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Adolescent Response to Having an HIV-infected Mother

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Abstract

In this study, late adolescents/early adults whose mothers were living with HIV (MLH) were interviewed in order to explore their perceptions of what it had been like for them to grow up under the shadow of their mothers' illness. Adolescents were asked to describe what the difficult aspects of growing up with an HIV-positive mother were as well as what, if any, were the more rewarding aspects. Interviews were conducted in 2009 - 2010 with a random sample of 40 adolescents being followed in a longitudinal assessment study. All study participants were English or Spanish speaking. Mean age was 18.9 ($SD = 1.9$) years; 67.5% were Latino; 27.5% African American; and 5% other/multi-racial. Results revealed that growing up with an HIV-positive mother had both challenges as well as rewards. On the challenge side, adolescents mentioned six main issues: (1) disappointment regarding mothers' missing of childhood activities and events; (2) worry about mothers' health; (3) worry about the possibility of mothers' death; (4) increased burden of adult responsibilities/caregiving; (5) feelings of secrecy/stigma associated with HIV/AIDS; and (6) need to self-monitor behavior and communication to avoid maternal stress. On the positive side, adolescents mentioned three main rewarding aspects of growing up with an HIV-positive mother: increased closeness in the mother-child relationship; fostering of positive personality traits (e.g., resilience, gratitude, open-mindedness); and "perks" accorded to HIV-affected families.

Keywords

HIV+ Mothers; Family Functioning; Chronic Illness; Qualitative Interviews; Longitudinal Study

A relationship exists between parental illness and child functioning (Armistead, Klein, & Forehand, 1995), through parental physical illness directly disrupting parenting, or indirectly through increased parental depression and/or increased uncertainty and conflict within the family relationship. Adolescents living with an HIV-infected mother live under considerable stress, as such families are exposed to risk factors such as stigma; economic deprivation; acute and chronic illness of the mother; and separations due to maternal hospitalizations (e.g., Gilbert, 2001; Lewis, 1995; Sowell et al., 1997). In families in which a parent becomes ill, there can be to some extent a role reversal in which the adolescent caretaking functions for the parent. Finally, these adolescents must cope with all of these risk factors as they are transitioning through a difficult developmental period.

It is not surprising researchers have suggested that adolescents with HIV+ mothers are at risk for alcohol and drug use (Rosenblum et al., 2005), and mental health problems (Havens

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& Mellins, 2008; Mellins, Kang, Leu, Havens, & Chesney, 2003). Higher rates of emotional and behavioral problems have been found among adolescents with an HIV-infected parent compared to youth with healthy parents (e.g., Esposito et al., 1999; Forehand et al., 1998; Forsyth, Damour, Nagler, & Adnopo, 1996). Worse physical functioning of mothers is associated with poorer 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, Marelich, Herbeck, & Payne, 2009).

On the other hand, some studies found no group differences between adolescents with an HIV-infected mother compared to adolescents with a non-infected mother. Mellins et al. (2008) found no difference on mental health outcomes: only youth knowledge of mother's HIV infection and overall health were associated with worse youth outcomes. Among adolescents with an HIV-infected mother compared to adolescents with uninfected mothers from ethnic minority, inner city communities, no differences were found in risk behaviors (i.e., sexual activity, alcohol/drug use; Mellins, Brackis-Cott, Dolezal, & Meyer-Bahlburg, 2005). The authors suggested that if there is additional risk of maternal HIV status it may be balanced out by protective factors, such as increased knowledge of negative ramifications of sexual and drug use.

While there have been a number of studies investigating family functioning from the perspective of HIV-positive mothers (e.g., Brackis-Cott, Mellins, Dolezal, & Spiegel, 2007; Murphy, Greenwell, Resell, Brecht, & Schuster, 2008; Murphy et al., 2009), literature on the impact of maternal HIV on adolescents from the perspective of the adolescent is very limited. One such study (Brackis-Cott, Mellins, & Block, 2003) conducted focus groups with regard to current life concerns among inner-city HIV-negative adolescents and their mothers--half of whom were HIV-positive and half HIV-negative. All adolescents were concerned about sexual activity, pregnancy, violence, and drugs. Adolescents whose mothers were HIV-positive also expressed concern about maternal health and death, adult responsibilities, and uncertainty about their future. Interestingly, when adolescents of HIV+ mothers were asked about the influence of maternal HIV on their life, initial responses were "no big deal" (Brackis-Cott et al., 2003, pg. 60). However, as they became more comfortable in the groups, they admitted more concerns and fears.

