A Mixed-Methods Approach to Understanding Barriers to Postpartum Retention in Care Among Low-Income, HIV-Infected Women

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Abstract

Optimal retention in HIV care postpartum is necessary to benefit the health and wellbeing of mothers and their infants. However, postpartum retention in HIV care among low-income women is suboptimal, particularly in the Southern United States. A mixed-methods study was conducted to identify factors associated with postpartum retention in care among HIV-infected women. Participants ($n=35$) were recruited during pregnancy at two county clinics and completed self-report demographic and psychosocial surveys. Twenty-two women who returned for a postpartum appointment completed a semi-structured interview about lifestyle factors and retention in care. Of the participants enrolled at baseline, 71.4% completed a follow-up with an obstetrician (OB), while 57.1% completed a follow-up with a primary care physician (PCP). High CD4 count at delivery, low viral load at baseline, low levels of depression, high interpersonal social support, and fewer other children were significantly associated with completion of postpartum follow-up. Barriers and facilitators to retention identified during qualitative interviews included competing responsibilities for time, lack of social support outside of immediate family members, limited transportation access, experiences of institutionalized stigma, knowledge about the benefits of adherence, and strong relationships with healthcare providers. OB and PCP follow-up postpartum was suboptimal in this sample. Findings underscore the importance of addressing depressive symptoms, social support, viral suppression, competing responsibilities for time, institutionalized stigma, and transportation issues in order to reduce the barriers that inhibit women from seeking postpartum HIV care.

Introduction

OPTIMAL RETENTION IN HIV CARE POSTPARTUM is necessary to benefit the health and wellbeing of women living with HIV/AIDS (WLWHA) and their infants. However, reported rates of retention in care postpartum among low-income women living with HIV are suboptimal.^{1–3} Regular follow-up and retention in care has been associated with increased survival rates, improvement in CD4 count, and better adherence to antiretroviral therapy (ART).⁴ Mortality among persons living with HIV/AIDS is increasingly

attributed to co-morbid conditions.⁵ The increasing prevalence of non-AIDS-defining malignancies, cardiovascular disease, hepatitis C, pulmonary disease, and psychiatric comorbidity among HIV-infected patients presents a further need to improve retention in care^{6,7} in order to decrease morbidity and mortality.

There is increasing evidence that HIV-infected women are more likely to adhere to both prescribed clinical follow-up^{8–10} and antiretroviral medications^{11–14} during pregnancy compared to postpartum.^{8–11} This is consistent with the Health Belief Model positing that women are more likely to maintain

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positive health behaviors if there is a perceived direct benefit to their unborn child.¹⁵ Non-adherence to HIV care postpartum, specifically not attending regular physician appointments, has previously been associated with younger age, initiation of care in the third trimester, more health-related symptoms, discontinuation of ART postpartum psychiatric co-morbidities, and African-American race.^{1,3}

Postpartum, HIV-infected women are instructed to schedule follow-up visits at 6 weeks following a vaginal delivery and at both 2 and 6 weeks following a Cesarean-section. Subsequently, women are asked to resume seeing their primary care provider (PCP) if they are on stable therapy, every 3–6 months.¹⁶ Despite less than optimal rates of postpartum follow-up among HIV-infected women, few studies have examined the complex factors that serve as barriers and facilitators towards retention in HIV-care during this critical time period.^{3,17} A better understanding of the barriers that inhibit women from seeking postpartum HIV care is necessary to develop interventions that will improve retention rates and associated clinical outcomes. Thus, the purpose of this study was to identify and describe the factors associated with postpartum retention in care among a sample of low-income, HIV-infected women in the southern United States. Because rates of HIV infection remain disproportionately high among low-income, minority women of childbearing age in the Southern region of the United States,^{18–20} and an increasing number of HIV-infected women bear children, addressing reproductive and HIV-related outcomes among this population is critical.

