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Disclosure and Impact of Maternal HIV+ Serostatus on Mothers and Children in Rural Haiti

Donaldson F. Conserve¹, Eddy Eustache², Catherine M. Oswald^{2,3}, Ermaze Louis², Gary King⁴, Fiona Scanlan³, Joia S. Mukherjee^{3,5}, and Pamela J. Surkan⁶

¹Department of Health Behavior, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

²Zanmi Lasante Sociomedical Complex, Cange, Haiti

³Partners In Health, Boston, MA, USA

⁴Department of Biobehavioral Health, The Pennsylvania State University, University Park, PA, USA

⁵Department of Global Health and Social Medicine, Harvard Medical School, Boston, MA, USA

⁶Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA

Abstract

Objectives—Mothers living with HIV (MLWHs) in the United States have reported that one of their main challenges is the decision to disclose their HIV serostatus to their children and the potential consequences of their disclosure. Little is known about the experiences of MLWHs regarding disclosing their HIV serostatus to their children and the impact of maternal HIV disclosure in the island nations of the Caribbean. Study objectives were to identify the factors influencing maternal HIV disclosure, examine the breadth of maternal HIV disclosure, and understand the impact of disclosure on mothers and the children.

Methods—Baseline interviews were conducted between 2006–2007 with 25 HIV-positive mothers and 26 children ages 10–17 participating in a pilot psychosocial support intervention for HIV-affected youth and their caregivers in Haiti. Interviews were transcribed verbatim and coded for topical themes by two investigators.

Results—Analysis of the interviews yielded several themes relevant to reasons for disclosure, including children's experience of HIV stigma in the community, social support and encouragement from psychosocial intervention workers. The main themes related to breadth of disclosure were brief disclosure and explicit disclosure with some mothers sharing information about how they learned about their illness diagnosis and their medication. Themes related to impacts of disclosure included emotional reactions for children and mothers, and children's desire to assist mothers with illness and become involved.

Conclusions—These findings suggest the need to provide more psychosocial support to HIV-affected families in the Caribbean region.

Keywords

HIV serostatus disclosure; Mothers; Children; Haiti

INTRODUCTION

The first case of AIDS in the Caribbean was reported in 1978 in the island nation of Haiti (1). Since then, poverty, limited access to healthcare and health-related information, stigmatization of people living with AIDS and their families, multiple sexual partnerships, sociopolitical instability, and Haiti's isolation from international participation in AIDS forums impeded early efforts to combat the epidemic (2). In addition, the risk activities associated with HIV in the 1990s shifted, resulting in an increase in infection among women from 15% in 1982 to 46% in 1992 and 6.6% for children in 1989 (1, 3, 4). Despite the challenges Haiti faced with the epidemic, a number of successes have been achieved. In 1995, the non-governmental organization Partners In Health (known as Zanmi Lasante (ZL) in Haitian Kreyol) started providing zidovudine, the first U.S. government-approved treatment for HIV therapy, free of charge to all HIV-positive pregnant women in the prevention of mother-to-child transmission (PTMC) HIV program (5). Moreover, between 1996 and 2010 ZL recommended formula feeding for infants born to women with HIV infection in its healthcare programs and reported that milk substitution was safe, acceptable, and feasible for HIV-infected women in the PTMC program in rural Haiti (6).

In spite of these achievements, Haitian women and children remain severely affected by the epidemic with 53% of the 120, 000 people living with HIV in Haiti in 2009 being women and 12,000 pediatric cases (7, 8). Given that women make up the majority of HIV-infected people in Haiti and are also the caregivers for their children, more research is needed to explore maternal HIV serostatus disclosure among mothers living with HIV (MLWHs) in Haiti. Previous research has shown that disclosure of maternal HIV serostatus to children is one of the main stressors that MLWHs in the United States face (9). Although the Caribbean region has the second highest rate of HIV in the world, little is known about maternal HIV serostatus disclosure to children in the island-countries in this region (10). A better understanding of the factors associated with maternal HIV serostatus disclosure to children in Haiti will assist in the development of the much needed family-centered psychosocial interventions for HIV-affected families in the region (11–13).

