**Heard, Informed, and Supported: Communication Preferences Around Infant Feeding Among Women with HIV in the United States**

Kira J Nightingale, Kaleb Branch, Chelsea Lise Mbakop, Noelle Burwell, Elizabeth D Lowenthal, Rebecca RS Clark

Thomas Jefferson University (KJN), University of Pennsylvania Perelman School of Medicine (KB, CLM, EDL), Children's Hospital of Philadelphia (KB, EDL), University of Pennsylvania School of Nursing (NB, RRSC)

**Background**: Prior to 2023, women with HIV in the United States were discouraged from breastfeeding due to the potential for HIV transmission. Updated guidelines now encourage shared decision-making (SDM) around infant feeding. However, there are considerable gaps in our knowledge about how to effectively engage in SDM around this topic. This study therefore sought to understand the experiences with and preferences for clinician communication around infant feeding among women with HIV in the United States.

**Study Design:** This qualitative study used semi-structured interviews with persons with HIV who were pregnant or had given birth within the past three years. Transcripts were coded using a combined deductive and inductive approach, and major themes were identified.

**Results:** Among 19 women in a diverse, national cohort representing 11 states, experiences with SDM varied widely, reflecting inconsistent implementation of revised guidelines. Participants described varying levels of provider willingness to engage in SDM, commonly interpreted as the extent to which their provider was “supportive,” combined with a range of perceived provider knowledge about breastfeeding with HIV. The intersection of support and knowledge shaped overall satisfaction with the encounter, with deficits in either area causing frustration. Participants were aware of the inherent power dynamics within the clinical encounter, and only some felt empowered to advocate for themselves regarding their preferred feeding choice. Participants described wanting complete, accurate, unbiased information; consideration of their values; and respect as individuals and mothers. Negative experiences involved unsupportive or uninformed providers, conflicting information over time or across providers, and stigma. Care was often fragmented across specialties and institutions, and participants with well-coordinated care teams reported greater satisfaction. Many conducted independent research and relied on peer support outside clinical encounters, which in turn shaped their interactions with providers.

**Conclusion:** Implementation of new infant feeding guidelines remains inconsistent, and many patients report negative provider interactions. Supporting SDM requires providers to understand risk-mitigation strategies, communicate them clearly, coordinate across care teams, and practice active listening while soliciting patient values and providing unbiased, comprehensive information.