morse, 2001; Murphy, Steers, & Dello Stritto, 2001) to 66% (Schrimshaw & Siegel, 2002). Research indicates that most mothers do not regret disclosing (Murphy, Roberts, & Hoffman, 2003; Serovich, McDowell, & Grafsky, in press) nor do they disclose the full nature of their illness (Murphy et al., 2001) preferring to indicate that they are sick or not feeling well (Kirshenbaum & Nevid, 2002).

Based on these studies, it appears that mothers are making decisions on a child-by-child basis (Simoni, Davis, Drossman, & Weinberg, 2000) and perceive more costs than benefits in disclosing (Armistead et al., 2001). Theoretically, it has been suggested that the decision usually occurs as a result of individuals weighing the pros and cons (Armistead et al., 2001; Black & Miles, 2002; Serovich, 2001). That is, women decide if the opportunities resulting from disclosing (e.g. support) would be greater than possible negative repercussions (e.g. rejection) (Draimin, 1993). Commonly researched factors associated with disclosure include children's ages (Armistead et al., 2001; Rotheram-Borus, Draimin, Reid, & Murphy, 1997; Simoni et al., 2000), gender (Armistead et al., 2001; DeMatteo et al., 2002; Shaffer, Jones, Kotchick, Forehand & The Family Health Project Research Group, 2001), concerns about family secrets (DeMatteo et al., 2002; Kirshenbaum & Nevid, 2002; Pliskin, Farrel, Crandles, & DeHovitz., 1993), level of child maturity (Pliskin et al., 1993; Shaffer et al., 2001), mother's

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age (Kirshenbaum & Nevid, 2002) and her ability to help her child understand HIV (Murphy, Koranyi, Crim, & Whited, 1999).

Studies have also demonstrated that harm can result from not disclosing to children (Forsyth, Damour, Nagler, & Adnopoz, 1996). Children may intuitively know something is wrong by reading signals such as mothers going to the doctor, taking medicine or losing weight. Theoretically, this could cause anxiety and confusion (Murphy et al., 2001). Although challenging, disclosing may offer some benefits to both mother and child. Disclosure may provide time for the child to grieve, social support for the child and an opportunity to clarify misconceptions that the child has regarding HIV, including transmission (Doll & Dillon, 1997; Zay & Roma, 1994).

The purpose of this study is to further explore the specific reasons for disclosing, as well as the perceived reactions of children to disclosure. As medical science advances and treatments become available and more effective, HIV-positive women are going to live longer. A better understanding of how the disease and disclosure process affect children is important clinically and for service providers.

Methods

Sample

Data for this project came from a larger investigation of disclosure among HIV-infected women. For this study eligibility included women with biological children aged 5–18 years. Sixty-six women in the larger study met eligibility requirements. Women ranged in age from 19–60 years with a mean age of 37.2. The majority of women were African American (71%) with the remaining reporting Caucasian (20%), Hispanic/Latino (6%) and other (3%). Half of the women were married, partnered or dating and 32% of the women were single. The mean length of time since diagnosis was 7.4 years.

Women tended to have large families with 23% having four or more children. To minimize non-independence, we randomly selected one child from each family reporting more than one child. The selected biological children were composed of 27 boys (41%) and 39 girls (59%). The children were aged 5–18 years and the mean age was 12.4. Forty-one children knew of their mother's diagnosis (62%) and 32 (48.5%) were disclosed to directly by their mother.

Procedures

Women were identified by personnel at AIDS Service Organizations. Participants were interviewed and assessed by trained doctoral students. Participation lasted approximately three hours and women were paid $35.

Instruments

Patterns of disclosure were assessed with a social network screening questionnaire. This screening ascertained the available social network and the actual number of persons to whom they have disclosed. An adaptation of Barreras' Arizona Social Support Interview Schedule (ASSIS; Barrera, 1981) was used for this purpose. The ASSIS consists of questions tapping seven dimensions of social support. After the administration of the ASSIS, the following demographic information was obtained for each network member: gender, age, race, relationship with the participant, length of the relationship, physical proximity, if this person knows they are HIV-positive and, if so, who disclosed to them and if they regretted this person knowing their HIV status.