The Disclosure Decision Model and an extended HIV-focused adaptation of this model assume individuals strategically manage their disclosure to control their social worlds and to achieve optimal social and personal goals (14, 15). The HIV-disclosure decision model proposes two factors that can influence HIV disclosure/non-disclosure (16). The first factor is the social environment in which someone lives, including cultural attitudes about HIV, close relationships, and self-disclosure. The second factor in the model focuses on the relational, individual, and temporal contexts surrounding the person living with HIV. These contexts consist of their social network; progression and length of time living with HIV; and personal and network members' characteristics. HIV-positive Haitian women who are financially dependent on their sexual partner and are afraid of domestic violence may choose to believe in magical explanations of HIV in order to avoid disclosing their HIV serostatus to their sexual partners (17). Researchers have also reported that Haitian women from rural and urban areas experience HIV-related stigma in their communities (18, 19). In addition, cultural factors, such as pressure from their families, the feeling that the experience of

motherhood was incomplete without breastfeeding and stigma HIV-related stigma serve as a barrier to prevention of mother-to-child transmission (20). In light of the specific sociocultural context of Haiti, and based on the integrative model of HIV-disclosure decision making we aimed to: 1) identify the factors influencing maternal HIV serostatus disclosure to children 2) examine the breadth of maternal HIV serostatus disclosure and 3) understand the impact of disclosure on mothers and children.

METHODS

This qualitative study was part of a larger feasibility study of a psychosocial support intervention for youth affected by HIV and their caregivers conducted in collaboration with Partners In Health/Zanmi Lasante (PIH/ZL) and the Haitian Ministry of Health (18). The study sites from Haiti's Central Department included Cange, Boucan Carre, Hinche, Lascahobas, Belladere, and Thomonde. MLWHs who reported thoughts of suicide and their HIV-affected children who reported that their psychological symptoms impacted his/her psychosocial functioning were recruited. Children who reported having no friends, were being abused and were being underfed were also recruited for the study (18). More than half of the youth (n = 492) recruited for the larger study were females (51.4%) and the mean age was 13 years (range, 10–17) (11). The majority of the youth (79.6%) resided with their mothers and twenty of them were HIV-positive. Approximately 54% of the caregivers (n = 350) reported a monthly household income of less than \$50 (11).

The psychosocial support intervention was developed by Rotheram-Borus et al., (2001) and employed the social cognitive theory to improve coping skills and augment social support (21). For more details about the adapted version of the intervention and Haiti's Central Plateau please see references (18, 22). The participants for this qualitative study included a sub-sample of 25 MLWHs and 26 HIV-positive or HIV-negative children between the ages of 10-17. Baseline in-depth interviews were conducted over 1.5-2 hours in Haitian Creole by trained psychologists or social workers. Mothers and their children were interviewed separately using an open-ended interview guide. Participants were encouraged to respond freely and assured confidentiality. The interview guide for the mothers included topics that covered their social and family history, medical diagnosis of HIV, methods of HIV serostatus disclosure to children, and the effect of their illness on the ability to support their children. The interview guide for the children included questions about their social and family background, psychosocial functioning, the impact of their mother's illness on their mood and their health status. The following are examples of two questions used in the interviews: How did you talk to your children about the illness? How did you feel after learning about your mother's illness? The interviews were audio-recorded and transcribed verbatim by Haitian study personnel. Participants were informed about the content of the study and the caregivers provided informed consent for themselves and their children, while the children gave their assent. The study was approved by the Office for Research Subject Protection at Harvard Medical School and the Zanmi Lasante Ethics Committee.

All interviews were translated from Haitian Creole into English by the first author, a native of Haiti who is fluent in Haitian Creole. Following the guidelines of Strauss and Corbin 1990, the first author used open and axial coding to develop categories and subcategories

from the participants' responses (23). The translated transcripts were also coded by the last author to ensure reliability and validity (24). In an iterative fashion, the constant comparative method was used to compare and contrast differences and similarities across the participants' responses in order to explore, organize and synthesize the data into meaningful categories that reoccurred in the transcripts (25, 26). In the comparing data step, similarities and differences within and between responses were compared to detect patterns. Data were then analyzed for themes related to reasons for disclosure, patterns of disclosure, and impacts of disclosure. The categories of themes evolved during the analysis, as more patterns and variations were identified (27).

RESULTS

Reasons for Disclosure

Children's experience of HIV-stigma (48%: n = 12)—One of the main reasons offered for disclosure among the mothers was that their children were being stigmatized in the community. For example, a mother recounted, "Yes he knows. I told him because they were teasing him, telling him that his mother is sick." Another mother stated, "When the kids tease him and call him *Ti Sidayis* (Little HIVer), I tell him that it does not matter that they tease you. I know I am sick and one day I will be healed."