In this study, late adolescents/early adults with a MLH were interviewed to explore their perceptions of what it had been like for them to grow up under the shadow of their mothers' illness. Adolescents described difficult aspects of growing up with an HIV-positive mother as well as what, if any, were the more rewarding aspects.

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 beginning in 1997 when the children were age 5 – 11. In 2002, the PACT II study continued to follow 81 original families as the children transitioned to early and middle adolescence, along with 37 new families (N = 118). The final study, PACT III, followed families (N = 95) beginning in 2008, as the early/middle adolescents transitioned to late adolescence/early adulthood. Qualitative interviews were conducted in 2009 - 2010 with a random sample of 40 youth (see Table 1).

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 minutes, and were digitally taped and transcribed. Participants were paid \$30 for participation. Respondents were asked: “How do you think your mom being HIV positive affected your relationship with her?; What were some of the scary parts about growing up with a mom who is HIV positive?; We talked a lot about some of the down sides to having a mom who is HIV positive, how about the up sides?” Questions were open-ended and follow-up probes explored topics that emerged during interviews.

Data analysis

Multiple readings of transcripts were performed by two members of the research team to identify major themes (Strauss & Corbin, 1990). Next, the second author (a Ph.D. level researcher who has been conducting qualitative research for about 15 years) conducted a line-by-line review of transcripts and field-notes. First-level codes were noted. 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 reviewed, and sub-codes were established to divide the first-level codes into smaller categories. Results correspond to the emergent categories.

Results

Adolescents revealed that growing up with an HIV-positive mother had both challenges and rewards. On the challenge side, adolescents mentioned six issues: (1) disappointment regarding mothers’ missing of childhood activities; (2) worry about mothers’ health; (3) worry about mothers’ death; (4) increased responsibilities/caregiving; (5) secrecy/stigma; and (6) need to self-monitor behavior and communication to avoid maternal stress. On the positive side, adolescents mentioned three rewarding aspects: increased closeness in the mother-child relationship; fostering of positive personality traits; and “perks” accorded to HIV-affected families.

Challenges

Disappointment about mothers’ missing of childhood activities—Respondents (60%) stated that one difficult aspect of growing up with a mother suffering from HIV/AIDS was the fact illness forced moms to miss childhood events.

“Sports, pretty much [she missed] four years [of games]” (18-year-old African American male).

“Playtime ... she never played with me” (19-year-old Latino male).

“Shopping ... the mall ... my mom wouldn’t even take me to the mall” (19-year-old Latina female).

“A lot of field trips. Six Flags. The school’s dances” (15-year-old Latina female).

For some, being ill and missing activities made their mother seem “different” than other moms. An 18-year-old Latino explained:

I’m going to school. People talk about their moms, what they do, this and that, and my mom, she never did anything ... Other people’s moms have a car ... a job ... I feel like they would make fun of me or my mom ... I would have this anger toward her—like why can’t you be like other moms? Why do you have to have HIV?

Worry about mothers' health—Close to half (42.5%) of respondents mentioned childhoods filled with concern for their mothers' physical health. In some cases, living with a mother with HIV/AIDS felt akin to a rollercoaster ride—the child never knowing what was around the next bend. An 18-year-old African American male explained: “Getting sick easy ... sudden changes ... [she] could be good one day, sick another day.” This could be disruptive to children's sense of security as a 21-year-old African American woman stated:

When she got sick or if I came home from school and they say ‘Your mom’s in the hospital, you have to stay with our aunt for a month ...’ I don’t want to leave my home! I don’t like living with other people.

Respondents also worried about their mothers' HIV/AIDS medications. A 19-year-old Latino male said medication side effects caused discord: “One minute she would be calm and happy and the next minute she’ll get upset ... later she’ll tell me ‘I’m on medication and it’s affecting my mood.’” An 18-year-old African American girl said, “I just worry about her more ... is she taking her meds? Is she okay?”

