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“Living for My Children:” Mothers Living with HIV Disease

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Rosemary N. Walulu, PhD, RN
Assistant Professor
Purdue University, School of Nursing
Email: walulu@purdue.edu

Sara L. Gill, PhD, RN, IBCLC
Associate Professor, Family Nursing
University of Texas Health Science Center San Antonio,
School of Nursing
Email: gills@uthscsa.edu

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Abstract

A grounded theory study was conducted with mothers living with HIV disease to produce a theoretical explanation of the processes by which mothers living with HIV disease manage mothering. Fifteen mothers from the Midwest living with HIV disease were interviewed. The in-depth interviews were audiotaped, transcribed and coded. Constant comparison method, open axial, and selective coding techniques were used to analyze the data. Data analysis revealed the process of *Living For My Children*, which had five areas consisting of: *Knowing My Diagnosis*, *Living With HIV*, *Taking Care of Myself*, *Seeking Support*, and *Being There For My Child*.

Keywords: HIV/AIDS; Mothering; Grounded theory

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Introduction

The HIV/AIDS epidemic is a persistent health threat to women in the United States, especially young women and women of color. The largest numbers of women diagnosed with HIV/AIDS are between the ages of 15 and 39, the prime child-bearing and child-rearing years.¹ Advances in treatment for HIV/AIDS have improved the quality of life for many women, and as a result, the number of women living with HIV/AIDS who are of childbearing age is constantly increasing.¹ These women may become mothers or continue mothering their children while living with HIV/AIDS.

Mothers are responsible for protecting, nurturing, and caring for their children at all costs.^{2,3} The responsibilities of mothering while living with a chronic and stigmatizing illness like HIV, however, can be overwhelming. Women living with HIV disease who make the choice to become mothers are sometimes considered cruel and uncaring^{2,3} and generally viewed negatively by society.⁴

Mothers living with HIV disease are often fearful and struggle with disclosing their HIV positive status to their children.^{5,6} They worry about how their children will be treated if the mother's HIV status becomes known. They worry about their children's ability to keep the secret of the mother's HIV status. Many mothers delay or avoid disclosing their HIV status to their children,^{5,7} believing that secrecy is necessary to protect themselves and their children from discrimination.^{5,6}

There have been mixed findings, however, about mothering while living with HIV disease. Tompkins, Henker, Whalen, Axelrod, and Comer⁸ found that 53% of HIV positive mothers reported that being HIV-positive had not influenced their parenting priorities, and these mothers continued using similar activities and routines to take care of their children. In the same study, 38% indicated that their illness had limited their activities with their children, but 88% of these attributed the change to fatigue. In contrast, Nelms⁷ reported that mothers with HIV/AIDS felt the burden of mothering with HIV, particularly in relation to their health status. These mothers faced an unknown future for themselves and their children and had concerns about staying alive to see their children grow, and the women sought to find meaning and purpose in their diagnosis.

Sometimes mothers with HIV have had to redefine the meaning of motherhood. For example, when HIV fatigue limited physical activities, motherhood was redefined to emphasize tasks like support and educational functions.⁹ Mothers with HIV also struggled to balance their health concerns with the demands and needs of their families. Some adapted to the mothering role by focusing on providing a happy environment for their children, even while dealing with a debilitating illness.¹⁰ However, little is known about how HIV-infected mothers overall manage their mothering. The purpose of this study was to describe how HIV-infected mothers accomplish and experience the mothering role.

Methods

The goal of grounded theory methodology is to generate comprehensive explanations of phenomena that are grounded in reality. Data collection, data analysis and sampling occur simultaneously. Sources for data are in-depth interviews, observational methods, and existing methods. Grounded theory has several steps: constant comparison, categories, core category, and basic social process.¹¹ Grounded theory was used in the study to guide participant selection, data collection, analysis and development of a substantive theory on managing mothering with HIV infection. The actual number of participants was not known until the study progressed and data saturation or redundancy was achieved.

A convenience sample of 15 mothers was recruited from two infectious disease clinics located in the Midwest, a women's clinic, and state health department sites that provided and coordinated the care of HIV positive women and their children. All participants were mothers living with HIV disease, at least 18 years old, with at least one child living in the home. Approval for the study was obtained from the Institutional Review Board of the sponsoring university and all sites where participants were recruited.

