

HIV Disease Impact on Mothers: What They Miss During Their Children's Developmental Years

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Abstract Adjusting to chronic illness is very complicated for families with children, as they are already faced with the challenge of development and childrearing. In this study, qualitative interviews were conducted with HIV positive mothers on a number of issues related to being an HIV positive mother raising young children. One topic of the interview was whether or not they felt that HIV had caused them to miss activities with their children while the children were growing up, what types of activities they had missed, the age of the child for each example, and how HIV had led to missing these activities. Interviews were conducted in 2008 with a random sample of 57 mothers being followed in a longitudinal assessment study. All study participants were English or Spanish speaking. Mean age was 44.1 (SD = 5.6) years; 47% were Latina; 35% African American; 11% White; and 7% other race. About 60% of the mothers disclosed that their HIV status had caused them to miss out on activities with their children while their children were growing up, ranging from daily care activities to major school and extra-curricular activities. Some mothers missed significant amounts of time with their children due to hospitalizations. In some cases mothers felt forced into a choice between mothering ability and their own health, including adherence to medications. Implications for the mothers and the children are discussed.

Keywords Family activities · HIV positive mothers · Qualitative interviews · Chronic illness

Introduction

Chronic diseases tend to share a variety of characteristics, including: uncertain course or disease trajectory; requirement of adherence to a treatment regimen; considerable self-care management; changes in role relationships; and identity changes as the patient attempts to integrate the illness into their life and self-conception (Corbin and Strauss 1991; Lubkin and Larsen 2002; Miller 1992; Royer 1998). HIV/AIDS meets the criteria for a chronic illness (Nokes 1998; Siegel and Lekas 2002): there is no cure for the disease; while the natural history of the disease has been outlined, the course of disease progression varies considerably among individuals; current multi-drug regimens can be complex and are not equally effective for all patients; and the disease has a profound impact on relationships (Siegel and Lekas 2002).

Adjusting to chronic illness is very complicated for families with children, as they are already faced with the challenge of development and childrearing (Montemayor 1982). Armistead et al. (1995), in a review of studies examining the relationship between parental illness and child functioning, concluded that an association does exist. They conceptualized that parental physical illness either directly disrupts parenting or may indirectly disrupt parenting through increased parental depression and/or increased conflict within the family relationship. Furthermore, parental illness, depression and family conflict are often reciprocal and transactional, in that, for example, illness may lead to relationship conflict, which in turn may lead to further deterioration in health (Armistead et al. 1995).

Some of the most frequently occurring disease symptoms among HIV-infected individuals are those that could impair parenting ability: fatigue, neuropathy, diarrhea, nausea, and depression (Holzemer et al. 2001). Moreover,

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the medications used to treat HIV may cause symptoms that negatively influence the ability to parent. Frequently reported side effects from antiretroviral (ARV) medication include diarrhea, nausea and vomiting, fat redistribution, and dermatological problems such as rashes (Haug et al. 2005; Johnson and Neilands 2007). Ammassari et al. (2001) found many of these side effects (i.e., nausea, skin rashes, abnormal fat distribution) were significantly associated with ARV non-adherence. Across a number of studies, fatigue has been reported to be one of the most common complaints of HIV positive women (Rose et al. 1998; Sarna et al. 1999; van Servellen et al. 1998). It was reported as the “worst” symptom by 98% of women with symptomatic HIV/AIDS (van Servellen et al. 1998).

