HIV care Equity & Access through Linkage (HEAL) Atlanta Innovation Project

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**Introduction-Background**

HIV medical care follow-up remains a significant public health problem. Data from the Centers of Disease Control and Prevention (CDC) reports that in the United States, “only about 50% of persons diagnosed with HIV receive regular HIV care” (Centers for Disease Control and Prevention, 2013). This global health issue greatly impacts HIV treatment outcomes of the patients at the Grady Infectious Disease Program (IDP) at Ponce De Leon Center, one of the largest, most comprehensive facilities dedicated to the treatment of advanced HIV/AIDS in the United States (Grady Health System, 2015).

Most recent unpublished raw data from the clinic showed that despite addressing and controlling for the typical known barriers to HIV care linkage such as cost of treatment and access, only 48% of HIV-infected pregnant women that deliver at Grady Hospital follow-up at the Grady Infectious Diseases Program (IDP) for HIV care within 6 months postpartum (A. Sheth, personal communication, December 12, 2015). Delayed and poor linkage to HIV care increases the risk for morbidity (Ulett et al, 2009) and perinatal transmission of HIV during subsequent pregnancies (Camacho-Gonzalez et al, 2015). For best outcomes “it is important that individuals with HIV know that they are HIV infected, link to and remain in HIV care, start and remain on ART, and adhere to treatment” (Mountain et al, 2014)

Addressing individual level as well as system level factors in order to reduce the barriers to postpartum care engagement is significant in improving adherence to treatment and clinical outcomes among HIV infected women after delivery (Buchberg et al, 2015). Therefore, the HIV care Equity and Access through Linkage (HEAL) Atlanta Project will explore barriers and facilitators to linkage in HIV care after delivery at the clinic in an effort to improve the health outcomes of HIV infected pregnant women seen at Grady IDP.

**Aim-Objectives**

Over 50% of HIV-infected pregnant women that deliver at Grady Hospital do not follow-up at the Grady IDP for HIV care within 6 months postpartum. To address this problem, a PICOT question was developed to guide the problem-solving process; in HIV infected pregnant women that deliver at Grady Hospital and referred to Grady IDP for postpartum HIV care, what are the specific barriers and facilitators to HIV care linkage within 6 months postpartum, and what interventions are effective in overcoming these barriers to improve linkage to HIV care?

The HEAL Atlanta Innovation project aims to improve postpartum HIV care for pregnant HIV-infected women delivering at Grady Hospital and referred to the IDP clinic, by investigating barriers and facilitators to postpartum HIV care linkage. The objectives of this project are 1) To examine and describe patients’ health beliefs regarding their HIV diagnosis and care, 2) To examine and describe patients’ perception of barriers to postpartum HIV care follow-up, 3) To examine and describe patients’ perception of elements that support and enhance continuity of care and 4) To develop patient-centered technology and health education interventions that will address the identified gaps.

**Methods**

a. General approach: This is a qualitative study, a grounded theory approach will be used for the HEAL Atlanta project. Semi-structured interviews of up to 50 HIV-infected women (up to 25 women who have achieved HIV care linkage by 90 days postpartum, and up to 25 women who have not linked to care by 90 days postpartum despite standard clinic referral and follow-up procedures

b. Study population: We will recruit up to 25 HIV-infected women who have at least 1 HIV care visit by 90 days postpartum and 25 women who do not have at least 1 HIV care visit by 90 days postpartum. We will recruit participants until thematic saturation
is achieved. Patients will be excluded if they are less than 18 years old, non-English speaking, or are unwilling to provide verbal informed consent.

c. Recruitment and enrollment procedures: Participants will be recruited exclusively from Grady HIV/OB clinic via provider (clinician, nursing, or social work) referral after they have attended their postpartum obstetrical visit (or been contacted regarding a missed visit). Postpartum women are routinely contacted via multiple methods by OB/HIV clinic nursing and social work for scheduling and reminder of postpartum obstetrical care visits and to assist with arrangement of HIV care linkage. Once a provider recommends a patient as a potential participant, the study team will contact them to assess eligibility and interest in participation.