Methods

Participants, setting, and recruitment

Participants were recruited from two county clinics in Houston, TX that provide obstetric care for uninsured and underinsured HIV-infected women. Eligible participants were HIV-infected women, 18 years of age or older, able to read and write in English or Spanish, in the second or third trimester of their pregnancy, and intending to continue care with the county postpartum. Participants attending prenatal visits were identified via electronic medical records (EMR) and approached in the waiting room by a member of the research team who informed them of the study details. Women whose primary language was not English or Spanish, as noted in the EMR, were not approached. All participants were compensated \$20.00 at baseline. This study was approved by the University of Texas Health Science Center Committee for the Protection of Human Subjects.

Baseline survey

After informed consent was obtained, participants completed an assessment consisting of various self-report demographic, behavioral, and psychosocial measures. Demographic variables and behavioral variables collected included race/ethnicity, level of education, use of public assistance, ART adherence, alcohol, tobacco, and drug use. Psychosocial measures included depression, social support, and internalized stigma. Variables included in the survey were identified through a literature review of factors associated with retention in care among minority HIV-infected women and pregnant HIV-infected women.^{1,4,8–11,15}

Scales and measures

Scales with established reliability and validity were administered at baseline, including the Center for Epidemiologic Studies Depression Scale (CES-D),^{21,22} Interpersonal Support Evaluation List (ISEL-12),^{23,24} and The Internalized Stigma of AIDS Tool.

Depressive symptoms. The CES-D is a 20-item scale that measures depressive symptoms by having participants answer how frequently they experienced the symptom in the past week. For example: I was bothered by things that don't normally bother me. Scores range from 0 to 60, with scores ≥ 16 indicating participants with severe symptoms of depression.^{21,22}

Interpersonal support. The ISEL-12 is a 12-item scale that measures perceptions of social support by asking participants if they would be able to find assistance for various types of situations, with responses ranging from definitely false to definitely true. For example: I feel there is no one I can share my most private worries and fears with. Scores range from 0 to 36, with higher scores indicating higher levels of perceived social support.^{23–25}

Internalized stigma. The Internalized Stigma of AIDS Tool²⁶ is a 10-item scale that asks participants to rate their feelings towards themselves since their HIV diagnosis, with responses ranging from strongly disagree to strongly agree. For example: I feel so ashamed about having HIV/AIDS. Scores ranged from 0 to 50 with higher scores indicating higher levels of internalized stigma.

Medical record abstraction

The county EMR system was used to obtain HIV-related data on disease progression and suppression including CD4 count (cells/mm³) and viral load (copies/mL) at baseline and delivery. All current and historical patient appointments are recorded in the EMR. The system is updated in real time with the status of the appointment to reflect if the participant was seen by a provider, was a no show, cancelled, or rescheduled.

Primary outcomes

EMRs were used to classify participants as adherent or non-adherent to postpartum care with their obstetrician (OB) and primary care provider (PCP). Participants were classified as adherent to OB care if they attended an appointment within 3 months of delivery and were classified as adherent to PCP care if they attended a PCP appointment within 6 months of delivery. Participants who had documentation in their EMR of transferring to another PCP were assumed to have completed a PCP follow-up. Participants that were documented as discontinuing care with the county before delivery were deemed ineligible for follow-up and not included in the final analysis.

Quantitative analysis

Descriptive statistics, such as, mean, median, standard deviation (SD), and interquartile range (25th and 75th percentile, IQR), frequency, and proportion were calculated as appropriate for socio-demographic variables, scales, and lab

tests in all women or by OB and PCP follow-up status respectively. CD4 counts and viral load values were logarithm transformed for further analysis. Two sample *t*-tests were used to test the differences in these variables with the outcome status of retention in postpartum OB and PCP care respectively. A two-sided *p*-value less than 0.05 was considered statistically significant. All analyses were conducted using IBM SPSS version 21 (Armonk, NY: IBM Corp).