Numerous studies provide insight into the role that illness plays in families affected by maternal HIV. Parental HIV often disrupts family structure, economic resources, and the developmental life cycle, for example, not only are children faced with potential loss of a parent to HIV/AIDS, but they may also be forced from their homes and schools when parental death results in discontinued rent subsidies (Rotheram-Borus et al. 2005). Qualitative analyses indicate that while HIV positive women found motherhood to be their most important role and their children to be their greatest source of motivation, child-rearing and relationships with their children were also significant sources of stress (Van Loon 2000). This, and other studies indicate declining health status of HIV positive mothers negatively affected their performance of certain parenting tasks including discipline, physical care, involvement in children’s activities (Tompkins et al. 1999; Van Loon 2000). Likewise, Schuster et al. (2005) found that being infected with HIV prompted some parents, particularly Latina mothers, to limit behaviors such as kissing and sharing utensils because of concern about transmission. Qualitative studies support these findings, indicating transmission-related fears were identified in a majority of families, and many of these fears were based on misconceptions about modes of transmission (e.g., Cowgill et al. 2008).

Other studies suggest there is evidence that: (1) maternal parenting skills are directly impaired by HIV and as illness severity increases; and (2) impaired parenting leads to poorer child outcomes. For example, children affected by maternal HIV reported significantly more externalizing problems relative to children whose mothers were not infected, and among HIV positive mothers, poorer parent–child relationships were associated with more child behavior problems (Tompkins and Wyatt 2008). Likewise, poorer physical functioning of mothers living with HIV (MLHs) was associated with lower parenting skills, and in families with more frequent routines and a high level of parental monitoring that was stable over time, children showed better outcomes (Murphy et al. 2009).

While it seems clear now that HIV impacts maternal parenting skills, less is known about the specific impact HIV has on family interactions that affect parenting and the parent–child relationship. That is, while we have overall associations, we have less detailed descriptive data regarding specific activities that parents may miss, or limit their participation in due to HIV. Qualitative interviews were conducted with MLHs to explore the following research questions: (1) to what extent do MLHs feel that HIV had caused them to miss activities with their children while the children were growing up? (2) What types of activities do MLHs miss, and what is the intensity and severity of how much they miss? (3) How has HIV led to missing activities? and (4) Are there coping strategies or protective factors that help MLHs avoid missing activities and events in their children’s lives?

Method

Participants

The Parents and Adolescents Coping Together III study (PACT III) is a continuation of two longitudinal studies (PACT and PACT II) assessing mothers with HIV/AIDS and their well children. The original Parents And children Coping Together (PACT) study followed a sample of 135 families every 6 months for 30 months beginning in 1997 when the children were age 6–11. In 2002, the PACT II study continued to follow 81 of the original families in the PACT study as the children transitioned to early and middle adolescence, and the original sample was supplemented with 37 new families, for a total of 118 families. The final study, PACT III, is now following 96 of the 118 PACT II families as the early/middle adolescents transition to late adolescence/early adulthood. Seven of the mothers from families in PACT III have died since their participation in PACT II, and one lost custody, however, with guardian consent if under age 18, their children are participating in PACT III. Of the 22 families in PACT II who are not participating in PACT III, five of the mothers died since their participation in PACT II (for a total of 12 deceased); two mothers lost custody (for a total of 3 without custody); thirteen families were out of the country or could not be located; and two families declined to participate in PACT III. Of the surviving MLHs with custody who participated in PACT II ($n = 103$), 85.4% ($n = 88$) are participating in PACT III. PACT III baseline interviews were conducted in 2008, and a random sample of 57 of the mothers were selected for this additional qualitative assessment, all of whom signed the IRB-approved consent form and participated in the interview.

All study participants were English or Spanish speaking. Mothers were recruited from primary care sites and AIDS service organizations in Los Angeles County. At the PACT III baseline interview, the mothers reported they had been living with HIV for an average of 14.4 years ($SD = 4.1$, range = 5–23). On average, mothers had completed 11.9 ($SD = 6.2$) years of education; mean age was 44.1 ($SD = 5.6$) years. Race/ethnicity was 47% Latina; 35% African American; 11% White; and 7% other race; 35% of the interviews were conducted in Spanish. Marital status was 12.3% currently married, 36.9% separated or divorced, 15.8% widowed, and 35.1% never married; 38.6% were employed in the last month. The mean monthly income from employment and other household member contributions was \$1,266 ($SD = 950$). Fifty-six percent of their children in the study were male; mean age was 18.1 ($SD = 1.9$) years; 81% of the study children were living at home with the mother.

