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## HIV-Positive Mothers With Late Adolescent/Early Adult Children: “Empty Nest” Concerns

**Debra A. Murphy, Kathleen Johnston Roberts, and Diane M. Herbeck**

Health Risk Reduction Projects, Integrated Substance Abuse Programs, Department of Psychiatry, University of California at Los Angeles, Los Angeles, California, USA

### Abstract

In-depth interviews about the “empty nest” were conducted with 57 HIV-positive mothers of late adolescent/early adult children. Empty nest worries included: (1) identity loss, (2) loss of social support, (3) financial insecurity, (4) worsening of physical health, and (5) death/dying. Hopes included: (1) self-improvement, (2) change of life focus, (3) travel, (4) romantic partners, and (5) familial ties. Respondents’ HIV/AIDS status colored their thoughts/feelings about the empty nest; some worries were specific to being HIV-positive, and would not occur for non-ill mothers. Midlife HIV positive women need healthcare/social service resources as they navigate health and social-psychological challenges to successful aging.

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The purpose of this study was to allow mothers living with HIV who have late adolescent/early adult children to tell their own stories about “empty nest syndrome” experiences. There has been very limited research conducted with mothers and empty nest in general, and even fewer studies conducted with mothers living with HIV (MLH). We found that even within concerns and hopes related to empty nest that you could expect would be typical of all mothers, the effect of their illness on MLH impacts how they experience these changes. While the sample of MLH for the present study was from one state in the U.S. (California), empty nest syndrome is prevalent in many countries and cultures (Mbaeze & Ukwandu, 2011; Mitchell & Lovegreen, 2009).

As adolescents of MLH transition to late adolescence/early adulthood, the MLHs may experience “empty nest” syndrome—defined as the phase of life when children become independent. In some studies this has been defined as the young adult leaving home; in other cases as independence from the parent even if still at home, since there is an increasing recognition that early adults may not leave due to low entry salaries and high cost of housing and unemployment, or leave but return due to increasing divorce and/or age at first marriage (e.g., Dennerstein, Dudley, & Guthrie, 2002).

Whether “empty nest syndrome” is always negative for mothers, or if it has positive aspects, has not always been clear in previous literature. Early investigator in the area of empty nest proposed that this period was traumatic and negative because of the loss of the parenting role that served as a source of meaning and purpose in mothers’ lives (e.g., Glenn, 1975), and indeed, a few researchers conducting early clinical studies found that mothers reported depression following the empty-nest period (e.g., Bart, 1972; Curlee, 1969), and other studies found increased marital conflict and low marital satisfaction during the transition to empty nest (e.g., Barber, 1989). But many of these study designs had methodological flaws

(Dennerstein et al., 2002), and there has been considerable social change in women's roles over the past few decades. Some investigators reported that mothers do not find this period to be stressful (Barber, 1989; Dennerstein et al., 2002), and that while they may experience some concern about the transition, they also may sense opportunity. White and Edwards (1990) had earlier found that empty nest was associated with improvement in overall life satisfaction when there was frequent contact with the nonresident children. In a longitudinal study on mothers' quality of life, Dennerstein and colleagues (2002) found that in the first year after the last child departed the home, there was an improvement in mothers' positive mood and total well being and a reduction in negative mood and number of daily hassles. However, this result was limited to those mothers who at baseline were not worried about their children leaving home.

Many parents enjoy greater freedom and more time to pursue their own goals and interests once their children leave home, plus seeing the child start toward successful adulthood may engender feeling of happiness and pride (e.g., Fingerman, 2000). Findings that the post-parental stage does not have negative consequences on psychological and physical well being have been replicated among Mexican-American women (Rogers & Markides, 1989). Bedford and Blieszner (1997) found that the empty nest phase may also bring about other positive outcomes, such as mothers being able to renew ties with other family members more strongly once children leave home.