Qualitative interview

Women who completed the baseline assessment and attended a postpartum OB visit (e.g., those who were successfully retained in care during their postpartum phase) were asked to complete the same self-report questionnaire and participate in a face-to-face in-depth qualitative interview. Participants who did not attend their first postpartum OB appointment were contacted regarding the follow-up via phone and offered the option of completing the surveys and interview over the phone. Interviews lasted approximately 30 min and were intended to explore women's social and clinical experiences related to living with HIV/AIDS, in addition to the barriers and facilitators linked to their retention in care. Questions included, "Describe some strategies, if any, that you currently employ to improve adherence to care?" "What barriers, if any, do you face in adhering to care?" "Where, if at all, do you access information about the benefits of adhering to care?" and "In your opinion, who is most equipped and why to assist HIV-positive women with adhering to care (i.e., doctors, nurses, social workers, etc.)?" Postpartum surveys and interviews were conducted up to 180 days postpartum to better accommodate the participants' schedules. Participants were compensated \$40 for completion of the postpartum follow-up.

Qualitative analysis

Qualitative interviews were digitally recorded, transcribed, and later analyzed separately by two members of the research team utilizing NVivo 10 software, a qualitative data management program. Two female coders with extensive expertise working with underserved, HIV-infected women and qualitative research coded the data. One coder was white; the other coder was black. A preliminary codebook to categorize participant responses was established by research team members prior to conducting interviews and searching for emerging codes in the data. Such organizational categories were developed based on the qualitative interview guide designed to directly address influences of postpartum care among HIV-infected women by exploring experiences living with HIV/AIDS, HIV and motherhood, and adhering to care. We then further defined codes based on themes observed in the textual data. Data-derived codes were then compared to the previously developed codes (researcher-generated codes) and the codebook was finalized through coder consensus. Utilizing the final codebook, two research team members independently analyzed the data coding for emerging themes, patterns, and perceptions from the open-ended responses. After researchers independently analyzed the data, they convened to discuss and critically describe, analyze, and justify identified themes. A subsequent consensus meeting was held to resolve coding discrepancies.

Although we ultimately seek to develop interventions for HIV-infected women who are not retained in postpartum care, the Positive Deviance/Hearth Methodology allows us to identify "positive deviants" who are defined as those persons who share similar demographic characteristics of other members of their community and yet find ways to overcome barriers and employ healthy behaviors, independent of external interventions.²⁷ In this study, the women that were retained in care served as "positive deviants" and provided information about barriers and facilitators to retention that might also exist for those women that were not retained.

Results

Forty-four women were approached for participation. Among them, thirty-seven (84.1%) enrolled during pregnancy. Seven women declined to participate with the primary reasons being not enough time (57.1%), feeling tired (28.6%), and fear of disclosure (14.3%). Two women discontinued care with the county prior to delivery and were excluded from the results. Four women were not approached due to language barriers identified in the EMR. The mean age (SD) of women in the baseline sample was 28.2 (6.2) years, with the majority of them being African or African American, unemployed, having other children and receiving some form of public assistance. See Table 1 for a full description of

TABLE 1. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF INTERVIEW PARTICIPANTS AT BASELINE (*N* = 35)

Characteristic	n (%)
Age, mean (SD)	28.2 (6.2)
Ethnicity	
Black/African	27 (77.1)
Hispanic	5 (14.3)
White	2 (5.7)
Other	1 (2.9)
Highest level of education ^a	
Less than high school	13 (38.2)
High school/GED	13 (38.2)
Associates degree/some college	6 (17.6)
4-year college degree	2 (5.9)
Job status ^a	
Employed	11 (33.3)
Unemployed due to health reasons	7 (21.2)
Unemployed due to other reasons	12 (36.4)
Can't find work	3 (9.1)
Mode of HIV transmission	
Heterosexual contact	26 (74.3)
Other	9 (25.7)
Number of prior children ^a , mean (SD)	1.5 (1.6)
Marital status	
Married/living with significant other	12 (34.3)
Single	23 (65.7)
Public assistance ^b	
Supplemental Security Income/Disability	9 (25.7)
Food stamps	21 (60.0)
WIC	24 (68.6)
Transportation assistance	5 (14.3)

^aData missing for some participants.