Data Collection

The Institutional Review Board at the University of California, Los Angeles, approved the study. Interviews were conducted in participant homes, lasted approximately 60 min, and were digitally taped and transcribed. Participants were paid \$20 for participation. Respondents were asked about how much HIV had caused them to miss out on doing activities with their children while the children were growing up. They were asked to give specific examples and to say how old the child was for each of the examples. Those respondents who stated that HIV had not caused them to miss out were asked further to explain why this was so. All questions were open-ended and the interviewers used follow-up questions and probes to explore the topics that emerged during the course of the interviews. Trained, bilingual interviewers fluent in Spanish conducted the interviews. The interviewers have Bachelors degrees, research experience, and the primary interviewer has been interviewing PACT families for over 10 years. The PACT III assessments and Spanish interview transcripts were translated by the Worldwide Translation Center (WTC) in San Diego, CA. A team of three translators (one translator and two editors) conducted the translations and analyzed the documents for accuracy, grammar and style.

Data Analysis

Multiple readings of the transcripts were performed by two members of the research team to identify major themes (Strauss and Corbin 1990). Next, the second author (a Ph.D. level researcher who has been conducting qualitative research in the field of HIV/AIDS for about 15 years) conducted a line-by-line review of the transcripts and

field-notes. First-level codes (descriptors of important components of the interviews) were noted in the margins. All codes were then tagged to associated text segments in Ethnograph, a software program for computer-based text search and retrieval (Qualis Research Associates, Colorado, version 6.0). Data corresponding to each of the first-level codes were printed and reviewed, and sub-codes were established to divide the first-level codes into smaller categories. The results correspond to the emergent categories.

In order to maximize the credibility/trustworthiness of the findings, steps were taken to bolster the transparency, consistency, and communicability of the data (Rubin and Rubin 1995). Transparency refers to how carefully data is collected and maintained as well as how clear the collection methods are to the reader of a qualitative report. In this study, all original digital transcripts as well as the subsequent printed hard copies have been kept in a secure location. Moreover, the codebook, developed in concert with the two researchers, has been retained as well as all of the marked up transcripts. During the coding process, any discrepancies regarding coding categories were discussed by the researchers until agreement was achieved. Consistency refers steps taken to ensure consistency both within and between interviewees. In this study, the interviewers, upon hearing any inconsistencies in the respondents' stories, further probed until clarity regarding the topic was achieved. Efforts were also made to assess how consistent themes were between respondents; percentages of respondents mentioning each theme are presented in the findings. Finally, communicability refers to how well the views of the interviewees are communicated in the final report. To achieve this, direct quotations drawn directly from the transcripts are presented to explicate each theme.

To examine sociodemographic characteristics by whether MLH's reported missing activities with their children, cross tabulations (chi square tests) and comparisons of means (t -tests) were conducted.

Results

A total of 34 of the 57 mothers (60%) disclosed that their HIV status had caused them to miss out on activities with their children while their children were growing up. This section will first discuss four main types of activities for which these women missed, or had limited or impaired participation. Second, it will detail the reasons why HIV caused them to miss out on activities with their children. Third, the viewpoints of the other women, explaining why they believed HIV had not caused them to miss activities with their children will be explored. Finally, information regarding whether or not respondents missed activities by race/ethnicity and other demographic characteristics is

presented in the last section. Table 1 presents the percent of women overall and by race/ethnicity who reported: (1) missing specific activities, (2) reasons for missing activities, and (3) reasons for not missing activities; an illustrative quote is provided as an example for each theme.

Missed Activities

The four most frequently mentioned activities were: (1) school/extracurricular events, (2) going places, (3) daily care, and (4) active, leisure-time play.