Their mothers' HIV/AIDS also led children to worry more about mundane health problems. A 17-year-old Latina disclosed, “Anytime she gets a cold or allergies, I get scared ... and want to take her to the ER.” A 17-year-old African American girl said, “Every time my mother gets a cold it’s like a stillness runs over the house ... she gets sick ... we get scared ... she’s not like everybody else.”

Worry about possibility of mothers' death—Almost a third (27.5%) of respondents worried about the possibility of their mothers' death. A 19-year-old Latino male revealed, “Knowing she might die on me, it was really stressful.” The worry about maternal death brought up strong feelings. An 18-year-old Latino said he experienced “feelings about depreciation [sic], loneliness, like I’m about to get abandoned by my mom.”

Increased burden of adult responsibilities/caregiving—A quarter of respondents (25%) mentioned they had increased responsibilities/caregiving during childhood. A 19-year-old multi-racial/ethnic male said: “I just grew up [too fast]. I ... missed out on a lot.” A 20-year-old Latina said, “It [HIV/AIDS] was just ... it just made me have to grow up faster ... I’m the oldest so I have to take care of them [siblings].” Sometimes they felt they were parenting their mothers rather than being parented by them. A 20-year-old Latina respondent said, “It sucks that I have to be the mom.” Likewise, a 19-year-old Latina girl explained:

[Normal kids] don’t have to worry about asking their mom ... “Hey, have you taken your medicine? Have you ate? Are you dizzy? Why do you look pale? Are you cold?” I felt like I had to be the parent ... health-wise.

Feelings of secrecy/stigma—A quarter (25%) of respondents mentioned stigma and/or secrecy as being a challenge. An 18-year-old African American girl said, “We went through a lot because certain people ... look at her differently ...” Sometimes it was the child that did the stigmatizing, leading to feelings of guilt and anxiety. An 18-year-old Latino boy said, “I got mad at her ... like I would blame her, like, ‘Oh, it’s your fault ... you’re dirty.’”

Secretive aspects included source of infection and disease course. An 18-year old Latina girl explained, “I used to think bad. Why did she get it? What happened? I want to know...it made me feel unimportant ... they never told me.” Similarly, a 22-year-old Latino male confessed, “I just wondered how she got it but I would never ask that.” A 17-year-old African American girl explained how her mom had a very closed-lip approach to discussing her illness:

I feel powerless ... I can't save my mother ... she says that's not my job. I shouldn't worry about her. And I think ... 'Who the hell do you think you are talking to?' I would definitely, honestly say that ... my mom's [being] HIV positive did f*** up our relationship.'

Self-monitoring of behavior and communication to avoid maternal stress—

Some adolescents (22.5%) felt the need to self-monitor their behavior and communication in order to not upset their mothers (lest this result in worsening health). A 19-year-old multi-racial/ethnic male said, "I try not to burden her. I don't bring my issues up ... I wouldn't tell her about my problems." Keeping their mothers "in the dark" sometimes proved to be exceptionally challenging, as a 19-year-old Latina girl explained:

I could be so freakin' sad, went through something on the street. I have to come in here cheerful. That's why I know how to front so good ... I don't want her stressing out so it's like, 'Mom, everything's great,' and inside, I'm like, 'Mom, I'm f***** dying.

Rewards

Closer-mother-child bond—Almost all the adolescents (92.5%) disclosed that HIV/AIDS had led them to develop a closer relationship with their mom. A 16-year-old Latino said, "If anything it made it stronger, knowing that her time is ... could be limited ... led to a stronger relationship." As mentioned earlier, MLH illnesses led some children to assume caregiving tasks; the silver lining of this was feelings of closeness. A 15-year-old Latina said, "I thought it got us closer ... I wanted to always be taking care of her ... I don't see it in a bad way. I see it in a good way." A 17-year-old Latina said, "Got closer to her. We do everything we can to help her ..., with bills, cleaning house, getting groceries, everything."

Fostering of positive personality traits—Over half (60%) of respondents reported their mothers' HIV/AIDS engendered development of positive personality characteristics. A 17-year-old Latino said, "I just admire my mom for being ... strong, having that kind of hard life and getting hit with that [HIV]—another nail in the coffin—she's been able to beat the coffin/death." A 21-year-old African American woman said, "It always made me stronger each time seeing her sick and getting better, knowing she would continue." A 17-year-old Latina similarly said, "I think a lot of people who are HIV-positive, they always try to make the best of everything. My mom is a really happy person."