Social Support (28%; n= 7)—Several of the mothers disclosed their serostatus for other reasons (fear of death, trust, closeness) related to social support. One mother stated, "I spoke with him (11 year old) because I thought life was over for me because I saw that I was not well." Another mother stated "After several workshops at Zanmi Lasante, I started going around informing and explaining to other people about the illness. Then, while I was educating other people about the illness, I understood that it is normal for me to have someone in my family that I trust and I would be able to tell that I have HIV and that is her (my daughter)." Another parent stated "He (15 year old son) knows I am sick because he is sick too. He was the one who was the closest to me after I became ill." One mother stated "I had to not hide it. I told him (10 year old son) that I was fighting the HIV illness. I told them about it because they are my children."

Encouragement from psychosocial intervention workers (24%; n = 6)—Some of the mothers who had not initially disclosed their HIV serostatus to their children reported that they eventually disclosed their serostatus during the recruitment process for the intervention. One woman reported that "When I was sick I did not really talk to her, it was when this program [psychosocial intervention] started to function here and when the health care professional came to talk to me that I told her about it." Another woman stated "It has not been long since I have spoken to him about the illness. It was when the lady [health care worker] who was with me in this project last week asked me if I told my child that I was sick [that I did it]."

Breadth of Disclosure

Brief disclosure (64%; n = 16)

"Mwen di li m'fè maladi Sida". I told her I have HIV: Although most mothers had directly disclosed their HIV serostatus to their children, some mothers were brief in their disclosure. An example of a brief disclosure is one mother who told her 12-year-old son "I am sick. They told me that I contracted TB and I have HIV/AIDS." Similarly, another mother stated "I sat him (13 years old boy) down. I told him 'I don't feel well. I am sick' and after that I told him what sickness I have."

Explicit disclosure (36%; n = 9)

"Mwen di'l rezilta egzamen 'm". I told her the results of my medical examination: A number of mothers who explicitly disclosed their serostatus reported that they used their medical examinations experience as an entry point to not only disclose their HIV serostatus but also to inform the children how they learned of their diagnosis. One mother stated "I told her (14 years old) how things went. I told her that I came to get my test result here (hospital). I told her the results of my medical examination are not good. I am sick. I have HIV." Another mother responded "When I arrived (home) I told the children that after I was examined the doctor told me that I am sick. He (14 years old) asked me 'What illness did the doctor say you have?' I told him, well, the doctor told me that I have a virus called HIV."

"Depi Bondye fè yo ba 'w medikaman". As long as God make them give you

medication: In addition to informing their children about the medical examination, some mothers encouraged their children and reassured them that their health would improve by discussing their HIV medication with them. A mother stated "I told him (15 year old) that I went to the hospital and they did an exam for me. I have an illness called AIDS but from the way I spoke to the doctor, he told me I don't need to be scared. I will find medication that will help my body so that I can continue to help you and your siblings." Another mother stated, "I went to the hospital. They told me I have the HIV illness. I told him to not be discouraged...He said 'Well, mother since I cannot change it then I will accept it, as long as God makes them give you medication." In one case, an older child (17 year old boy) became aware of his mother's illness because she was taking medication. She stated "I told him 'My son, your mother is sick'. He said, 'Mother, I know you are sick because I see they give you medication all the time. Whenever I see them give you medication, I know it is because you are sick'."

Impacts of Disclosure

Emotional reactions for child and mothers (69%; n = 18)—Some of the mothers reported that their children experienced a variety of emotions after becoming aware of their mothers' illnesses. One mother stated "When I told him he cried and said that he is going to lose his mother." The children's reactions also affected the mothers. One mother recounted "When I told her that (I had HIV), she became sad in front of me. You understand? Then I saw tears coming out of my eyes." Sometimes the children were not only sad because their mothers were ill but also because of the stigma they experienced. One mother stated "He tells me that what makes him sad is that sometimes other children tell him that (your parent

has HIV)." Another mother reported, "Also, what creates another little problem is that when she goes to school. Every time she has a dispute with the students in the school they always humiliate her. They tell her, 'Don't you see that your mother has HIV?' and she always come and tell me that."

The majority of the children expressed that they had an emotional reaction after learning that their parents were infected with HIV. Many of the children reported they were sad, hurt, or upset. In one instance, one 13 year old child mentioned that she felt angry towards her father after learning that her mother was sick. She stated, "I felt that it was my father's fault since he knew that he was sick. I don't know if it's out of spite that he transmitted the virus to my mother. I told my mother that I wanted to hurt my father but after that she told me not to do that because God knows everything." One younger child (11 years old) who did not know as much about the illness stated, "I did not feel normal because I know when a person has that illness he will not last long. I felt sad because once a person has this illness if you mistreat the person you might have it too."