School and Extracurricular Events

As shown in Table 1, of the women who reported missing out on any activities with their children ($n = 34$), 47% reported missing school and extracurricular events. School events included parent–teacher meetings, special events hosted by the school, field trips, etc. A Latina mother said, “The school was far away, sometimes I didn’t have the energy...I didn’t go to the meetings...the teachers would call me.” An African American respondent said she missed out on a lot of her child’s school activities because “a lot of time I was just sick.” Another woman summed up her involvement with her child’s school life as follows, “All

his life I missed a lot...I didn’t go to the PTA meetings—none of that stuff.”

Extracurricular activities included sports and arts-related events. An extreme example of a mother missing out on her child’s sports activities was the African American mother who stated she had missed so many of her son’s basketball games that “I did not know until his junior year...that he was captain of the team.” Similarly, a mom said in regard to her daughter’s performing arts activities, “A lot. I missed out on doing things with her [such as] her plays [and] concerts.”

Going Places

Going places with their child for fun was the next most frequently mentioned theme. Forty-two percent stated they had missed out on going places with their kids due to their HIV disease.

All of the following were outings women stated that they had missed: going to beaches, playgrounds, zoos, amusement parks, movies, fairs, camping trips, and water parks. A Latina respondent explained, “When a certain time of day comes, I can’t do anything. So when my son wants to go to the movies...I can’t take him...I couldn’t do many things.” Fun outings were quite important to many

Table 1 Impact of HIV/AIDS on mothers’ ability to attend activities with their children: percent of mothers indicating each response overall and by race/ethnicity

Activities/reasons	Total (%)	Latina (%)	African American (%)	Multi-racial (%)	White (%)	Illustrative quotations
Mothers who missed out on specific activities ($n = 34$)						
School and extracurricular activities	47	53	50	25	0	“The school was far away, sometimes I didn’t have the energy...I didn’t go to the meetings...the teachers would call me”
Going places	42	53	21	50	50	“When a certain time of day comes, I can’t do anything. So when my son wants to go to the movies...I can’t take him...I couldn’t do many things”
Daily care	35	27	36	50	50	“You feel useless. You cannot cook for your kids, take care of them”
Active, leisure time play	18	27	7	0	50	“There was a lot of things. I think a lot of it had to do with just being able to go out and experience a lot of physical things”
Reasons for missing activities ($n = 34$)						
Poor physical health	94	87	100	100	100	“I was so sick so it was hard taking care of him”
Poor mental health	26	33	15	50	33	“I’d rather sit home and do nothing in my depression than get out of it and let him have more of a normal childhood”
Stigma/secretcy	12	7	15	0	50	“I wanted to hide...I was very ashamed”
Reasons for not missing activities ($n = 23$)						
Good physical health	78	92	71	0	50	“I pretty much haven’t been ill during their whole life”
HIV as motivator to do “more”	17	8	14	0	50	“I think it caused us [to do] more”
“Powering through” limitations	17	17	29	0	0	“I just push myself and just go and catch up with rest later”

women and they were distressed to have been unable to do them with their child. An African American mother said, “I wasn’t able to do nothing with my children and that hurted me.”

Daily Care

About one-third of women (35%) stated that their HIV status had caused them to miss the daily tasks of caring for their children (i.e., cooking for their kids, cleaning the house, bringing the kids to school, helping with homework, etc.). These women claimed they had gone through periods in their disease when they were so sick that they simply could not do any of these necessary, daily activities for their child. A Latina respondent said, “You feel useless. You cannot cook for your kids, take care of them, take them out...It was very frustrating. I felt bad.” A Latina mother said, “I would not take him to school. I could not do that. He was alone. I could not do much.”

Hospitalizations were especially difficult for women as they led to a physical separation from their children and a hiatus to their day-to-day mothering responsibilities. A Latina mother said, “I [was] hospitalized...Take her to school? No, I couldn’t!” A multiracial mom said, “I was in the hospital...I missed the entire summer!” Hospitalizations often led to respondents’ children being placed in the care of others while the respondents recovered. An African American respondent said, “That period, she was with her step-dad, staying with him, because I couldn’t take care of her.”