Some youth thought having a mother with this disease led them to be more open-minded. A 22-year-old multi-racial/ethnic respondent said his mom's illness led to his "being more mature about other people who have AIDS. I'm not freaked out by it." Likewise, a 16-year-old Latina said, "I got exposed to seeing like the different problems that everyone else is facing ... I've got exposed to ... the whole homosexual community." A 19-year-old Latino said: "It probably made me a better person ... more humble ... more educated ... not quick to judge people."

"Perks" for HIV-affected families—About a third of youth (30%) maintained that another "silver lining" was the perks the disease accorded them. A 22-year-old Latina said she enjoyed getting "free stuff ... like food ... and Christmas presents." Several youth discussed camps for HIV-affected children as opportunities for them to connect with others in similar circumstances. Because youth often lived with limited economic resources, these perks were a big deal, allowing them to do and experience things that otherwise would be out of reach.

Summary—In regard to gender, proportionately more girls than boys reported: their mothers missed childhood activities (18 vs. 9); and increased caregiving responsibilities (7 vs. 3) and the related “perk” of developing strength and resiliency (17 vs. 7). This may be a reflection of the gender norm of female serving as caregivers.

Discussion

We have rarely heard the perspective of youth affected by maternal HIV/AIDS, and when studies have included this perspective, it has often been from quantitative work where the ability to ascertain an in-depth understanding of how youth feel and function over time living with an HIV-positive mother is limited. This study sought to remedy this gap in the literature.

Some of the youth comments confirmed previous findings, such as concern about maternal health and death, and their own adult responsibilities (Brackis-Cott et al., 2003). However, youth in this study also brought up issues related to disappointment about what their mothers missed sharing with them in terms of childhood activities. This confirms findings from MLH, who also report a sense of loss over missed opportunities to participate in childhood activities due to fatigue or illness when their children were growing up (Murphy, Roberts, & Herbeck, 2012). In addition, youth in this study spoke of the burden of monitoring themselves in terms of their own behavior and communication with their mothers, in an attempt to lessen maternal stress. Both of these issues—missed events with their mothers as they grew up, as well as monitoring themselves to protect their MLH—appeared to cause some stress for youth and be a factor in terms of them “having to grow up too fast.” This came in the form of taking on added responsibilities and feeling the need to be sufficient unto themselves, since at times they could not count on their mother. While these factors may have some benefits in terms of making the adolescents stronger, it seems to come at a cost, which is apparent from reading their stories.

Another addition from this study to the literature is the fact that an overwhelming number of youth (92.5%) found a benefit in their mother dealing with HIV/AIDS, and a majority (60%) realized this had assisted in their development of positive personal characteristics. The fact that youth recognized value in their life due to watching their mother cope with HIV/AIDS may serve to mitigate for them some of the negative aspects that they reported.

Findings suggest children of MLH may benefit from supportive interventions throughout their developmental period, to help them cope not only with the long-term stressors they have lived with during their childhoods but also new stressors they face as adults pertaining to their mothers¹ illness. Findings here showed that the children often helped care for their MLH, so the transition to becoming an independent adult while helping to care for an ill mother may be difficult. Many MLH in this study have lived with HIV/AIDS for 15 years or more, and for many their health has declined over time. From these interviews, it is clear that some children who were “partial caregivers” may become more intensive caregivers. The issues of youth successfully becoming independent adults and starting their own families while a caregiver to an ill mother is an area ripe for investigation, as the HIV/AIDS diagnosis of one generation may continue to affect future generations in unknown ways.

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Table 1
Youth Demographics at Qualitative Interview (N = 40)

	<i>M or %</i>
Age (<i>M, SD</i>)	18.9 (1.9)
Female (%)	60.0
Ethnicity (%)	
Latino	67.5
African American	27.5
Other/multi-racial	5.0
Education (%)	
Dropped out of high school	7.5
Currently in high school	45.0
Completed high school	35.0
Completed some college/vocational school	12.5
Currently employed	42.5