Community Engagement to Explore Mothering and Infant Feeding Practices Among Black Women Living With HIV

Dr Josephine Etowa¹, Dr Jean Hannan², Dr Seye Babatunde³, Dr J. Craig Phillips¹, Dr Bagnini Kohoun³, Dr Hugues Loemba³, Dr Nnanna Onyekwere⁴ and Yvette Ashiri¹

¹University of Ottawa, Canada; ²Florida International University, USA; ³Centre for Health and Development, University of Port Harcourt, Nigeria; ⁴Rivers State Ministry of Health, Nigeria

Introduction

- Women of childbearing age account for nearly half of the world’s HIV cases. Black women are disproportionately affected. Evidence indicates that breastfeeding presents a 20% risk of HIV transmission to infants.
- Black women in the African diaspora share socio-cultural perceptions of motherhood, vulnerability to HIV infection through heterosexual contact, and socio-economic barriers to needed health and social services.
- Meaningful community engagement is an effective framework for studying a complex topic such as this.

Research Purpose

- To examine the ethno-cultural context of infant feeding practices among childbearing HIV positive Black women.
- To build individual, community, and organizational capacity and leadership to optimize HIV and infant feeding care for Black women.
- To develop a successful approach to infant feeding that is grounded in the experiential knowledge of Black women living with HIV.

Objectives

1. Identify the principles of community based participatory research (CBPR) for meaningful community engagement.
2. Describe key strategies.

Theoretical Framework

- Community based participatory Research (fosters community engagement and Capacity building).
- It is not only an approach to studying phenomena from the perspectives of those being studied; it is also a means of mobilizing for collective social action to address the community needs and for creating change at multiple levels.
- Goals are: Research, Education & Action
- Values: what people know and believe by using their present reality as a starting point and building on it.
- Creates critical awareness and subsequent transformation
- Fosters empowerment through the process of engaging in experiential learning and collective action.

Research Design

- We use a multi-phase, multi-site, mixed methods research approach that is guided by the tenets of community-based participatory research (CBPR) and post-colonialism.
- Community engagement and participation are integrated throughout the research and includes the formation of advisory groups, consultation meetings, and data analysis.

CBPR Strategies

- Strategic composition of the research team with researchers of diverse backgrounds.
- Community-based analysis of the key issues/Social Determinants of Health.
- Adopting the principle of valuing people’s capacity to think and work together for better living and healthier choices.
- Meaningful community engagement e.g. The use of CAG (Community Advisory Group) was a lever for transformation.
- In Ottawa: empowered women are self-advocating for visibility from local researchers and better services from clinicians.
- In Miami: CAG is raising awareness and mobilizing community members for more actions to educate the public.
- In Port Harcourt: leveraging on community-based support groups, women mobilized to identify with research and promote policy change.

Looking Ahead

- While project is ongoing, the research process is already creating impact in the communities in the study sites.
- It is already increasing awareness and generating knowledge to improve cultural competence and cultural safety.
- Innovative use of CBPR mechanisms is helping our team to:
  ▪ employ the most effective and acceptable means of collecting relevant and valid information.
  ▪ ensure the clinical relevance and cultural suitability of recommendations.
  ▪ inform the development of policy and health actions that will improve the health and healthcare of Black women living with HIV and their infants.

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References