Active, Leisure-Time Play

A total of 18% of women reported missing out on active, leisure-time fun with their children due to their HIV, including such activities as running, hopping, dancing, fishing, camping, and just general “playing.” A Latina mother said:

There was a lot of things. I think a lot of it had to do with just being able to go out and experience a lot of physical things...going out and being able to, I mean, it sounds kind of silly, but just to go out and jump around and play and be...more physical with him and run around and play and have the energy to do the things that I wanted to do with him and keep up with my boy.

Mothers truly regretted being incapable of doing these fun activities with their kids and sometimes they would try to force themselves to do such things, even if they truly felt too ill or exhausted. An African American woman said, “I just wanted to do a lot with them when they were young. Kids like to go to the park a lot...It was just hard for me.”

The physical limitations of their bodies proved to be really frustrating for respondents as these limitations had a negative impact on how they could mother their children, minimizing or even eliminating activities that were important to them. A Latina mother said, “I use to love to dance—I was a dancer...I used to show them [my children] how to dance...Not anymore...I cannot dance too much.”

Why HIV Caused Respondents to Miss Out

Respondents stated that HIV had led to: (1) poor physical health, (2) poor mental health, and (3) feelings of stigma and secrecy. Each of these areas led to women being unable or unwilling to participate in activities with their child during the child’s growing up years.

Poor Physical Health

HIV took a toll on the health status of 94% of mothers who missed activities with their children. HIV led to overwhelming fatigue for respondents—women were so tired that they simply could not do activities with their child. An African American mother said, “Fatigue...I feel like I get tired—it will come like you can’t control it...It’s not tired whereby I will try and force myself. No—it’s that and that’s it.” Many respondents talked about HIV as negatively affecting their mothering because it caused them to simply be unable, at times, as one African American woman stated, to “get out of bed.”

Side effects from their HIV medications also negatively affected women’s physical health and subsequent ability to mother their child. A Latina mother said, “Many times he wanted me to take him to the park and I was...suffering from the side effects of the medicine. He got frustrated, angry...he really wanted more attention—the park.” When asked how many times she had to stop doing things with her child because of HIV, a Latina respondent replied, “Many...since I started taking medicine. Maybe we wanted to go out and we couldn’t because I felt like I was going to throw up.”

Sometimes women’s health deteriorated so badly that they ended up being hospitalized, for periods ranging from days to even months. When a multiracial respondent was asked about how much her illness caused her to miss out on activities with her child, she responded, “These last 2 years, a lot, because I have been in the hospital most of the time.” As mentioned earlier, hospitalizations caused women to be unable to do any of the daily care that their children required. Hospitalizations also seemed to affect the overall mother–child relationship in some cases, causing children to have difficulty coping with the separations. Mothers believed that young children simply did not understand these long separations:

I was so sick so it was hard taking care of him.... When they hospitalized me for three months straight, I wasn't there for him and I couldn't—three months seemed like not a long time, but it is for his age. He was like 2 or 3. He wanted momma and I couldn't be there.

Mothers stated that older children, too, had trouble coping with the long separations due to hospitalizations. One Latina mom said, “One day he came home from school and told me, ‘Mommy, I am going to tell you something...sometimes I am at school and I am thinking about the hospital and what is happening to you...that is happening to me a lot.’”

Poor Mental Health

Not only did HIV lead to physical health problems for respondents, but it led to mental health difficulties for 26% of respondents as well. These women voiced concerns about the impact that depression, anxiety, stress, worries and fears, and generalized emotional turmoil had on their ability to mother their children. An extreme example of this is a multiracial respondent who reported having to repeatedly go to the emergency department of a local hospital (bringing her child with her) because of panic attacks. She explained how her HIV coupled with her mothering role led to this extreme anxiety, “I think the reason I had the anxiety attack [was] because I thinking I going to die and nobody take care of him [her son].” A Latina woman explained how depression affected her mothering abilities:

I was so much in my own world and so much wrapped up in myself and my own crap. You know, I couldn't put it aside to take care of him and to really be there as he needed me to be...It was because of my illness...I'd rather sit home and do nothing in my depression than get out of it and let him have more of a normal childhood.