Participants were recruited via flyers posted at the sites, which contained a contact telephone number and email address. In addition, staff at each site identified prospective participants who then contacted the researcher. Prospective participants were screened for eligibility when they contacted the researcher. Written informed consent was obtained from each participant. Interviews took place in a private location convenient for the participant, such as the participant's home or a private office at the study sites.

A semi-structured interview guide was used to facilitate discussion using the following questions:

- Tell me about being a mother with HIV disease.
- Can you tell me about your day to day life as a mother with HIV disease?
- Tell me about tools that help you in the process of being a mom.
- Can you tell me more about your thoughts and feelings about being a mother living with HIV disease?

Probes were used to clarify information or elicit additional information. The interview guide was revised as needed to generate new information and fill in the gaps of developing categories. Participants were interviewed one time, and interviews lasted 45 to 90 minutes. After the interview ended, participants completed a demographic questionnaire. Interviews were tape recorded, transcribed verbatim, and reviewed for accuracy. Participants' non-verbal reactions and any other pertinent observations were recorded as field notes. The field notes were transcribed immediately after each interview and included in the data for analysis. Participants received a \$20 Wal-Mart gift card for their participation in the study.

Data collection and analysis occurred simultaneously, beginning with the first interview. The constant comparison method was used for all data. Open, axial and selective coding were used to identify and develop categories.¹¹ The transcribed data were broken down into units of meaning (concepts), labeled, and critically examined. Conceptually similar categories formulated by constant comparison during open coding were grouped together.¹¹ Finally, a central or core category was selected that integrated all other categories to explain the overall social process. The codes were constantly compared to the data to ensure that they were grounded in participants' experiences. Demographic data were analyzed using descriptive statistics.

Several strategies were used to ensure the trustworthiness or rigor of this qualitative inquiry. Throughout the study, the investigator maintained a reflexive journal documenting personal values, biases, and feelings. Additionally, the researcher

recorded design decisions, including sampling and analytic decisions. Interviews were conducted until data saturation was achieved. The first author coded all interviews. The second author independently coded the first four interviews and reviewed the coding for each subsequent interview. Peer debriefing meetings with the researcher's committee members were used to provide an external check on the research process.¹² All notes and comments received from the researcher's academic committee were kept by the first author for the audit trail.¹³

Results

Participants ranged in age from 29-55 years with a mean age of 41.6 years. All had at least one child younger than 18 years of age living with them at home. Their children ranged in age from 9 months to 17 years with an average age of 11.4 years. Ten of the mothers were white (66.6%), and five (33.3%) were African American. The majority were low income and unemployed. Seven mothers made less than \$999 per month, six mothers made between \$1000 and \$2999, and two mothers made between \$3000 and \$5999. At the time of the study, all participants had been aware of their diagnosis for more than four years. Names used in this paper are pseudonyms.

The core category which emerged from the interviews was *Living for My Children*, which involved five areas: *Knowing My Diagnosis*, *Living with HIV*, *Taking Care of Myself*, *Seeking Support*, and *Being There for My Child*.

Knowing My Diagnosis

Participants had learned of their HIV status at different times during their childbearing years. They described feeling shocked, sad, hurt, mad, and devastated when they learned that they were HIV-positive. One said:

....They took us down to the far end of the hall where there was no other people around, and they told us that I was positive and my husband fainted and hyperventilated and I was just shocked, I was just in shock.

Another mother added, "It was a shock – the sky looked different, everything like looked really clear blue, but you're scared... so, I stayed alive, I never touched drugs again...."

After learning the diagnosis, the mothers worried about transmitting the HIV virus to their child/children or their spouses. Mothers were also concerned about living long enough to raise their children and see them grow up.

Mothers developed strategies to help them be present and available for their children. Anna described balancing taking care of herself with taking care of the children:

I feel that sometimes I let my children down because I don't always have as much energy and because I do take a nap every day. ...and I feel I do not give them what they deserve, but at the same time, in order for me to give my best and be able to give my all and be here as long as I can, I do have to take care of me.

