

Holistic Care and Respect for Persons: Exploring the Motivations and Concerns of Pregnant Women When Considering HIV Research Engagement

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Background: The ethical principle, respect for persons, suggests investigators must design research that is responsive to participants' preferences and concerns. This is especially important when engaging vulnerable populations, such as pregnant or recently pregnant women with HIV (PWHIV). This qualitative study aimed to explore the understanding and prioritization of holistic care by PWHIV when considering research participation.

Methods: This study was conducted within the Academic Model Providing Access to Healthcare in Eldoret, Kenya. We performed 45 semi-structured interviews between January and September 2024. Interview participants were currently or recently pregnant [29 with HIV, 16 without HIV] participating in HIV research with their infants. Interviews were audio-recorded, transcribed, translated, and analyzed by coders using a priori coding, constant comparison, axial coding, and triangulation.

Results: Holistic care was a major motivation facilitating longitudinal participation. Dimensions of holistic care included monitoring of their children's health and development, increased access to referrals and healthcare, reimbursement, and learning about topics including parenting, HIV, prevention of perinatal HIV transmission, and child health. Most participants viewed contact with the research team as an opportunity for positive healthcare interactions without stigma where PWHIV felt cared for, free to ask questions, accepted, and empowered.

Participants identified actions for investigators engaging PWHIV in research that promote respect and holistic care. These included return and explanation of all tests results, dynamic reimbursement based on burden of participation, availability of a supportive visit environment, communication with participants between visits, and offering educational resources, referrals, and guidance. Participants expressed concerns regarding how they will navigate the loss of support when study participation ends and desired clear communication about what should be expected at that time.

Conclusion: Holistic engagement and understanding of the factors affecting participation of this population will help researchers promote respect for participants, prevent harm, and uplift PWHIV and their children.