There has been a growing recognition of the "feminization" of HIV, in that women are the fastest growing population infected with HIV (Quinn & Overbaugh, 2005; Wingwood, 2003). Women account for nearly half of the 40 million people living with HIV worldwide, with even higher proportions in developing countries (Quinn & Overbaugh, 2005). HIV-positive mothers in the United States experiencing "empty nest" often face unique life circumstances that may affect how they handle their child becoming independent and/or leaving home. These women often live in disenfranchised communities that are plagued by high rates of poverty and violence. They often have low incomes, are women of color, and have important family responsibilities, potentially complicating the management of their illness (Kates & Carbaugh, 2006). Moreover, HIV positive women have been found to be in poorer health and succumb to AIDS faster than men (Keigher, Stevens, & Plach, 2004).

As treatments for HIV improve, the "graying" of HIV has also been recognized (Emlet, Gerkin, & Orel, 2009; Poindexter & Keigher, 2004), and it is estimated that by 2015, about half of all HIV-positive individuals will be older than 50 (Rivero, 2011). In 1994, 8% of women with AIDS were over the age of 50, and by 2000, that proportion had nearly doubled to 15% (Centers for Disease Control, 2000). With the numbers of women and older adults living with HIV increasing, issues and challenges faced during the menopausal transition stage of life are expected to take on greater significance and affect growing numbers of MLHs. However, upon review of current status and challenges of HIV interventions for midlife, Levy, Ory and Crystal (2003) concluded that despite recognition of the increasing experience of HIV/AIDS at later stages of the life course, we still know little of how HIV/AIDS affects older adults.

Menopausal transition can, over the short term, represent a source of stress for some women, including transient worsening of sleep and mood (Grady & Sawaya, 2005). Over the long term, menopause brings with it an increased concern about chronic diseases of aging (e.g., cardiovascular disease, type 2 diabetes mellitus, osteoporosis, and increased risk of some types of cancer) and research indicates that compared to HIV negative women, positive women are at heightened risk for these diseases (Santoro, Fan, Maslow, & Schoenbaum, 2009). Older HIV positive women have also been found to have different social support needs than their younger counterparts. A study by Emlet, Tangenburg, and Siverson (2002)

found that older women attending HIV support groups reported they could not relate to issues addressed in groups with younger women (e.g., pregnancy and vertical transmission), however, groups that address issues such as menopause, bodily changes, and interacting with their adult children better met their needs. Emlet et al. (2002) also found that problems specific to poverty, racism, sexism and HIV stigma remained relevant regardless of age.

In addition, for mothers living with HIV, “empty nest syndrome” may be experienced differently, since many of these women have been living long-term with a chronic illness. Some of them may have relied on their adolescents to assist them in illness-related areas, including reminders to take medication, and doing household chores when MLHs were fatigued. Other mothers, through perceived stigma or physical fatigue, may have limited their social contacts and relied heavily on their early adult children for social support.

Few studies have been conducted in the area of HIV-positive mothers facing the empty nest time of their lives. Keigher et al. (2004) conducted a qualitative study of the prospects for successful aging for nine midlife women living with HIV, and found they have a complex set of health, social, and economic needs that they will bring to the health care and social service systems as they age. These women struggled with dwindling financial resources, conflictual relationships with their adult children, and a range of obstacles to successful aging.

In this study we explored the maternal transition to “empty nest” for mothers living with HIV. In order to allow women to “tell their own stories” about their empty nest experiences, a qualitative methodology was utilized. In-depth interviews were conducted with HIV-positive mothers of late adolescent/early adult children, in which the mothers were asked about the empty nest stage of their lives, including thoughts and concerns they had for themselves, as well as any concerns they had about their children; most importantly, they were asked how their HIV status affected their concerns.

## Methods

### Participants

The Parents and Adolescents Coping Together III study (PACT III) is a continuation of two longitudinal studies (PACT and PACT II) that assessed mothers with HIV/AIDS and their HIV-negative children. The Parents And children Coping Together (PACT) study followed a sample of 135 families every six months for 30 months beginning in 1997 when the children were age 6–11. Mothers were recruited from clinical primary care sites and AIDS service organizations in Los Angeles County. Medical records abstraction of CD4 count and viral load were reviewed to verify diagnosis and study eligibility. In 2002, in PACT II, we continued to follow 81 of the original families, plus and additional 37 new families, every six months for 36 months as the children transitioned to early and middle adolescence. Attrition analyses indicate that PACT families who participated in PACT II did not differ on primary demographic, behavioral or health variables from those who did not (Murphy, Greenwell, Mouttapa, Brecht, & Schuster, 2006). In our final study, PACT III, we followed 96 of the 118 PACT II families every six months for 36 months as the early/middle adolescents transition to late adolescence/early adulthood. Baseline interviews were conducted with mothers ( $n = 88$ ) and youth ( $n = 95$ ) in 2008.