The mothers' desire to live was partially motivated by wanting to be there to protect their child/children from negative influences, such as drug use and risky sexual behaviors. This need to protect was prompted by their experience of living with HIV disease. Participants described feeling a greater protectiveness toward their children than normal. Lucy, for example, described her feelings thus: "I'm still very protective. More so than normal. With a 14-year-old you wouldn't think I'd be very protective, but I am." Mothers wanted to protect their children from becoming infected with HIV, and they worried about transmitting HIV to their children. As Georgia noted: "And because of my disease I'm very protective over her. I worry if I do something to pass it to her. I know she cannot get it from me kissing on her, playing with her, but I still worry that I might scratch her and give it to her."

Participants took precautions in their daily activities to protect their children and themselves from becoming sick. The mothers were aware that they could become sick from other diseases because of their HIV, and they took measures to protect themselves. They were hypervigilant in cleaning and teaching their children about routes of transmission, especially concerning blood contact.

Mothers felt that they had more worries than when they had not known about their HIV status. Some mothers worried about how they would be perceived by others if it became known that they were living with HIV. Maya described this feeling: "Accepting it, well, I've accepted it actually.... I worry about what they will say and will push me away and I don't want that. It's hurtful to an extent. But if I keep it to myself, I don't have to worry about it as much."

Mothers also worried about how disclosing their HIV status would affect their relationship with their children. They were concerned about being rejected by their children and by other family members. The mothers' approaches to disclosing to their children were very different. Each mother had to decide when, what, and how to disclose. They considered the age of the child and how the child might respond.

Being afraid was an experience shared by all the mothers, but it was evidenced differently by each. There was an underlying feeling that people would think they were bad people because they were HIV-infected. As Nancy explained, “There are still people afraid of you, there are people who think you are a bad person or you must have [been]...” Mothers were also afraid of pain associated with HIV disease and of dying early. Latoya described her experience this way: “You’re scared of dying and what you’re going to go through while dying...I know HIV and AIDS kills.” To deal with their fears, the participants shared their experiences of living with HIV disease in support groups, participated in research about HIV, got involved in AIDS service organizations, and wrote articles about living with HIV disease.

Living with HIV Disease

Mothers focused on living with HIV disease and taking actions to live for their children. Christy affirmed, “Having a child and living with HIV has just made me stronger to know there is something out there that I need to live for and continue on for instead of throwing the towel in and giving up.”

The mothers said that living with HIV was hard. Participants explained that *hard* was not necessarily bad, but that mothering was always difficult and living with a chronic illness made it even more difficult. Daily living with HIV was a series of ups and downs, of good days and bad days. Participants described many of the complications they experienced. One said, “Some days you don’t feel real well, some days you feel great. It’s a struggle trying to get out of bed and doing the things I know I must do. It’s hard.” For some participants, mothering was hard because they lacked the physical stamina to keep up with the activities of their young children.

Fatigue caused by HIV disease and the medications used to treat the disease were issues for these participants. However, the degree, intensity, and causes of the fatigue differed for the 10 mothers in the study who reported experiencing fatigue. One said, “My issue about being a mom is just being tired. I’m tired a lot. She doesn’t understand why we don’t go here, why we don’t go there. I do a lot of going but some days I just can’t do it. I don’t have enough energy.”

The drugs used for treatment increased their fatigue by making it harder to sleep. One mother said, “I didn’t have that problem before I became HIV-positive and had to start on the meds. I think the meds have a lot to do with my fatigue.” Mothers used many different strategies to manage their fatigue, including taking naps during the day, sleeping more

hours, sleeping longer on the weekends, not doing some necessary activities like cooking dinner or doing laundry, and getting help from the child/children, family members, and friends.

Taking Care of Myself

Having a child was the major motivation for the mothers to take care of themselves. Mothers believed they had to take care of themselves so they would be healthy enough to care for their children. One said, "Take care of yourself and try to take care of your child the best you can. I try to eat healthy." Mothers used three primary strategies to take care of themselves: *Learning About HIV Disease*, *Not Giving Up*, and *Leaning on God*.

The mothers expressed a need to learn about HIV disease so they could take better care of themselves. They sought information from a variety of sources, like AIDS service organizations and healthcare providers and through serving on HIV/AIDS panels and support groups. Maya explained, "The education is out there: educate yourself. There are places that will help you educate yourself and be aware." Mothers sought a broad range of information, including the actions and side effects of drugs used to treat HIV. Kalin had this to say: "I had no idea about all the drugs they have and those kinds of things. I had to be educated first by the AIDS resource group." After a severe reaction to one of her medications, Bella said, "I wanted to know what the generic name was for everything, what's in it. When he wanted to put me on...Kaletra. I wanted to know the side effects."

