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Maternal HIV illness and its impact on children well-being and development in Haiti

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Abstract

Little is known about the impact of parental HIV illness on children's well-being and development in the island nations of the Caribbean. Study objectives were to examine mothers' experiences of impact of HIV illness on their children's well-being and development in Haiti. Baseline interviews were conducted between 2006 and 2007 with 25 HIV-positive mothers as part of a larger study that examined the feasibility of a psychosocial support group intervention for HIV-affected youth and their caregivers in central Haiti. Interviews were transcribed verbatim and coded for topical themes by two investigators. Main themes related to impact of maternal HIV illness on children's well-being were the lack of mothers' physical strength to take care of their children, and their difficulties in providing housing and food for their children. Children's school enrollment, attendance, and performance were also affected by their mother's illness. Mothers reported that although their children were HIV-negative, children were distressed by HIV-related stigma that they and their mothers experienced. Findings suggest that children living in HIV-affected families in this region face disadvantages in nutritional, educational, and psychological outcomes. These considerations should be taken into account when designing interventions to support children living in HIV-affected families in this setting.

Keywords

Human immunodeficiency virus; maternal health; children; development; Caribbean

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Introduction

According to the 2010 UNAIDS report on the HIV prevalence in the Caribbean, prior to the 2010 earthquake an estimated 120, 000 people were living with HIV in Haiti, of which 53% were women. The adult HIV prevalence was 2.2% and represented 47% of all people living with HIV in the Caribbean (UNAIDS, 2010). A number of successes have been achieved in the fight against HIV in Haiti, with a notable decrease from 6.2% in 1993 to 3.2% in 2004 reported among pregnant women in Haiti (Gaillard et al., 2006). Researchers have attributed the decline in HIV prevalence among women to a decrease in sexual partners and higher rates of condom use (Hallett et al., 2006). In addition to sexual behavior change, organizations such as Groupe Haitien d'Etude du Sarcoma de Kaposi et des Infections Opportunistes (GHESKIO) and Partners In Health and its Haitian sister organization Zanmi Lasante have been providing integrated HIV prevention and care services in both rural and urban Haiti, with a reported 8,175 patients seeking voluntary counseling and testing (VCT) services at GHESKIO in 1999 and more than 7,000 HIV-positive patients being monitored by Zanmi Lasante (Fraser et al., 2004; Koenig, Leandre, & Farmer, 2004; Peck et al., 2003; Walton et al., 2004). The rate of mother-to-child transmission of HIV has also decreased from 27% to 10% in 2005 (Deschamps et al., 2009; Noel et al., 2008).

The effects of the HIV/AIDS epidemic on the lives of mothers living with HIV (MLWH) in resource poor countries such as Haiti range from deteriorating physical and mental health to their inability to provide for their children, sometimes due to economic hardships exacerbated by the presence of HIV (Castro & Farmer, 2005; Smith Fawzi et al., 2010; Surkan et al., 2010). The impact of HIV on many families in Haiti is often compounded by socio-economic stressors such as inadequate shelter and food insecurity, experienced by 40% of Haitian households (Gage & Hutchinson, 2006). Most Haitian adults are unemployed and more than 70% live in U.N.-defined extreme poverty (Malow, Rosenberg, Lichtenstein, & Dévieux, 2010). The compounded effects of these challenges make it difficult for children living with HIV-affected families to receive the proper attention, care, and support needed for their development.

Bronfenbrenner's ecological framework situates child development within the context of a system of relationships that form a child's environment (Bronfenbrenner, 1979). The interaction among the different systems, for example, the family, the community, and the wider society, influences the direction of growth of the child; changes in any of the systems will have a ripple effect on the other systems (Bronfenbrenner, 1979). A number of studies have documented the negative effects parental HIV has on children's development in terms of time parents spend with children, the lack of care they can provide to their children, and increases in children's domestic responsibilities (Fostera & Williamsonb, 2000; Ji, Li, Lin, & Sun, 2007). For example, a study comparing HIV related orphans and vulnerable children (HIV-OVC) and children from families unaffected by HIV in the same neighborhood found that a greater number of HIV-OVC experienced family displacement than other children and more guardians of HIV-OVC reported that the disease affected their children's education (Mon et al., 2013). Another study of HIV-OVC reported that HIV-OVC worked more frequently and longer time on domestic chores than comparison children and that domestic chores workload was positively associated with depressive symptoms (Yu et al., 2013).