Of the 30 mothers in PACT II who did not participate in PACT III, 12 have died; three lost custody; thirteen were out of the country or could not be located; and two declined to participate. Of the surviving mothers with custody who participated in PACT II ( $n = 103$ ), 85.4% are participating in PACT III. Institutional review board approval was obtained for

the study protocol, and informed consent was obtained from all study participants. All study participants were English or Spanish speaking.

A random sample of all English-speaking mothers and two-thirds of Spanish-speaking mothers were drawn from the sample of 88 PACT III mothers. The full sample of Spanish-speaking mothers was not included because over half of the sample (53%) was Spanish-speaking, and the cost of translating and transcribing more than half of the interviews was prohibitive. However, the final qualitative study sample consisted of a large proportion of Spanish-speaking participants (35%,  $n = 20$ ). Participants were continuously selected and interviewed until it was determined that the same themes, trends and types of responses were repeated numerous times. A total of 57 mothers were asked to participate in the qualitative interview, and all 57 signed the consent form and completed the interview. Participants did not differ from those in the larger study in terms of age, education, marital status, or child's gender. Although nearly half of the qualitative study participants were Latina, in the full sample 62% were Latina ( $p < .05$ ).

Of the mothers participating in the qualitative interview, 47.4% were Latina; 35.1% African American; 10.5% White (non-Latina); and 7.0% other race. On average, the mothers had completed 11.9 ( $SD = 6.2$ ) years of education and 38.6% were employed in the last month; 12.3% were currently married, 36.9% were separated or divorced, 15.8% were widowed, and 35.1% were never married. The mothers' mean age was 44.1 ( $SD = 5.6$ ) years, and they reported an average of 14.2 years since they first tested positive for HIV ( $SD = 3.8$ , range 5–23). About half (56.1%) of their children in the study were male with a mean age of 18.1 ( $SD = 1.9$ ) years. Nineteen percent of the youth have already left home; the rest of the youth are living at home with the mother but will be entering adulthood and are likely to leave home within the next couple of years.

### Data collection

Semi-structured interviews ( $N = 57$ ) were conducted in participants' homes by an interviewer trained in qualitative procedures. Interviews lasted approximately 60 minutes and were digitally audio taped and transcribed. Spanish-speaking subjects were interviewed in Spanish. The Spanish transcripts were translated and back-translated by the Worldwide Translation Center (WTC) in San Diego, CA. A team of three translators including a professional translator, an editor for translation and grammar accuracy, and a style editor conducted the translations. Participants were paid \$20 for participation.

Respondents were asked about the empty nest stage of their lives, including what worries or concerns they had for both themselves and their children during this time and if/how their HIV played a role in these worries. All questions were open-ended and interviewers used probes to explore topics that emerged during the course of the interviews.

### Data analysis

This study utilized a two-stage data analysis protocol. First, in line with traditional qualitative thematic analysis (Braun & Clarke, 2006), all transcripts were read and re-read multiple times by two members of the research team (K.J.R. & D.M.) in order to identify patterns (themes) within the data. An inductive approach was used to identify the themes: the themes emerged directly from the data rather than being preconceived by the researchers. A codebook describing these themes was created. One member of the research team (K.J.R., a Ph.D. level researcher who has been conducting qualitative research in the field of HIV/AIDS for about 15 years) then reviewed all transcripts line-by-line and noted relevant codes 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).

In the second stage of analysis, a content analysis was undertaken in order to evaluate the prevalence of the themes across respondents. Specifically, Ethnograph was used to print all chunks of data, for each of the respondents, for each of the key themes. Counts were then taken of how often participants mentioned each theme. This mixed approach allowed the key themes to emerge directly from the respondents' experiences and accounts, but also allowed for counts to determine the prevalence of the themes across respondents.