Participants believed it was important not to give up. One said, "I get pleasure taking care of her. I'm gonna stay strong and stay positive. I know they've got a cure and I'm not gonna give up. I've got too much to live for and I'm gonna be here when they give out that cure." She added, "Don't give up because they need their momma, regardless, they need their momma." Another said, "I have been positive going on 11 years and it has become a way of life. I am not an HIV-positive mother, I am a mother first, then a person first and I have this." Participants used strategies such as finding a healthcare provider/physician or care coordinator who would work with them. Taking medicine was another way of not giving up. Mothers strengthened their ability to not give up by seeking support and reaching out to others. One said, "...there is a lot of support and do not ever, ever give up...." Another added, "I guess I decided that God is keeping me here for a reason...to reach other people and educate and make people realize that someone like me can get it."

Some participants believed it was important for their children to know that someone else loved them besides their mothers. *Leaning on God* was a strategy mothers used to continue to live for their children. One said, "My faith helps me

in being a mom because there are times when I think I cannot move another step.” The participants attributed their good health and longevity to God.

Seeking Support

These HIV-infected mothers identified multiple resources that helped them live for their children, though the types and amounts of support that each of the mothers required differed. Mothers identified healthcare providers, family members, and others like coworkers, friends, and support groups as resources. Initially support came from healthcare providers, either a doctor or nurse or care coordinator from an AIDS service organization. Mothers emphasized the need to find a healthcare provider who was willing to listen to their views and share in their care. They accessed healthcare providers at different times, beginning with the diagnosis of HIV-positive status.

During difficult times, family offered emotional and financial support, provided assistance with childcare, and sometimes accompanied participants to their doctor appointments. Children were involved in watching out for their mothers’ medical care. They might also assume responsibility for household chores to help their mothers. The participants also described support like financial and childcare tradeoffs from coworkers, friends, AIDS service organizations, and support groups.

Mothers received encouragement by participating in support groups. By networking with other mothers, they learned about the resources available to them, and acquired information on how to access food pantries, AIDS services organizations, and other support groups in their communities. They also learned how to negotiate transportation to attend support groups. Mothers also were informed about clinical trials and other studies in the community, the eligibility requirements for participation in the trials or studies, and ways they could be involved with HIV/AIDS-related activities.

Being There for My Child

Mothers shared their feelings about the importance of being a mother and why they wanted to live for their children.

I always pray to God to let me see my daughter grow up and let me be able to get her to an age that she doesn’t have to depend on this person and that person. I pray to God to let me raise her. That’s the main thing that’s always in my mind – that I won’t get to see her grow up. . .

Participants said that living with HIV made them appreciate the time they had with their children. They were afraid they might not have the time for their children because the medications might not work and they could get sick or their health would deteriorate. One said, "I know some medications do not work for people or make them sick--I've been on many of those too, it is not easy. But just enjoy the time that you have, you never know."

Mothers wanted to be there for their child/children to spend time with them, teach them, and share experiences. They wanted to give their children the skills necessary to grow, develop, and be independent--to instill in their children what they believed was important.

While sharing what they knew with their children was important for all the mothers, the content and method of teaching differed for each mom, depending on the age of the child. Mothers taught their children about mistakes they had made. One said, "Teach those children the mistakes that you made and what's out there. Don't be afraid, be cautious." Teaching the children about HIV was very important to these mothers: "I definitely also teach my children about HIV ... even though medicine is available and the transmission rate is lower." After learning about their diagnoses, some mothers started teaching their children about HIV infection by telling their children to avoid her blood if she cut herself.

Mothers took joy and shared in the experience of seeing their child learn and live. One mother said, "I think it's a privilege to be a mom--it's a blessing. She loves to be around me and I love to take care of her. I love her! Knowing that she needs me and she is very dependent on me. It's a nice experience seeing her learning and living life, you know. I tell myself she needs me. I motivate myself to get up and do those things; I need to because I know I have to."