d. Semi-structured interviews: Trained interviewers will conduct the interviews by telephone after verbal consent is obtained. Participants will receive a $25 VISA gift card for participation in the study. The interview guide will include open-ended questions about barriers and facilitators to receiving care such as stigma, discrimination, symptoms. We will also include specific questions about structural barriers such as transportation, childcare, health insurance, clinic factors. In addition, consistent with grounded theory methodology, salient issues that are uncovered through initial interviews may lead to modifications to later interview questions. Although we will not be able to assess non-verbal behavior, we will note tone of voice and other cues (laughing, crying, etc.) that will convey emotional responses during the interview. Interviewers will briefly summarize, review, and clarify information with each participant (data checking) at the end of each interview. Debriefing with interviewers will occur weekly.

e. Data management, monitoring, and analysis: All interviews will be digitally recorded and transcribed. All data including interview transcripts will be kept on encrypted, password-protected, HIPAA compliant drives that are restricted to study staff members working directly with the data. Interviewers will remind respondents not to use personal identifiers when responding to questions while being recorded. Recordings will be transcribed exclusive of any personal identifiers accidentally disclosed by the responded. Audio recordings for transcription will be destroyed, once the data has been transferred to the encrypted electronic format. Descriptors will be used to replace personal identifiers in the transcripts. Transcripts will be coded using NVivo 10.0. The initial phase will involve line by line transcript review to identify categories, emergent themes, and structural code development. Open coding of larger segments of text (e.g., content coding) will then commence. Axial coding will include assessment of possible relationships between code groups. Descriptive sub-codes and categories will then be developed. Codes may be restructured throughout the entire comparative analysis process until it is determined that saturation is attained. The codebook will be refined as needed during this process. Routine checks of inter-coder consistency will be performed and maintained at a level of ≥0.80 among the coders. If any coder falls below that level, we will conduct retraining on code definitions and intended meanings. Coding analysts will continually re-review, reconcile, and revise any discrepancies to ensure consistency of thematic coding. Two investigators (Drs. Holstad and Goswami) will review the themes and categories and codes and reach agreement. If agreement cannot be reached a third investigator will be queried. Both Drs. Holstad and Goswami have extensive experience in conducting qualitative research with vulnerable and marginalized groups.
**Anticipated Results**

Exploration of patient perceived barriers and facilitators is integral to informing the much needed practice change process at Grady IDP. We anticipate that by exploring barriers and facilitators to HIV linkage, we can identify and eliminate individual and microsystem level issues in order to improve processes in care and facilitate HIV care linkage. Currently only 48% of postpartum patients link to HIV care at Grady IDP after delivery at Grady Hospital (A. Sheth, personal communication, December 12, 2015). Desired outcomes will be demonstrated by at least 85% HIV care retention (having ≥2 outpatient visits at least 3 months apart during each year) by December 31, 2018.

**Impact on Healthcare Delivery**

The SEED-Scale Model of Sustained Transformation (Taylor-Ide & Taylor, 2002) will be used as the framework for the HEAL Atlanta project. Selection of this framework is influenced by the model’s focus on social change. It can be expected that the transformation of the linkage to HIV care practice issue will rely on addressing social factors/barriers (Bauman et al, 2013). Applying the four principles/catalysts for change (building on success, establishing a 3-way partnership, data-guided decisions, and practice change) used in the SEED-Scale model is an appropriate fit to catalyze delivery of care and health transformation of the HIV patients at the Grady IDP clinic.

Current evidence has shown that identifying barriers and facilitators informs development of customized interventions to support HIV care linkage and retention, thus improving health outcomes (Buchberg et al, 2015). HEAL Atlanta will utilize a systematic process to build capacity, create the vision, and act in order to improve healthcare delivery. The specific customized patient-centered technology and health education intervention will be informed by the results of the qualitative interviews. This process will facilitate the streamlining of the delivery of healthcare at the IDP. Therefore, identifying patient perceived barriers and facilitators to linkage in care will be crucial to facilitating practice change and building capacity in order to improve delivery of healthcare, and potentially lead to healthcare cost savings in the long run.
References