In order to maximize the credibility/trustworthiness of the findings, steps were taken to bolster the transparency, consistency, and communicability of the data (Rubin & 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 transcripts. During the coding process, any discrepancies regarding coding categories were discussed by the researchers until agreement was achieved. Consistency refers to 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, quotations drawn directly from the transcripts are presented to explicate each theme.

## Results

Respondents' thoughts and feelings about the empty nest period of their lives were complex. They had numerous worries about this life period but they also voiced hopes for the future. Specifically, the most common worries expressed by respondents regarding the empty nest period of their lives related to: (1) loss of social support, (2) worsening of physical health, (3) loss of identity, (4) death/dying, and (5) financial insecurity. The most common positive aspirations regarding the empty nest period of their lives related to: (1) self-improvement, (2) change of life focus, (3) travel, (4) romantic partners, and (5) familial ties.

### Concerns About the Empty Nest Period

**Loss of social support**—The most common worry, expressed by 53% of respondents, was that the empty nest period would result in a loss of social support. For many of these mothers, their children were a major part of their social worlds. A mother said, "I do not have anyone .... My family is my two daughters." Another mom said, "I depend on her a lot and she's the only other one than my mother that I depend on." Hence, the empty nest period for women was akin to losing major components of social support. One woman summed up the empty nest period very well by saying, "Damn! Why did I have kids? All they do is grow up and leave!" Not surprisingly, some women acknowledged that they were not ready to loosen their social bonds with their children. A participant stated, "I'm not ready to cut the strings. Just talking about it makes me cry." Another mother said: "I am going to feel like an abandoned puppy." The loss or potential loss of these important social bonds was incredibly difficult for some participants. Another mom described her child's moving out as "everything collapsed on me ... in a single moment, I lost everything."

Having their children with them at home filled up the space in participants' homes and their lives. A mother said, "When we are faced with a terminal illness, our security usually comes from those we love .... Considering a separation of Hannah moving out on her own--me being left behind--is scary for me."

**Worsening of physical health**—About half of the respondents (49%) worried that their HIV would worsen during the empty nest period of their lives: "I am worried that my condition will get worst [sic]." These HIV-positive mothers recognized the link between the stressors of the empty nest period and the potential worsening of their health status. A respondent said, "If I get very depressed ... the [T-] cells go down." Another woman stated, "Your happiness affects your immune system and because HIV is obviously your immune system ... anything bad that happens is going to affect that .... So I think it [the empty nest] would definitely make me sicker."

Many mothers acknowledged that their children served as their caretakers during bouts of illness. They worried there would be no one around to take care of them when they become ill. A mother said, "There won't be nobody to help me ... if I would get sick." Since their children often were the only ones who had ever taken care of them in the past, some participants had no idea who would step up to fill that role. A woman said, "I am scared ... if I get sick I do not have them next to me .... Lisa is the only one ... that has worried about me, and the only one that has been there when I was sick."

Some mothers acknowledged they would miss their children's help in other domains, including grocery shopping, cleaning, cooking, driving, and running errands. A mother said, "She makes me dinner. When she left home three months ago, I was like 'Who's going to fix the meals? Who's going to fix the meals?'" Another mother stated that she would miss her son because of "help he will give me, like little handy man, little things he'll do around the house ...." Such support was absolutely vital during periods of severe illness when women simply could not do these tasks for themselves. A woman said:

I do miss him ... I leaned on him a lot through his whole life ... I leaned on both my sons .... You know, I be in the bed, couldn't go up and down the steps sometimes ... If I needed tea, they would bring it to me. If I needed them to go shopping, they know my PIN number for my ATM card .... They were there for me.

**Loss of identity**—About a third (33%) of respondents worried that the empty nest transition would result in a loss of their identity. Motherhood has played a major part of many of these women's identities. In fact, some participants acknowledged that their children are and have been the overwhelming focus of their lives. One mother explained, "I've based all my existence on him." Having their children leave home may have a major impact on a women's sense of identity and self-esteem. A respondent said:

I've already been feeling the empty nest .... What do I do with myself? ... I'm like, okay, now what do I do? My life has been so much involved with raising my children ... I forgot who I am. I don't have anybody ... to focus on.