Having a child was in itself an exciting experience for these mothers; indeed, their HIV-positive status made them view the child as a miracle. One said, "Be positive about it, don't think of, 'My gosh I am gonna have a kid that is sick.' Then it's not about you. You've had this exciting experience of having a child. Then you say, after the child is born, they are a miracle. I fed them with my blood, which had HIV, and they don't have it. It is a miracle. She is proof of that." Sharing experiences of being a mother with other mothers or family members was helpful in decreasing stress. Being a mother with HIV disease was a learning experience for these mothers, and they used it as an opportunity to teach their children about compassion.

Discussion

HIV- infected mothers deal with the extraordinary task of balancing their own physical needs and the needs of their children.¹⁴ Having children gave these participants a reason to live, which is consistent with earlier research findings.^{2,3,15} The mothers worked to maintain their well-being for the sake of their children and engaged in strategies to maintain a positive attitude. They wanted to live long enough to see their child/children grown up.

The HIV-positive diagnosis was followed by a variety of emotions, including shock, devastation, anger, sadness, and hurt. The diagnosis was the causal event that motivated these mothers to change their lifestyle and to make choices enabling them to stay alive. The reasons the mothers in this study gave for routine HIV testing during prenatal visits, after news about or from a partner, or a critical illness, blood donation and after blood transfusion, were similar to reasons found in earlier studies.¹⁶⁻¹⁹ These mothers were overwhelmingly resolved to take care of themselves so as to live for their child/children. They focused on the present, especially taking every day and living it to the fullest with their children.

Living with HIV disease, however, made mothering hard and participants found mothering with HIV challenging. Difficulties included limited physical activities with their child/children, decreased financial resources, and inability to accomplish all mothering tasks such as cooking and laundry. This was similar to findings from Barroso²⁰ and Sandelowski and Barroso.²¹ Despite reporting that HIV made it hard to mother, the participants in this study described how they loved being mothers. Similarly, Marcenko and Samost²² found that an HIV-positive diagnosis was a motivating force for participants to reorganize their lives and reestablish relationships.

Mothers in the study said that having children motivated them to take care of themselves, similar to findings reported by Shambley-Ebron¹⁷ and Shambley-Ebron and Boyle.¹⁸ By caring for themselves, the mothers felt they could live longer and take better care of their children. They planned activities and schedules to spend time with their children, taught their child/children about HIV transmission, financial responsibility, and practical skills, and shared the joys of having a child/children. Mothers chose to focus on positive thoughts to avoid fears of living with a chronic illness. They *Took Care of Themselves by Educating, Never Giving Up, and Learning on God*, similar to strategies identified by participants in other studies.¹⁶⁻¹⁹

Social support is a buffer in coping with HIV-related stressors for persons living with HIV disease.²³ All 15 mothers in this study stressed the significance of support. They received emotional, physical, and financial support from healthcare providers, family, and others. Three of the mothers had selectively disclosed to healthcare providers and some family members, but not their children, and this limited the support they received. Similarly, Kalichman et al.²⁴ reported that their

participants disclosed selectively to some people and not others, and the rate of disclosure was associated with anticipated social support.

Wanting to *Be There for Their Children* was a motivation for the mothers in this study to live. This is consistent with the findings of recent qualitative studies, [2,4,9,16-18,21,25](#) that participants were determined to live and survive being HIV-positive to be there for their children. The promise and hope of raising children motivated the participants to make positive lifestyle changes.

More research on mothers living with HIV disease is needed, to compare *Living for My Children* among various ethnic and socioeconomic groups. The replicate study will focus on HIV-infected mothers in rural communities since majority of HIV-infected mothers globally live in rural areas. The child-bearing intentions of HIV-infected mothers should also be explored, the number of HIV-infected women aged 15-39 continues to increase, especially among minority women,¹ and intentions to have children will play a role for mothers in this age group. Mothers in this study shared that HIV made mothering harder. More research on the caregiving burden of mothers living with HIV disease would be valuable.

The mothers in this study identified the importance of support from health providers and others. Providers need to ask direct questions about tangible resources available to HIV-infected women on initial encounter and link the women to appropriate community resources such as public transportation, child care, respite care, support groups etc. Therefore, providers need to know their community resources and policies related to the care of HIV-infected women. Healthcare providers need to develop strong client-provider relationships; this is important in predicting adherence to medical regimen.²⁶

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