^bParticipants chose all that applied.

demographic information. Overall, postpartum OB appointments were attended by 25 (71.4%) of participants within 3 months of delivery, while only 20 (57.1%) attended a PCP appointment within 6 months of delivery. Fifteen (42.9%) women attended both an OB and PCP appointment, with 9 (25.7%) attending an OB appointment but not a PCP appointment, and 5 (14.3%) attending neither an OB nor a PCP appointment.

Predictors of retention in OB and PCP care

In the bivariate analysis, higher CD4 count at delivery (Median [IQR]: 512 [364, 746] vs. 369 [285, 637]; $p=0.04$) and a lower number of other children (Mean $\pm$ SD: 1.13 $\pm$ 1.26 vs. 2.40 $\pm$ 1.96; $p=0.03$) were significantly associated with successful retention in OB care at 3 months. Lower levels of depression (15.28 $\pm$ 8.11 vs. 23.50 $\pm$ 15.81; $p=0.05$) and higher levels of interpersonal social support (28.33 $\pm$ 5.54 vs. 23.67 $\pm$ 7.05; $p=0.05$) were marginally associated with OB follow-up. Lower viral load at baseline (83 [48,541.5] vs. 3900 [49, 35500]; $p=0.03$) was significantly associated with successful retention in PCP care at 6 months. Women with lower levels of internalized stigma (26.31 $\pm$ 9.63 vs. 33.00 $\pm$ 11.40; $p=0.07$) tended to achieve successful PCP retention. A comparison of means for independent variables and primary outcomes is shown in Table 2. No statistically significant differences were observed in demographic characteristics (i.e., race, age, use of public assistance) between the women who were retained in OB and PCP care as compared to those who were not.

Barriers and facilitators to retention identified in interviews

Twenty-two women completed qualitative interviews. All interviews were completed in the clinic as no one opted to complete on the phone. Two of these women did not attend a follow-up OB appointment within 3 months of delivery, but completed the interview during other appointments at the same clinic within 180 days of delivery and therefore were included in the analysis. Five women who attended a postpartum OB appointment within 3 months of delivery did not complete the follow-up: one woman declined to complete the follow-up for this study, two did not attend their first scheduled postpartum appointment, and two were not located.

Through qualitative interviews, four barriers and two facilitators associated with retention in care were identified. Barriers included competing responsibilities for time, lack of social support outside of their immediate family, limited transportation access, and experiences of institutionalized stigma. Facilitators included knowledge about the benefits of adherence to care, and strong relationships with healthcare providers. See Table 3 for specific quotes from participants pertaining to major themes.

Discussion

To our knowledge, this is one of the first studies to utilize mixed-methods data to examine factors associated with retention in care among HIV-infected women postpartum. Pregnancy may serve as a “teachable moment” when women are more receptive to making positive behavioral changes and may be an optimal time to instill the benefits of retention in care. Regular follow-up and retention in care is necessary to improve clinical HIV-related outcomes, manage comorbid and psychiatric conditions and increase survival rates.^{4–7}

This study used self-report demographic and psychosocial measures, measures of disease progression, and in-depth interviews from women receiving obstetrics HIV care at two county clinics in Houston, TX to understand factors that influence and predict retention in care postpartum. Quantitative findings were supported by participant-generated responses in qualitative interviews. Successful postpartum retention in care was quantitatively associated with lower measures of disease progression at both baseline and delivery, lower levels of depression, high interpersonal social support and fewer other children. Qualitative findings suggest that knowledge about the benefits of adhering to care and strong relationships with healthcare providers facilitate postpartum retention, while competing responsibilities for time, limited transportation, lack of social support outside of the immediate family and institutionalized stigma act as barriers.