Being a mother lent a sense of purpose and normality to respondents' lives. They feared that the loss of the 24/7 nature of childrearing responsibilities would lead to a huge void in their lives, and that they would have way too much time on their hands—time that may lead them to focus too much on their HIV. A mother stated:

Being a mother is one of those things that ... gives me a sense of normality. You know what I mean? Like ... I'm able to do the normal things that other people do, being a parent, doing the everyday, day-to-day things that a mother does. And, in a

way, staying busy all the time, it does allow me to not focus so much time on HIV. I think when she's gone, I'll have a whole lot more time to think about it.

**Death/dying**—Twenty-percent of women worried that they may die during the empty nest period. One said:

I want to be an old woman. I'm thinking my options are just so not there .... I'm thinking what I would look like with wrinkly apple face and gray hair. I'm like, "Man—I may not make that." Everything is different because of HIV and it really sucks. It changes everything. Everything.

The prospect of an early death was frightening because many of them really hoped and dreamed to see their children become independent. A mother said, "I feel my time is limited. I want to be sure he is self sufficient before anything happening [sic] to me." Another mom said, "I'm not going to be around forever .... That whole independence thing .... Do it now! Do it now while I'm still alive."

**Financial insecurity**—Fourteen percent of respondents voiced concerns relating to their financial well being for the empty nest stage of their lives. Women had concerns about being able to provide for their children, specifically being able to provide the material things (e.g., college tuition or a car) to assist children in becoming independent.

Respondents also worried that their children leaving the home would have a negative impact on their financial state because their children provided some income that helped to maintain the household. Many children either worked or received some type of financial support, and shared some of this with their mothers--either directly by giving them money or indirectly by buying items such as food or gasoline for the household. A mother explained that her son's moving out of the house was going to "affect the economic side because he helps a lot with the economy [sic]." Similarly, another mother said, "Sometimes you ... fear not having enough money or being financially instable [sic] because if you were dependent on some income you were getting from them, now I'm not getting from them."

### Hopes for the Empty Nest Period

**Self-improvement**—The most common hope, expressed by 52% of respondents, was that they would improve themselves during the empty nest years, in terms of their education, career, and health status. Numerous respondents mentioned the idea of going back to school once their children were independent. Educational improvement meant completing high school or trade school for some respondents or going to college or even earning an advanced degree for others. A woman said, "I'm going back to school to get some other kind of education ... I was like looking at going back and get my high school diploma." Another mother said, "I am really going to go back to school .... I don't care if I'm going at 55, 60—but I'm getting a college degree." Some respondents also mentioned taking classes in order to improve their English language skills. A woman said, "My expectations are ... to learn English and try to find a good job."

Many women thought the empty nest years would provide an opportunity to switch careers and begin working in a desired field for the first time. A respondent said, "I would like to start focusing my time and energy on women and children ... who are infected, just learning they are infected or pregnant, and be the bridge to them ... the transition ..."

Similarly, another woman said:

I have wanted to volunteer in some hospital, to visit the patients .... I would like to go visit the sick, even to meet other sick persons, who for the first time you talk to them and you can give them some support and tell them, 'Look—don't lose hope.'

Another way that some women hoped to improve themselves during this period was by focusing more time and energy on their own health. This included exercising more (joining gyms), watching their diets more carefully now that they no longer were meal-planning for a family, and managing their stress levels in more positive ways.

**Change of life focus from child to self**—Almost half of women (44%) hoped that during this period they would be able to change their life focus from their children to themselves. A respondent said, "It will be good because I am going to have more time for myself." Women had varying memories and feelings about their years of being a mother, but all agreed about the full-time demands of the job of motherhood. A woman explained:

I'm always worried about him. [Did] he wake up to school on time? If he leave the house some time [is] he in too [much of a] hurry and don't lock the door? . . . . does he have something to eat? . . . . [did] he get ready for his appointment? .... I never enjoy myself .... It's all about him .... I want to have my own moment, you know, my own room, my own house.

Another woman put it this way: "focus on myself ... get myself my own life, my own issues, dramas, concerns ... balance life out again." Yet another said: "What do I look forward to? Probably not having to talk when I don't feel like [it] and not having to be a mom when I don't want to."