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Reasons for disclosure and non-disclosure were assessed with an adapted version of scales designed for adults and have solid reported psychometrics (Derlega, Winsted, Greene, Serovich, & Elwood, 2002). The instrument was adapted to address children and to garner both the positive and negative consequences. The adapted reasons for disclosure instrument contained 16 items ($\alpha = .88$) and the non-disclosure instrument contained 20 items ($\alpha = .88$). Participants were asked to rate reasons on a five point Likert-type scale ranging from "Not at all a factor" = 1 to "Very much a factor" = 5. Participants were asked to consider each child separately.

Reactions were measured with two author-derived scales. Both measures contained 23-items, one measuring immediate reactions and the other measuring long-term reactions, meant to ascertain child adjustment to disclosure over time. Items for both measures include those that are emotional (e.g. "Responded/s with anger"), inquisitive (e.g. "Asked/s whether she/he is HIV-positive"), avoidant (e.g. "Tried/s to change the subject") and comforting (e.g. "Hugged/s me"). Participants were instructed to indicate on a 5-point, Likert-type scale the degree to which each child reacted immediately upon disclosure as well as over time. The term "over time" was not defined and was left open for the mothers' interpretation for their experiences with each child.

Results

Reasons for disclosure

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; and wanting to reassure the child. Ninety percent did not regret telling their children (Table 1).

Reasons for non-disclosure

The most strongly endorsed reasons mothers gave for non-disclosure included: believing the child deserves a carefree childhood; not wanting the child to worry; and not wanting to scare the child (Table 2).

Immediate reaction

Immediate reactions to maternal disclosure involved comforting, showing concern and wanting more information. When women first told their children about their HIV diagnosis, women reported their children: hugged them; were worried; comforted them; and asked questions about HIV/AIDS or the meaning of being sick (Table 3).

Long-term reaction

Long-term reactions involved comforting the mother along with some remaining worry and concern. Women reported that after time had passed since disclosure, as compared to immediately following disclose, their children responded to their HIV status by: hugging them; comforting them; telling them that it is going to be okay; and being worried about the mother or the family (Table 3).

Discussion

Results suggest that women want to take a leading role in disclosing to their children and make the decision based on the child's ability to handle the information without being excessively worried or scared. They are protective of their children and gauge disclosure decisions based on perceived maturity and emotional stability. After deciding whether or not to disclose, 48.5% of the women directly disclosed their HIV status and only three reported regretting their

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decision. This suggests that when mothers decide the time is right, no matter the repercussion, they are satisfied with their decision.

When women decided not to disclose, reasons centered on timing and concern for the child's well-being. Mothers were concerned that disclosure would take away from the joys of being a child. They wanted to wait until the child was mature enough to handle the news, to cope without being overwhelmed and to maintain confidentiality.

Immediate and long-term reactions provided more opportunities than negative repercussions. Children responded with gestures of comfort, acceptance and opportunities to discuss concerns. Thus, disclosure may provide children time to grieve, an opportunity to talk openly about the diagnosis and an opportunity for the mothers to clarify misconceptions children have regarding HIV. Disclosure also brought about opportunities for the mother to gain comfort, not rejection, from her child.

The findings from this study contribute to the current literature by providing a more detailed understanding of how the disease and disclosure process affect the children and also by challenging other researchers to further investigate this issue. Results demonstrate a need to further address the issue of disclosure; to provide assistance and guidance for women as they decide; and to provide support services to help children cope.

Results should be considered in light of their limitations. This study was conducted using quantitative methods. Women had to rate predetermined responses on a Likert-type scale. It is plausible that there are other important issues to be considered in disclosing to children. In addition, children's reactions were reported from the mothers' perspective. Children may present one exterior to mothers but may actually be experiencing something very different. Further research should allow for children to report their own reactions and to indicate interventions or services that would help them cope. Future researchers should consider incorporating multiple perspectives on this phenomenon, such as teachers and other community members. Finally, women in this study were primarily African-American and all lived in the Midwest. Studies using larger samples of diverse women from coastal cities would offer an opportunity for generalization.

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Table 1

Means and standard deviations for reasons for disclosure.