Consequently, the stressors associated with longer work hours and domestic chores may reduce the time HIV-OVC have to focus on their school (Yu et al., 2013).

The impact of parental HIV illness on children in the Caribbean region has received little attention, with the exception of recent studies that have reported on the psychosocial functioning of HIV-positive caregivers and their children in Haiti (Conserve et al., 2013; Smith Fawzi et al., 2012; Surkan et al., 2010). In a recent systematic review on the impact of parental HIV/AIDS on children's psychological well-being, Chi and Li (Chi & Li, 2012) reviewed 30 articles and none of the studies reported in the review were from the Caribbean region. Eighteen of the studies were conducted in African countries and the rest in the US, Italy, and China. After sub-Saharan Africa, the Caribbean has the second highest rate of HIV infection in the world (UNAIDS, 2010), resulting in many HIV-affected families faced with the challenges of caring for HIV related orphans and vulnerable children. Given the unique social, economic and cultural context of Haiti, we aimed to fill the gap in the literature by examining the impact of maternal HIV illness on the system of relationships that affect children's well-being and development in Haiti.

Method

Participants

This qualitative study was part of a larger feasibility study of a psychosocial support intervention for youth affected by HIV and their caregivers that was conducted in collaboration with Partners In Health/Zanmi Lasante (PIH/ZL) and the Haitian Ministry of Health (Smith Fawzi et al., 2012). A total of 330 caregivers were enrolled in the larger study. The average age and number of children of the participants in the larger study were 39.4 years and 3.6 children. Approximately half of the participants were employed, with 32.3% working in subsistence farming and 22.1% as market vendors. More than 70% reported a monthly income of less than or equal to $50. Only 14.6% of the participants reported living in a house with a thatched roof and less than half (42.3%) had a latrine. However, the qualitative interviews for this paper were conducted prior to the main intervention study and included 28 caregivers (25 mothers and 3 fathers). Due to the small number of fathers interviewed and very little information from the fathers about how HIV affects their children, the responses from the fathers were excluded. (For more information on the complete sample, please see Smith Fawzi et al., 2012). Enrollment criteria for the larger study included mothers, fathers, or other relatives or guardians who had a child affected by HIV and were receiving HIV treatment and care at the six designated PIH/ZL sites. A child was affected by HIV if he/she was HIV-positive; had a parent or caregiver who was HIV positive; or had lost one or both parents to HIV.

Procedure

The intervention was designed for caregivers and their children in an effort to expand the HIV care at PIH/ZL to address psychosocial issues impacting HIV-affected children (Smith Fawzi et al., 2012). The study sites from Haiti's Central Department included Cange, Boucan Carre, Hinche, Lascahobas, Belladere, and Thomonde. Participants were informed about the content of the study and the caregivers provided informed consent to participate

and to be audio recorded. Baseline in-depth interviews were conducted over 1.5–2 hours in Haitian Creole by trained psychologists or social workers. Mothers were interviewed using an open-ended interview guide. Participants were encouraged to respond freely and were assured confidentiality. The information collected in this study was kept in a separate and locked file cabinet and only study staff had access to the file. The interviews were transcribed verbatim by Haitian study personnel. All interviews were translated from Haitian Creole into English by the first author, a native of Haiti who is fluent in Haitian Creole. The study was approved by the Office for Research Subject Protection at Harvard Medical School and the Zanmi Lasante Ethics Committee.

Measures

The interview guide was developed based on the objectives of the qualitative component of the study to understand from the participants' point of view what the challenges that families affected by HIV were facing in central Haiti and how these challenges influenced their children's well-being. Given our study's objectives and the focus of Bronfenbrenner's ecological framework on how the challenges families face can interact with the environment, and community to foster or impede a child's development, it provides us with a lens to further delineate the possible negative consequences of maternal HIV infection on children in Haiti (Bronfenbrenner, 1979). The interview guide included information about the mother's social and family history, medical diagnosis of HIV, methods of HIV serostatus disclosure to children, and the effect of maternal HIV on the ability to support their children. The following are examples of a few questions used in the interviews: *What was the most important change in your child's life since you became sick? How often does it happen that you do not have anything to eat? How does this affect your child? Does she go to school every day? If she misses any days in school, why?*