Feelings of Stigma and Secrecy

For four respondents, HIV led to a sense of shame and stigma that negatively affected how women mothered their kids, including what activities they could do for and with their children. An African American woman described the stigma of HIV as follows: “It's very much [like] I have been defiled.” Women talked about avoiding social situations because they feared others might guess their HIV status. An African American mom avoided her child's school activities because “I wanted to hide...I was very ashamed.” A white mom avoided going on group camping

trips with her child and others because “I didn't want anyone else [in the] group to know what I was.” Women also talked about avoiding social situations because they feared the stigma of their HIV might “rub off” onto their child. A Latina mother said:

I was more fearful about being open about my status in her school activities...afraid if they knew my status they would take it out on him. So, I really kept my distance...I was afraid if they knew, it was going to reflect on him.

Mothers Who Did Not Experience “Missing Out”

A total of 23 of the 57 mothers in this study (40%) felt their HIV had not caused them to miss activities with their children. The primary reason given by 78% of these women was sheer good fortune that they had remained in good physical health, despite their HIV diagnosis. A respondent said, “I pretty much haven't been ill during their whole life...God's blessed me.” Respondents seemed to recognize the importance of the “timing” of their HIV disease—having “good periods” during their child's growing up years allowed them to fully mother their children. A Latina mother, whose youngest child is now grown up, said:

My boys are older—they're men. Now I'm failing...It's the timing of the illness. If somebody is as ill as I am today and have little ones, I feel really bad for them because you can't do anything. You are that zapped...I mean, it takes a lot of energy to raise kids.

While enjoying good health, 17% (4/23) women found that their HIV inspired them to do more (rather than less) with their children. An African American woman said, “I did more with John than I would have if I had not been [HIV positive] because of the fact that I wanted to spend more time...do everything...every moment was precious...more so than before.” When asked if her HIV had caused her to miss out on activities with her children, a white mother replied, “I don't think it did at all. I think it caused us [to do] more.”

Several mothers (17.4%) reported using coping strategies to manage significant physical limitations due to HIV so that they would not miss out on their children's activities; these women acknowledged that they would simply “power through” such limitations in order to still do all the “normal” activities with their children. An African American mother said, “Sometimes I feel like I need to take a nap. I just push myself and just go and catch up with rest later.” A Latina woman explained how, even while experiencing a bad vaginal infection, she did not stop to

rest and recover: “I do not have time to lay down [at] home.”

An African American respondent had an unusual way of “powering through” her feelings of illness associated with her HIV medications’ side effects—she simply stopped taking them whenever there was an important event for which she needed to be present during her child’s growing up years. Non-adherence to her HIV medications allowed her to mother her child how she ideally wanted to mother him:

When I knew there was something going on, I didn’t take the medicine...holidays, school events...things like that? I don’t take the medicine because if I take the medicine, I’m going to be sleepy, I’m going to have diarrhea, I’m going to be nauseated, dizzy, can’t drive, pain in my legs, all that. When I don’t take the medicine, I’m fine.

Demographic Characteristics and Missing Out

Table 2 presents the percentages of women in each racial/ethnic group who reported missing out or not missing out on activities with their children due to their HIV. Although not statistically significant, among African Americans and Latinas, more reported missing out than not missing out.

