

## “PAIN IN MY HEART”: PERINATAL DEPRESSION AND ENGAGEMENT IN HIV CARE IN MALAWI

The scale up of antiretroviral treatment to all pregnant and breastfeeding women, known as Option B+, has the potential to dramatically improve maternal health and end mother-to-child HIV transmission.<sup>1</sup> However, lack of engagement in HIV care among peripartum women, especially those with perinatal depression (PND), threatens to limit the positive impact of Option B+ on HIV care outcomes. PND is common among pregnant and postpartum women, and especially among those living with HIV.<sup>2-4</sup> PND has many negative effects on both the mother and baby and can interfere with engagement in HIV care and antiretroviral medication adherence.<sup>5-7</sup> Consequently, understanding how PND affects women’s health and engagement in HIV care is a high priority.<sup>8,9</sup> Our goal with this project was twofold: (1) to understand the experience of PND and its relationship to HIV care among women with HIV and (2) to obtain women’s and providers’ perspectives on the feasibility and acceptability of screening and treatment for PND for women living with HIV. Once we develop this understanding, we ultimately plan to develop tailored interventions to address PND among women living with HIV.

We conducted 24 in-depth interviews (14 with prenatal and 10 with postnatal HIV-infected women with PND) to explore women’s experiences of PND and its impact on HIV care engagement and to explore women’s preferences for screening and treatment. We also conducted 10 in-depth interviews with HIV and mental health providers to assess the feasibility of PND screening and to explore providers’ perspectives on staff resources, cultural appropriateness, and barriers and facilitators to PND screening and treatment. Interviews were conducted in Chichewa at five antenatal/antiretroviral therapy clinics in Lilongwe District, Malawi: four rural (Kawale, Lumbadzi, Kabudula, and Mitundu Health Centers) and one urban (Bwaila Family Health Unit). All interviews were audiotaped and transcribed. Data were analyzed using deductive and inductive coding.

Women were, on average, 27 years old and most had multiple children, were married, unemployed, and had at least some education (Table 1). Of 73 women screened, 24 (33%) had PND; prevalence was higher at the four rural sites (range: 29-71%) than at the urban site (13%) (Table 2). Of the 73 women screened, 14 (19%) reported suicidal ideation, with prevalence also being higher at the four rural sites (range: 24-63%) than at the urban site (0%) (Table 2). Nine women received their HIV status in their most recent pregnancy and one additional woman was starting antiretroviral medication for the first time. Most women (71%) had received their HIV status over two years ago and most stated that they began having feelings of depression

around the time of their HIV diagnosis. Women had not been screened for or diagnosed with PND previously.

Women frequently described the event of HIV diagnosis as closely linked to their feelings of depression. Many women were first diagnosed with HIV when tested routinely during antenatal care, and the diagnosis came as a shock. The unexpected HIV diagnosis was often accompanied with worry about transmitting HIV to their child both during their pregnancy and while breastfeeding. Women were often stigmatized in their community, simultaneously being told that their life has ended with this new diagnosis and that they should not be sad and should continue life as normal. This often led to women's anxiety around disclosing their HIV status and subsequent marital issues after disclosure, as many women said that their husbands did not understand their situation. These many worries often contributed to women feeling ashamed to take HIV medication, which sometimes contributed to their low adherence to HIV medication. These many new worries and concerns often led to women feeling isolated and made them likely to develop PND. HIV-infected women experiencing PND discussed their double burden of having both a newly diagnosed mental and physical illness and a concern that their depression would never go away, as their HIV status is both lifelong and a source of their PND.

All women participants were open to receiving PND screening, counseling, and medication, and all healthcare staff also felt that this was necessary. While most staff said that screening and counseling could be integrated into antenatal care, some staff stated that there was a lack of human resources to provide these services. Women and staff agreed that nurses at the HIV and antenatal care clinics would be the best equipped to screen and counsel patients as they have the most interaction with patients and know patients' histories. Participants stated that counseling should begin during pregnancy and continue into the postpartum period, as PND is often more pronounced once the child is born. Many women stated that they needed someone to discuss their worries with, as they were not able to talk openly about their PND or HIV diagnosis with others. Most women and staff believed that one-on-one counseling would be preferable to group counseling, as women would be more likely to be open in a private setting and would not fear disclosing their HIV or PND status to group members. However, some women and staff believed that group counseling would be beneficial as well, as women in similar situations could encourage each other. Women and staff generally preferred counseling before receiving medication. Staff believed that only women with severe and persistent PND should receive medication in addition to counseling.

These findings highlight the need to address the burden and negative consequences of simultaneous PND and HIV diagnoses during the perinatal period in Malawi. The potential to

improve outcomes for PND and to improve engagement in HIV care in a simple, low-resource intervention holds considerable promise for optimizing the gains of the Option B+ program and improving health outcomes for HIV-infected women. We plan to use this formative research to develop an intervention adapted to the unique needs of HIV-infected women during the perinatal period that is enhanced to support engagement in HIV care. Addressing PND and its influence on engagement in care through an integrated counseling intervention is expected lead to improved mental health, HIV care engagement, and ultimately better clinical outcomes for HIV-infected women.

| Table 1: Women and Provider Demographic Information |          |
|---|----------|
| Women's Demographic Information                     | N (%)    |
| Age (Mean)  | 27       |
| Type of Participant                                 |          |
| Prenatal Woman                                      | 14 (58%) |
| Postnatal Woman                                     | 10 (42%) |
| Initiating ART for the first time                   |          |
| Yes   | 1 (4%)   |
| Diagnosed during this pregnancy                     |          |
| Yes   | 9 (38%)  |
| Pregnancy Number                                    |          |
| First   | 3 (13%)  |
| Second  | 9 (38%)  |
| Third   | 6 (33%)  |
| Fourth  | 4 (17%)  |
| Fifth or more                                       | 2 (8%)   |
| Length Living with HIV                              |          |
| 2+ years  | 17 (71%) |
| 1-2 years   | 1 (4%)   |
| 6 months – 1 year                                   | 1 (4%)   |
| Diagnosed in last 6 months                          | 5 (21%)  |
| Marital Status                                      |          |
| Married   | 20 (83%) |
| Separated   | 2 (8%)   |
| Divorced  | 2 (8%)   |
| Education   |          |
| None  | 2 (8%)   |
| S1-S7   | 12 (50%) |
| S8  | 2 (8%)   |
| Secondary or More                                   | 8 (33%)  |
| Provider's Demographic Information                  |          |
| HIV provider  | 7 (70%)  |
| Clinic director                                     | 1 (10%)  |
| Mental health provider                              | 2 (20%)  |

**Table 2: Perinatal Depression (PND) Screening**

| Clinic Site | Number Screened for PND+ | Number with PND | Number with Suicidal Ideation | Percent with PND | Percent with Suicidal Ideation |
|-------------|--------------------------|-----------------|-------------------------------|------------------|--------------------------------|
| Bwaila      | 30                       | 4               | 0                             | 13%              | 0%                             |
| Kawale      | 17                       | 5               | 4                             | 29%              | 24%                            |
| Lumbadzi    | 11                       | 5               | 3                             | 45%              | 27%                            |
| Kabudula    | 7                        | 5               | 2                             | 71%              | 29%                            |
| Mitundu     | 8                        | 5               | 5                             | 63%              | 63%                            |
| Total       | 73                       | 24              | 14                            | 33%              | 19%                            |

+ Women were screened until 4 to 5 were found to have PND at each site.

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