Women had a variety of ideas about what this focus on self would entail. But, the common thread for all was that the women would once again have time to do things that they found enjoyable. So, for women who enjoyed dancing, the empty nest years would be a time to dance again. For women who loved reading, the empty nest years would be a time to read again.

Notably, some women mentioned their wish to have a chance to do many of these enjoyable activities (that they had often put on hold during the childrearing years) before they became too ill from their HIV to do them.

Going places and doing things ... different things I want to do. Learn how to ride a motorcycle, learn how to surf, things that, you know, I wanted to do before I get sick. So, I have a "To-Do" list. Not a "Bucket List," a "To-Do" list.

In short, women simply hoped the empty nest years would be an opportunity to, as one respondent explained, "accomplish my little dreams."

**Travel**—About a quarter of respondents (26%) expressed the hope to travel during the empty nest period of their lives. Many women had not traveled much during their lives, either due to financial limitations or just not being able to get away due to their responsibilities to their children. One woman said her hope for the empty nest years was "to travel, to go with my husband, to be together." Another respondent said she wanted "to go to my homeland ... to my preferred homeland .... I wanted to go back to my [home] town."

**Romantic partners**—Twenty-two percent of women voiced the idea that the empty nest period of their lives would provide an opportunity to improve their relationship with an existing partner or finding a romantic partner. Those currently in romantic relationships hoped that the empty nest period might bring the opportunity to focus more time and attention on their partners. Other women noted that having a love interest would help ease



their fear of being alone, and of feeling lonely, during the empty nest years. A mother said, “[I hope] I can find a boyfriend .... I am not going to stay alone.” Some women in the study had deliberately chosen to not date while raising their children. Such women acknowledged that the absence of their children during the empty nest period would allow them to once again focus on dating and love. A mother said:

I’ve brought them tension of living with HIV and they have to handle that and the handling of a partner or something, no. So, that’s why I’ve subtracted it. They have enough to handle, that’s it. But, afterwards, like when maybe they are gone. For the partner and so forth, that is when I will be able to think about it. When my girls go.

Women mentioned the idea that motherhood is all about giving/providing love and that they are now ready, in this empty nest stage, to be the receivers of love. Yet, due to their HIV status, some women recognize that it might be difficult to find a romantic partner. One woman stated that she would be most comfortable finding a partner who was also infected with HIV: “I want to find a mate that is infected like me .... I prefer to hang out with people that have my disease.”

**Familial ties**—Some women (16%) voiced the hope that they continue to have strong relationships with their children, and in some cases, their grandchildren as well. In a couple of cases, women hoped to actually live with their grown children and their families as they aged. For women who were in turbulent relationships with their children, many hoped that the empty nest years would bring about more peace. A mother said, “I [am] not going to argue so much with him.” Another woman mentioned that she is looking forward to “quietness” in the empty nest years because “I hate for them [her children] to fight and I say, ‘Go outside and leave me alone. I like peace and quiet, girl!’”

## Discussion

Many of the HIV-positive mothers in this sample expressed concerns—and also hopes—that any mother may have about their children becoming autonomous and leaving home, regardless of their health status. These types of concerns included loss of identity, loss of social support; their hopes included time for self-improvement, and for romantic partners. Yet even within these categories common to both MLH and mothers in good health, the effect of their illness on MLH impacts how they experience these changes. For example, any mother may experience loss of identity of the role of mother as their children leave home, but the HIV-positive mothers had often used their “mother role” as a way to normalize their life and in some ways to escape their illness status. Thus, their child leaving home not only results in general loss for the mother living with HIV, but also results in a loss of ties to “normal roles” that make them feel a part of society and not as stigmatized.

Similarly, while all mothers may lose some support—social and/or financial—as an adult child leaves home, for HIV-positive mothers that child may have been one of the only people who know her status. The loss of support is not just of general support, but also of caretaking when she is ill, reminders for medication adherence, and someone who can attend doctor’s appointments with her. Consistent with these findings, Emlert (2006) suggested that among people of color with HIV, older adults had less emotional and instrumental support than their younger counterparts, and higher levels of these types of support were significantly correlated with reduced HIV stigma. The mothers in our study have expressed very real concerns, as Emlert’s study indicates that older HIV positive adults were more likely to live alone compared to younger positive adults, and among HIV positive people of color, 54% of older adults were at risk for social isolation compared to 25% of younger HIV positive adults.