Data analyses

Following the guidelines of Corbin and Strauss (2008), the first author used open and axial coding to develop categories and subcategories from the participants' responses (Corbin & Strauss, 2008). The translated transcripts were also coded by the last author to reduce coding errors and increase thoroughness and reliability of the data coding. Both authors discussed differences, resolved these differences, and reached consensus on the final codes. We employed the constant comparative method to facilitate theme development (Boeije, 2002; Morse, 1996). In this step, similarities and differences within and between responses were compared to detect patterns and variations. Additional categories of themes evolved during the analysis, as more patterns and variations were identified. Further analyses identified themes that emerged most frequently across the transcripts (Xu et al., 2009). Data were then analyzed for the impact of maternal HIV illness on their children's wellbeing.

Results

Mothers' inability to take care and provide food for children

A diagnosis of HIV often had a negative effect on mother's income; some women were no longer able to provide housing, and food for their children. The impact of mothers' illness on their ability to take care of their children is illustrated in the following four cases.

Case P2 is a mother of six children. She was diagnosed with HIV during her fifth pregnancy while seeking antenatal care at the Zanmi Lasante's women's health program in Cange. "It was when I came here (to the women's health program) while I was pregnant that they sent me to do several medical exams and then they told me I was sick. Now the child is 4 years old. I did not feel anything wrong with my body. It is now I have a problem because I don't feel my strength at all." She described how the illness affected her physical health and prevented her from taking care of her children sometimes. "Yes, there are times I feel like I cannot take care of them. I would wake up in the morning and would not feel any strength so I would stay in bed."

Case P6 is a mother of three children who sought medical care at Zanmi Lasante three years after becoming ill, when she started losing weight and feeling weak. "I started feeling sick in 2000. I started to lose weight and in 2003 I came to the hospital. They did a medical examination and that is when I became aware that I was HIV-positive." She recalled how during the time she was sick she was unable to take care of her children sometimes because her family could not help and she lost her job. "Yes, that caused me a lot of problems when I could not take care of them. I come from a family that is very poor... It resulted in a lot of problems also because I lost my job and could not work."

Case P4 is a mother of four children who became ill with a fever in 1996 but still felt weak afterwards. "When the fever stopped my body still felt broken". Despite feeling broken she managed to keep working but at times she just could not work. When asked how her illness affected her child, she responded "It affects him a lot. For example, when I do not have food to give him I go to my mother's. If my mother has food then I give him some. If she doesn't have food then I am left without food [to give my son]."

Case P8 is a mother of six children who became ill six years after her children's father died from the illness without being diagnosed and treated. "My stomach was hurting and I had a diarrhea. The children's father also had diarrhea when he died." During the period she was ill, she relied mostly on her mother to take care of her and her children. "I did not have anyone. My parents did not really have the courage. It is only my mother…she is the one who takes care of me and the children." Even with her mother's help, she described that it was still difficult to provide food for her children because her mother was not able to help her all the time. "Well, there are things that changed in the child's life. I cannot help her because I am dependent on my mother and there are times my mother does not have anything to give me. The child is not able to enjoy life because she may want to eat but there is no food even for me, so how can there be food for the child."

Children's School Enrollment, Attendance, & Performance

All the mothers emphasized it was important for their children to attend school and have a career so they would have a promising future. However, due to the mother's illness, some of the children were unable to attend school. Among the children whose mothers were able to send them to school, they sometimes went to school without eating food throughout the day, as illustrated in the following three cases.

Case P3 is a mother of three children who tested HIV positive in 2000. She described the importance of school for her children. “Yes, I find it is very important so he can learn how to read. Even if I die he will always talk about me saying that his mother had put him in school…The school can help him when he’s working and when he’s learning a trade.” She then continued to explain how her children had to stop going to school when she was very ill. “When I was very sick I was bedridden for 4 years, he spent the 4 years without going school.” My other son was going to the 12th grade, he lost 4 years as well and was not able to go to class.” After she had partially recovered she was able to send her children back to school but the children sometimes did not have food before the school day. “Yes, he likes school a lot. There are times I tell him that I don’t have food. He tells me that even if he doesn’t have any food he will still go to school.”