Measures of stable disease, including higher CD4 count at delivery and lower viral load at baseline, were significantly associated with better retention in care. Bardeguez² and Rana¹ previously reported better adherence to ART during pregnancy as compared to postpartum. An analysis of factors in the same two county clinics in this study from 2006 to 2011 found in a multivariable logistic regression model that younger age, black race, late entry into prenatal care, and no

TABLE 2. MEAN VALUES OF PREDICTORS OF OB/PCP RETENTION

Variable, mean (SD)	OB follow-up within 3 months			PCP follow-up within 6 months		
	Yes (n=25)	No (n=10)	p Value	Yes (n=20)	No (n=15)	p Value
Baseline CD4 count ^a	428 (325,683)	382 (269,655)	0.25	443 (369,663)	324 (211,686)	0.27
Baseline viral load ^a	148 (48,3900)	361 (48,4430)	0.81	83 (48,542)	3900 (49,35500)	0.03
CD4 count at delivery ^a	512 (364,746)	369 (285,637)	0.04	493 (382,689)	549 (285,686)	0.46
Viral load at delivery ^a	48 (20,73)	48 (28,486)	0.24	48 (20,61)	48 (30,486)	0.14
Internalized stigma score ^b	28.13 (9.66)	31.80 (13.46)	0.37	26.31 (9.64)	33.00 (11.40)	0.07
Depression score ^c	15.24 (8.11)	23.50 (15.81)	0.05	16.21 (7.62)	18.97 (14.45)	0.48
Interpersonal score ^d	28.33 (5.54)	23.67 (7.05)	0.05	26.67 (6.18)	27.53 (6.49)	0.70
Number of children ^e	1.13 (1.26)	2.40 (1.96)	0.03	1.47 (1.61)	1.53 (1.60)	0.92

^aMedian (IQR); T-tests conducted with log transformed variables. ^bInternalized Stigma of AIDS Tool, range 0–50. ^cCenter for Epidemiologic Studies Depression Scale, range 0–60. ^dInterpersonal Support Evaluation List-12, range 0–36. ^eExcluding current pregnancy.

TABLE 3. INTERVIEW GENERATED RESPONSES OF BARRIERS AND FACILITATORS ASSOCIATED WITH RETENTION IN CARE

Barriers

Competing responsibilities for time

"They tell you that you're supposed to relax, get bed rest for 6 weeks or whatever, but they set your appointments right after you get out...We had like 3 or 4 appointments for the baby and I'm trying to shuffle mine and I'm tired...It's just too much." (Age 29)

Transportation access

"I was so stranded. That day I stayed [at the clinic] from 12 until 8, until somebody came after work to pick me up. There was no help." (Age 32)

Institutionalized stigma

"A nurse said that, 'The next time you want to bring a child into this world, you might want to reconsider.' I was like, 'How are you going to say that?'" (Age 19)

Lack of social support outside of the immediate family

"Well my family knows and I'm very skeptical about telling certain people because not everyone is mature, so I be careful who I tell." (Age 34)

Facilitators

Knowledge about the benefits of adhering to care

"When you have children, it's not really about you anymore; it's about the kids so you have to take care of yourself for them." (Age 36)

Strong relationships with healthcare providers

"[Healthcare providers] will help you one on one...Overall, you get a good feeling about yourself. You don't feel like you're going just because you're sick." (Age 28)

plans for contraception were associated with loss to follow-up.²⁸ During pregnancy, provider education emphasizing the benefits of adherence to medications and appointments postpartum is necessary to monitor disease progression. Women in this sample described a desire to take preventive actions for the health and well-being of their unborn child, indicating a possible "teachable moment" for this type of information.

Multiple competing responsibilities were a prominent barrier to retention in care in the qualitative analysis. In quantitative analysis, having more children (excluding the current pregnancy) was a factor significantly associated with poor retention in care. Participants reported that appointment times often conflicted with picking up their children from school, doctors' appointments for the children and that they often had no option for childcare aside from bringing them to the appointment. Higher parity has previously been associated with both a lack of postpartum retention³ and poorer adherence to ART.²⁹ These issues could potentially be addressed with clinic childcare options, more flexibility in appointment times, and a clear plan outlining when and how the patient will transition back to care with her PCP.