Desire to assist mothers and become involved (32%; n = 5)—A small number of children reported they wanted to help their parents. One 15-year-old child stated, "What we could do for her, if we had the money? We could look for a way to bring her to the hospital because once you are sick it's at the hospital you can come to find treatment to calm the illness." Another child (14-year-old) reported that her mother's disclosure initially bothered her but she eventually developed a better understanding about the illness through her participation in a mini film. Learning more about the illness allowed her to have a more positive attitude toward the illness. She stated, "It caused me a lot of problems, but afterwards I participated in a mini film. I played the role of the person with the illness and saw that it was nothing. It's an illness just like any other illness."

DISCUSSION

The primary purpose of this study was to identify the factors influencing maternal HIV serostatus disclosure to their children in a low resource setting in the Caribbean. The reasons for disclosure included HIV-related stigma in the community, encouragement from health care workers in the intervention, and the need for social support. Similar findings have been reported among HIV-positive mothers in the United States who reported that disclosure prepared the children for indirect disclosure from gossip in the neighborhood and the possibility that their mothers may die from the illness (28, 29). Receiving encouragement from a health care professional regarding the disclosure process was also consistent with a study in the US where some mothers sought the help of a therapist or guidance from support groups to assist them with the process of disclosure to their children (28). Some mothers in the US even included their children in support and educational programs for children of HIV-infected parents to help them express their feelings or prepare them for the death of the parents (29). Similar resources would be beneficial for children of MLWHs in Haiti, for children at risk of acquiring HIV, and children who have lost a parent or parents from HIV/AIDS (30).

The breadth of disclosure or the different array of topics covered during the disclosure event varied greatly (14). The difference in the amount of information mothers share with children during disclosure has been attributed to maternal health status (9). In a study conducted in the US, mothers with higher T-cell count disclosed a broader range of information to their children compared with mothers with lower T-cell counts (31). The authors suggested that mothers with better health feel comfortable disclosing more details to their children than mothers with compromised health. In our study, we found that mothers who provided information not just about the illness but also about their medication were able to comfort their children by reassuring that the medication would improve their health. Therefore, it becomes important for HIV-positive mothers to not only tell their children they are ill but also to inform and educate their children about the life saving treatments for HIV. Such disclosure strategies could reduce the possible negative impacts of disclosure on children and promote positive reactions to disclosure such as family cohesion and improved communication among mothers and their children (32).

Consistent with other studies, children reported a variety of reactions such as desiring to care for the parents, worrying, and feeling sad (29). One explanation for the different reactions among the children is related to their cognitive development and their understanding of HIV/AIDS (33). While most of the children expressed grief, they did not describe whether their sadness was a result of fear for losing a parent or whether they understood HIV to be different from other illnesses. Other studies have reported that fear of parents' death as one reason children experienced anxiety after disclosure (32, 34). Other factors causing grief may be the feeling of helplessness that children experience (35). Another finding from this study that resonates with the existing literature is illustrated by the child in this study who reported feeling angry at her father for infecting her mother (32). Children's reactions were not only affected by their anxiety for their parents' health but also the stigma they have experienced. Stigma and discrimination against HIV-affected youth have been reported to be common in central Haiti (36). Programs designed to combat the stigma associated with HIV can be helpful in the children's long term adjustment.

One of the strengths of our study is that we did not rely on mothers' accounts for the effect of disclosure on the children. Another strength of our study is the recruitment of participants from more than one town. However, considering that the mothers all had access to and were receiving treatments, and were participating in a psychosocial intervention for HIV-affected families, the findings may not be generalizable to all HIV-positive mothers in Haiti. Although the study included participants from six different locations, all of the women were residing in communities where Zanmi Lasante has been providing services for several years. Another limitation is that only one of the mothers' children was interviewed. Future studies should explore the disclosure experience of mothers prior to initiating treatment, and include more than one family member, e.g. other children or relatives, in order to explore the impact of HIV disclosure on MLWHs and other family members.

In this study, we found that MLWHs tended to disclose their HIV serostatus to their children in the context of the medical system and after being encouraged by social workers. As expected, most of the children worried about their mothers' health initially, until they were reassured by their mothers that their health would improve. Mothers with declining health

who had not disclosed to their children, however, were not able to benefit from the encouragement and hope experienced by mothers in better health who had disclosed to their children directly. Children were often informed of their mothers' illness after being stigmatized in their school or neighborhood. Implications for health services in the island nations of the Caribbean are that healthcare providers can use post-test counseling sessions as opportunities to discuss approaches to disclosure methods that parents can use with their children. In addition, HIV-affected families in the island nations of the Caribbean region can benefit from culturally appropriate psychosocial interventions aimed at improving communication, providing support, and providing socio-economic assistance.

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