Table 2 Demographic characteristics by whether mothers reported missing out on activities with their children due to HIV (*N* = 57)

	% did not miss out	% missed out	Statistical test	<i>p</i>
Race/ethnicity			$\chi^2_{(3)} = 4.9$.182
African American (<i>n</i> = 20)	35%	65%		
Latina (<i>n</i> = 27)	44%	56%		
White (<i>n</i> = 6)	67%	33%		
Multiracial (<i>n</i> = 4)	0%	100%		
Language preference			$\chi^2_{(1)} = 1.2$.275
Spanish (<i>n</i> = 20)	50%	50%		
English (<i>n</i> = 37)	35%	65%		
Mothers’ marital status			$\chi^2_{(3)} = 10.6$.014
Married (<i>n</i> = 7)	71%	29%		
Separated/divorced (<i>n</i> = 21)	14%	86%		
Widowed (<i>n</i> = 9)	44%	56%		
Never married (<i>n</i> = 20)	55%	45%		
Child’s gender			$\chi^2_{(1)} = 0.0$.962
Female (<i>n</i> = 32)	41%	59%		
Male (<i>n</i> = 25)	40%	60%		
Mother’s age <i>M</i> (<i>SD</i>)	42.8 (3.9)	44.9 (6.5)	$t_{(55)} = -1.4$.177
Child’s age <i>M</i> (<i>SD</i>)	18.0 (1.9)	18.2 (1.9)	$t_{(55)} = -0.4$.690

All multiracial respondents reported missing out. Only among white respondents did more report not missing out than missing out on activities with their children due to their disease. In line with this, no white women reported missing school and extracurricular activities, the most frequently mentioned theme among the sample as a whole, nor did any white women mention poor mental health as a reason for missing activities. Also, as indicated in Table 2, married women were less likely to report missing out on their children’s activities relative to those who were not currently married.

Discussion

Mothers living with HIV/AIDS (MLHs) already have a number of problems to deal with before taking into account their HIV status and their parenting role. First, most HIV-infected women fall in the lowest socioeconomic class and are faced with barriers to health care (Ickovics and Rodin 1992). Overall, women with HIV are disproportionately low-income, with 64% having annual incomes below \$10,000 compared to 41% of HIV positive men (Bozette et al. 1998). Hough et al. (2003) found that in one metropolitan area, overall, 96% of mothers with HIV/AIDS were on public assistance—factors which put them at risk for emotional distress. In addition, most live in large metropolitan areas (CDC 2008), often in neighborhoods with high crime rates, and are faced with multiple adversities. These mothers also have to deal with having a chronic, stigmatized illness while performing their parenting role.

Similar to previous research (Van Loon 2000; Tompkins et al. 1999) our findings provide detailed qualitative data describing the impact HIV has had on mothering. The current study provides specific activities, events and experiences MLHs missed with their children over an average of 14 years due to their HIV status. Previous research indicates 38% of MLHs had limited their activities with their children due to their illness (Tompkins et al. 1999), whereas a higher rate (60%) was observed in our study. The types of activities that mothers missed ranged from daily routines to major events in the child’s development (e.g., school play, sporting event, etc.) However, it was the “small” things, such as being able to run and play outside with one’s children that were the most difficult for many women to deal with. The wide variety of activities missed with their children highlights the difficulty HIV positive women face in managing their disease while caring for their children.

The intensity/severity of how much mothers missed ranged; however, for some mothers lengthy hospitalizations led to not only missing some of their child’s events, but being completely unable to function in the mother role

at those times, since they were not at home. Such breaks in the parent–child relationship, added to the activities missed due to the disease or medication side effects, would be expected to have strong effects on the parent–child relationship. This is consistent with the model proposed by Armistead et al. (1995) in which the degree of incapacitation is considered an important dimension of physical illness that has serious implications for the amount of stress imposed upon the family, and the degree to which parenting abilities may be disrupted.

Results from this study also highlight that for HIV, as with many chronic illnesses, mothers' ability to fulfill their parenting role varies with changes in health. Poor physical health was the primary reason women noted for why they had missed activities with their children. A respondent poignantly noted that she would have been unable to mother her children well if she had been very ill while they were young. This comment underscores the fact that as women's illness trajectories worsen, so does their ability to mother their children. Women in this study who had remained healthy reported showing up to every school conference, never missing a play or sporting event. Those who had the misfortune to be less healthy were forced to miss out on these as well as the other, smaller, day-to-day activities with their children, such as taking a walk or bike ride together. This supports previous research in which declining health status of MLHs was found to change role performance for some mothers who were no longer able to meet the day-to-day needs of their children (Van Loon 2000).