A lack of interpersonal social support outside of the immediate family, feelings of internalized stigma, and high levels of depressive symptoms were identified in quantitative and qualitative results as being associated with poor retention in care. In previous studies, a lack of social support among HIV-infected individuals has been shown to be associated with higher levels of perceived stigma, lack of HIV/AIDS disclosure, greater reluctance to seek care, and higher levels of depressive symptoms.^{30–32} In interviews, women spoke of a reluctance to disclose their HIV status to others outside of their immediate family because of past experiences in which they felt stigmatized after disclosure. As a result, they described a limited network of social support beyond that provided by their family. This might have ex-

acerbated feelings of competing responsibilities since the women spoke of difficulties coordinating their appointments with work, school, and childcare commitments, but only reported being able to ask for assistance from immediate family members. Stigma has previously been associated with a reluctance to seek care and non-adherence to treatment plans.^{33,34} Foster³⁵ reported that HIV-related stigma may be more prevalent in the South due to the close-knit nature of communities and entrenched beliefs that HIV-infection is an automatic death sentence. High levels of depressive symptoms during pregnancy for HIV-infected women have previously been associated with poor adherence to ART,³⁶ social isolation, and perceived stress.³⁷ Identification and treatment of psychosocial issues during pregnancy is necessary to prevent adverse outcomes for both mother and child postpartum.

The women with strong social support networks reported an easier time getting to appointments and taking their medications. During the course of this study, a support group was established for the women in the clinic and was well attended. Some women described it as their first opportunity to talk to other women who shared similar experiences. Similar to our results, Boeme reported that strong relationships between women and their healthcare providers are important to improve adherence in a population in southeastern United States.¹⁷ The women in this sample who described positive relationships reported being motivated to attend their appointments. These relationships may increase perceptions of social support. Women who are more trusting of their providers might be more likely to heed their advice. It is important for providers to understand their patient's medical history as well as personal factors that affect adherence to care. Beach found that patients who reported that their provider saw them "as a person" were significantly more likely to adhere to ART, have undetectable viral load and miss fewer appointments.³⁸

Transportation and institutionalized stigma were two institutional-level factors identified by women in qualitative interviews as critically impacting adherence to care. Results from a recent study identified transportation vulnerability as a barrier to service utilization for HIV-infected individuals, including insufficient transportation infrastructure, incompatible fit between transportation and health systems, and insensitivity to privacy issues.³⁹ Thus, additional assistance is necessary to increase the availability, accessibility, and affordability of transportation services. Service planners should highlight transportation as a priority in this patient population and thus aim to improve the quality of existing transportation assistance programs. Increased awareness of institutionalized stigma and sensitivity among providers is necessary to avoid discouraging women from seeking care. These experiences seemed to occur in hospitals or clinics that were not HIV specific. Nyblade⁴⁰ suggested that addressing privacy measures with all patients while enacting individual, environmental, and policy level interventions that increase the support and acceptance patients perceive when receiving care is necessary to prevent experiences that would deter patients from seeking care.

Several limitations exist with this study. This report is based on findings from women that were receiving care at two county clinics in Houston, TX. Thus, findings cannot be generalized to all sites and are not necessarily representative of the experiences of all HIV-infected women. However, the demographic characteristics of this sample are similar to those in the sample of HIV-infected pregnant women in the Southwest United States described by Siddiqui et al.²⁸ and Nacius et al.⁴¹ In addition, those women who were lost to follow-up and were not interviewed may have had different experiences due to data that we were unable to capture. Nevertheless, these important study findings provide valuable information by identifying and describing the factors that influence retention to care postpartum among this sample of women. These findings can be used to inform clinical decision making. To our knowledge, these findings represent one of the first mixed-methods studies to explore the factors associated with postpartum retention to care among low-income, minority women infected with HIV. Through surveys and qualitative interviews with HIV-infected women during the critical pregnancy and postpartum period, this study identified salient, modifiable factors that, if targeted by interventions, have the potential to improve the rate of postpartum adherence to HIV care among women living with HIV. These factors occur at the individual, interpersonal, and institutional levels and will require multi-level approaches to improve the treatment experience of HIV-infected women and help transition them from OB care to long-term PCP care. Support groups, motivational interviewing, healthcare personnel education, and transportation assistance may be helpful.

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