Item	*M*	*SD*
1. I wanted this child to hear the information from me.	4.69	0.64
2. This child had a right to know.	4.50	0.92
3. I wanted to reassure this child.	4.41	0.76
4. I wanted to prepare this child for what might happen.	4.34	1.15
5. I wanted this child to know what was wrong with me.	4.31	1.03
6. This child needed to know how sick I was or could become.	4.19	1.12
7. I wanted to get this child to get the support he/she needed.	4.16	1.14
8. I did not want to keep secrets from this child.	4.09	1.25
9. This child could handle the truth.	3.88	1.10
10. I thought this child was mature enough to know.	3.84	1.37
11. I felt like I could not hide it anymore.	3.50	1.48
12. I rely on this child for practical support (e.g. help around the house),	3.34	1.45
13. I rely on this child for emotional support.	3.25	1.44
14. I was worried that this child might overhear information about my diagnosis.	3.03	1.51
15. This child kept asking me questions about my being sick.	2.84	1.53
16. I did not think about telling this child; I just blurted it out.	2.41	1.56

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

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Table 2

Means and standard deviations for reasons for non-disclosure.

Item	*M*	*SD*
1. This child deserves to have as carefree a childhood as possible.	4.38	1.13
2. I do not want this child to worry about me.	4.37	1.25
3. I do not want to scare this child.	4.19	1.41
4. I do not want this child to be hurt by the reactions of others.	4.19	1.3
5. I want to protect child so others will not hurt him/her because of my status.	4.19	1.36
6. This child does not need to be burdened.	4.11	1.25
7. I want to keep this information from this child as long as possible.	3.85	1.51
8. This child is not old enough to know.	3.81	1.55
9. It would be too stressful for me to tell this child.	3.81	1.52
10. This child cannot handle the truth right now.	3.78	1.55
11. This child is not mature enough to know.	3.46	1.63
12. I fear this child might tell others of my HIV status.	3.46	1.68
13. My diagnosis is personal.	3.22	1.53
14. This child does not need to know how sick I am or could become.	3.15	1.59
15. This child does not have any reason to know.	3.11	1.5
16. I am afraid this child will ask too many questions.	2.73	1.61
17. I am afraid this child will ask questions that I am not prepared to answer.	2.69	1.64
18. I am afraid this child will be angry with me.	2.5	1.45
19. I am afraid that I will have to tell this child how I contracted HIV.	2.38	1.39
20. I am afraid this child will lose respect for me.	2.23	1.5

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

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Table 3

Means and standard deviations for immediate and long-term reactions to disclosure.

Item	Immediate		Long-term	
	M	SD	M	SD
1. Hugs me.	3.94	1.59	3.91	1.60
2. Is worried about me or the family.	3.77	1.65	3.65	1.52
3. Comforts me.	3.69	1.53	3.89	1.59
4. Asks questions regarding the meaning of HIV/AIDS or the meaning of my being sick.	3.68	1.61	3.40	1.72
5. Starts to cry to show emotional distress.	3.55	1.52	2.50	1.48
6. Tells me it is going to be okay.	3.31	1.66	3.71	1.64
7. Is shocked or stunned.	3.20	1.69	2.49	1.44
8. Asks whether other people were or are HIV-positive (e.g. child, father, sibling).	3.15	1.73	2.68	1.85
9. Is fearful about the future.	3.11	1.59	2.71	1.71
10. Asks questions about how the diagnosis will affect his/her life.	2.94	1.69	3.11	1.78
11. Feels sorry for me.	2.86	1.70	2.53	1.64
12. Asks whether she/he is HIV-positive.	2.85	1.72	2.32	1.70
13. Does not seem to understand what this means.	2.80	1.68	2.74	1.74
14. Tells me that she/he is scared.	2.74	1.69	2.49	1.42
15. Responds with anger. Anger at the infecting person; God; you.	2.47	1.74	1.77	1.37
16. Is physically upset (e.g. shaking, complained of stomach ache).	2.24	1.54	1.32	0.98
17. Is in denial or disbelief.	2.17	1.44	1.77	1.17
18. Told someone else about my HIV status.	1.91	1.40	1.83	1.34
19. Appears disinterested or bored.	1.83	1.27	1.88	1.37
20. Tries to change the subject.	1.71	1.29	2.21	1.61
21. Becomes violent.	1.51	1.04	1.35	0.98
22. Does not want to touch me because she/he was scared she/he might get it.	1.46	1.01	1.57	1.12
23. Rejects me or tells me to leave.	1.40	0.98	1.26	0.79