Other concerns among this sample were very specific to being HIV-positive, and would not occur for non-ill mothers. These included worsening of physical health, and death and dying. In fact, some of these MLH believed their concerns and the stress of their children leaving home might actually cause a worsening of their illness status. The loss of a caretaker appeared to be a major issue for these MLH. For MLH whose child has been a caretaker during her periods of illness, the fear of what will happen when the child is gone is stressful. While many non-ill mothers may have this concern as a general “in the future” issue, concern among MLH is more immediate as they have already experienced debilitating periods and hospitalizations. Many of the women in this study have been living with HIV for many years. Those MLH who have experienced severe symptoms from HIV/AIDS already know the fears of debilitating illness and may now be facing the loss of their closest care and support system. We believe our findings, considered within the context of heightened risk for specific chronic health conditions for HIV positive women (Santoro et al., 2009), suggest midlife HIV positive women may have a greater need for healthcare and social service resources, as they navigate numerous health and social-psychological challenges to successful aging.

Women in this study were cognizant of the fact that the stress of the empty nest (or even just worrying about a future empty nest) could have a negative impact on the course of their HIV. This suggests that HIV-positive women may benefit from support services designed especially for this period of their lives. In addition to traditional mental health services, more grass-roots type of support services for empty nesters have become more prolific in recent years. For example, “Empty Nest” workshops have become a popular offering in some communities (Rochman, 2009) and various on-line magazines and support groups have developed on the Internet to allow women who are going through similar circumstances to connect with and lend support to each other (e.g., Bonner, 2009). Health care professionals who care for women living with HIV may want to add inquiry into women’s household status to routine office visits and offer linkage to support services for those individuals who seem to be having difficulty with the empty nest transition.

On the other hand, living with HIV/AIDS also appears to motivate some of these women’s hopes for the future once their children have left home. For example, a minor theme was a wish to work with other infected women to try to assist them through the initial shock of being diagnosed and being able to inspire them and show such women that there is a future for them. Others wanted to volunteer in other capacities, and yet others wanted to begin school or job opportunities they felt they had put off. These women seem to realize that the “empty nest” period of their life may require some effort and work but that it can be fulfilling. Similar to we found in our study, Crystal and colleagues (2003) found HIV-positive older adults reported experiencing a range of diverse life circumstances, and that quality of life and health care and social service needs vary to a greater extent for older compared to younger HIV positive adults.

Due to the qualitative nature of the study design, results from this study cannot be generalized. All respondents in this study were drawn from the city of Los Angeles, CA. Women residing in different geographical areas may well face different challenges pertaining to the empty nest period. Moreover, due to the use of in-depth, face-to-face interviews, it is possible that social acceptability biases may account for what women were willing and able to disclose.

Despite the study limitations, we have raised a number of interesting questions for future research, including how does experiencing an empty nest affect HIV-positive women’s adherence to treatment regimens? Many of the women in this study relied on their children’s help and support to manage their disease—what happens when their children are gone?

Second, what effect does the “empty nest” have on HIV-positive women’s love relationships? Previous investigators have shown that the empty nest can actually improve women’s relationships with husbands/partners (e.g., Gorchoff, John, & Helson, 2008). However, some women in this study did not currently have a partner and raised concerns about being able to find a romantic partner, due to their HIV status. Finally, do the children of HIV-positive women alter their plans for the future in order to care for or stay close to their mothers? Mothers in this study had great fears of losing the social support of their children. Do such worries affect these women’s children and their plans for adulthood?

In closing, we learned that the impact of the “empty nest” on women’s well being can be mixed, with both positive and negative outcomes. This study is unique for both its focus on women living with HIV, a previously under-studied population in the empty nest research arena, and its use of a qualitative methodology. Using in-depth interviews to explore the empty nest stage allowed an up-close, personal view of these women’s experiences and perspectives, allowing better understanding of their hopes and worries for this time of their lives.

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