The mothers missed activities with their children due to their HIV disease, but even this is complicated, because it was not simply the physical effects of illness that caused lack of participation, but also related mental health problems and perceived stigma. Similarly, a qualitative study of the challenges parents face when living with HIV concluded that the lives of HIV positive parents have become complicated and exhausting, and these complications stem from discrimination, being a single parent, and the parents' changing physical and mental health status (Antle et al. 2001). In terms of the physical impact of the disease, one issue that was common among the women was fatigue. This is consistent with previous research indicating fatigue is one of the most troublesome symptoms experienced by HIV positive women (van Servellen et al. 1998), and of those who limited their activities with their children due to HIV, 88% did so due to increased fatigue (Tompkins et al. 1999). While treatment for HIV has improved significantly over the years, this study indicates that HIV positive moms who are on ARV medication regimens miss out on significant parts of their children's lives. In fact, while the medications may be prolonging the life of these mothers, in some cases they

feel forced into a choice between mothering ability and their own health, including adherence to their medicines. Studies suggest there are multiple influences on ARV adherence that change over time, and intentional non-adherence frequently stems from physical side effects (Remien et al. 2003). Our study provides added detail to illustrate these findings, suggesting if MLHs' medication regimens cause them to miss a significant event in their child's life, they may decide at times to forego taking the medication in order to be able to participate.

On the other hand, as medication regimens have improved, many of our HIV-infected mothers have been able to live fairly "normal" lives. In this study, a large group of women said they had remained very healthy, and reported not missing many of their kids' activities. However, some coping strategies that these mothers employed, such as "powering through" and forcing themselves to do activities instead of rest, may actually be detrimental for the course of their HIV disease. Thus, in numerous ways, HIV positive mothers are forced into making decisions at times that may negatively impact their own health, in order to fulfill their maternal parenting role.

Mental health difficulties such as depression and anxiety are common with those coping with a chronic illness such as HIV, and such problems also affect how women mother their children. Our findings suggest that a significant proportion of HIV positive women who experience psychological distress may feel unable or unwilling to participate fully in their children's lives during their developmental years. Armistead et al. (1995) note that for parental illnesses with a progressive course such as HIV/AIDS, parents are often likely to experience depression, which in turn has been shown to disrupt parenting. Such problems also can lead to the need for increased health care utilization, which in turn can take time away from parental pursuits. Finally, and related, the stigma of HIV also has a negative impact on women spending time with their children. Mothers in this study avoided social situations with their children in order to both reduce the risk of others finding out about their disease and minimize the chance that the stigma of their disease would "spread" to their children.

While this study provides a unique and important glimpse into the difficulties faced by HIV positive mothers, the study also has several limitations. First, although the impact of experiences described by study respondents, such as fatigue and stigma, would perhaps affect parenting for MLHs overall, the exploratory, qualitative nature of the design limits the generalizability of the results. In addition, the study relies on retrospective recall, thus, potential memory problems overall or related to HIV disease may have affected respondents' ability to fully remember and report their experiences and activities. Future studies could aim to explore the challenges faced by HIV positive

women in their mothering roles with larger samples of women recruited from more diverse geographic locales.

These study findings carry implications for future research and interventions to support families affected by maternal HIV. Results highlight the importance of focusing attention on the children of HIV positive mothers. Discerning what mothers' and children's perceptions are of mothers' involvement/engagement in their children's activities may lead to interventions to help HIV-affected children better cope during the "bad" times of mothers' illness trajectories. In addition, there is a need for intervention strategies that assist MLHs in negotiating the multiple challenges of self care and parenting/family activities.

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