Case P19 is a mother of four children who was diagnosed and treated for TB in 2000 and eventually diagnosed with HIV in 2003. One of her children became ill and was eventually treated for HIV at Zanmi Lasanate. Her first husband died and her second husband left her after he learned that she was on treatment for HIV. After becoming ill she sold her house and went to live with her parents. She described how her child who is HIV-positive returns home from school because of lack of food. “When I was sick she spent two years without going to school…The only times now she goes to school and comes back early is when she goes without food. She is not living in the same house with me. She stays at my brother’s house and if I don’t send food for her she doesn’t have anything to eat. There are days she goes to school without eating. If she arrives in class after taking her HIV medication without eating, she doesn’t feel like she can stay, so she comes back home.”

Case P24 is a mother of six children who was diagnosed with HIV in 2003. Upon learning of her illness her husband left her. She described that the most important change in her child’s life due to her HIV diagnosis is the fact she could not send him to school. “He started missing school because I did not have the opportunity to send him. I lost what I had because I sold all I had for the illness and for the older children. This makes him suffer because he cannot go to school.” When she was able to send him to school, she mentioned that he was less able to focus because he was worried about her. “Yes, there are changes in the way he learned. He failed one semester. He would be studying and then he would stop and start to think. I would ask him what is wrong with him. ‘He said it is because he sees that I am sick and I am going to die. He won’t have anyone to help him. That makes him sad.”

Effect of Mothers’ HIV-related stigma on Children

Mothers reported experiencing HIV-related stigma in the community and described how their children were affected by the stigma. As illustrated in the two cases below, even when the children were HIV-negative they often suffered humiliation and criticism associated with having a family member with HIV.

Case P1 is a mother of two children who was diagnosed with HIV in 1994 and began HIV treatment in 1999 when it became available. She described that a major problem was the treatment she received from people in her community after starting treatment. “The thing that changed was that when I first became sick I did not have medication… But now I don’t feel comfortable with the people in my community who criticize me. Whenever I talk to

them, they say that ‘you are a sick person.’” She continued to describe how her HIV-negative child is also affected by stigma resulting from her HIV status. “He always says that what makes him sad is that if a child is talking to him and they tell him that [your mother has HIV]. When he was younger if a child cursed him he would come and ask me if I was really sick and tell me that the kids are cursing at him. Now, the way it affects him is that there are times the children curse him saying ‘look at you *ti sidayis (little HIVer)* -- your mother has HIV. “

Case P20 is a mother of five children who was diagnosed with HIV when she was pregnant with her eighth child. Of her eight children, three did not survive due to illnesses unrelated to HIV. Upon learning about her infection she informed her children that she was HIV-positive and that the nurse told her to not breastfeed her newborn. She described how the stigma in the community affected one of her children. “Well, I don’t see anything that has changed with him since I became sick. The only problem is the way people talk. They’re talking and telling me certain things that make him think and worry… Once people hear that you are sick, they criticize you.”

Discussion

The primary purpose of this study was to describe how maternal HIV illness affects the well-being and development of their children in Haiti. Our findings demonstrated not only the enervating effect of HIV on mothers’ ability to work and maintain property ownership, but also how the impact of maternal HIV illness extends to her children in terms of their access to food, school, and their psychosocial functioning. Many mothers described how the illness prevented them from caring or providing food for their children because of the illness’s effects on their physical health as well as their economic conditions. Mothers reported difficulties in paying their children’s school fees which resulted in a number of children missing school. Among children who were able to return to school, they sometimes went to school without eating and spent the day without any food. Some of the children’s school performance was affected due to their concern about their mother’s health. Lastly, the discrimination and stigma experienced by the mothers caused the children psychological stress and in some cases children were also discriminated against even though they were not ill themselves. Our findings support the negative consequences reported in a global review commissioned by the President’s Emergency Plan for AIDS Relief (PEPFAR) and the United States Agency for International Development (USAID) to document the immediate and short-term effects of adult HIV infection on children (Sherr et al., 2014). In particular, the authors describe the challenges HIV-affected children face due to their parent’s compromised physical health and the economic constraints that may prevent parents from meeting the nutritional and educational needs of their children (Sherr et al., 2014).

Studies have described direct and indirect effects of maternal HIV illness on the health and nutritional status of children (Magadi, 2011). Direct effects occur when the children themselves become infected with HIV through vertical transmission. Research has shown that HIV-positive children residing in communities with high HIV prevalence in sub-Saharan Africa are more likely to suffer malnutrition than HIV-negative children (Bunn, 2009; Nalwoga et al., 2010). Indirect effects of maternal HIV illness on children can result from

the disruption in the mother's ability to adequately take care of her children (Kotchick et al., 1997). In our study, we found that mothers who were working and had a stable source of income often lost these resources after becoming infected with HIV. Due to loss of their income and lack of support, they were unable to provide sufficient food for their children and often became dependent on family members. This is consistent with findings from Uganda showing that after the onset of HIV some individuals had to stop working, sell their capital and household properties, and receive support from family members (Wagner, Ryan, Huynh, Kityo, & Mugyenyi, 2009). Sudden changes in family structure and economic status after HIV can lead to inadequate food supplies for children and malnourishment, as suggested by our study. These conditions may lead to children affected by HIV to be more likely to be stunted, wasted or underweight compared to their counterparts of similar demographic and socio-economic background (Magadi, 2011).

A recent review of the global literature on the effects of parental HIV-related illness or death on children's schooling reported that children affected by HIV face educational disadvantages including school enrollment and attendance, school behavior and performance, school completion and educational attainment (Guo, Li, & Sherr, 2012). Factors influencing the effect of HIV/AIDS on children's education were gender of child, living arrangement, and household poverty (Guo et al., 2012). Although child gender was not reported to play a role in children's education in our study, our findings support the review article in that mothers in our study also mentioned that their living arrangement and poverty were barriers to their children attending school. Children from families living with HIV in Haiti and elsewhere often also face psychosocial stressors related to HIV/AIDS stigma from community members and increased responsibilities in housework and caring for self, younger siblings and parents with illness (Ji et al., 2007; Skovdal, Ogutu, Aoro, & Campbell, 2009; Xu, Wu, Duan, Han, & Rou, 2010; Zhang et al., 2009). Among the children who were able to attend school in our study, the psychosocial stressors they experienced influenced their behaviors and school performance.

As suggested by Bronfenbrenner's social ecological model, the ripple effects of maternal HIV illness on children's well-being described in this study may potentially place them at risk for HIV in the future, as they are prone to engage in high risk behaviors because of their unstable economic situation (Dévieux, Rosenberg, Saint-Jean, Bryant, & Malow, 2013). Economic insecurity, 'lamize' or economic despair in Creole, has been reported to be associated with early initiation of sex and dependence on sexual relationships for survival among Haitian youth, where 15% of boys and 11% of girls who were sexually experienced report exchanging money for sex in the past 4 weeks (Speizer, Beauvais, Gómez, Outlaw, & Roussel, 2009). Lastly, the lack of opportunity to attend school may also provide children with more unstructured time to seek out risky sexual behaviors that may lead to HIV infection. A study examining the association between school attendance, HIV infection and sexual behavior among young people in South Africa found that male students were less likely to be HIV positive than non-students (Hargreaves et al., 2008).

One of the strengths of our study is the recruitment of participants from a small city and several towns, representing a diversity of experiences based on mostly rural HIV-affected families in the central plateau of Haiti. However, considering that some of the mothers may

have reported suicidal ideation and they all had access to and were receiving HIV care treatment, the findings may not reflect the experiences of all HIV-positive mothers in Haiti. Also, the length of time since data collection is another potential limitation. Additionally, although the study included participants from six different locations, all the participating women were residing in communities where Zanmi Lasante has been providing services for several years. Another limitation is that we did not explore the role of fathers in helping the mothers as they adjusted to living with HIV and caring for their children. Furthermore, we did not measure the child psychological well-being and children's perceptions regarding the stigma were reported by the mothers. Future research should collect data from multiple sources, including spouses, and family members, and children.

Our findings point to some specific considerations relevant to the Haitian setting such as the unstable economic conditions that could be taken into account when designing interventions to support children living in HIV-affected families in this setting. Such programs could address stigma associated with living with an HIV-infected family member and would pay special attention to meeting children's nutritional, educational, and psychological needs.

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