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Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and healthcare providers in a rural South African context

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ABSTRACT

Although there is extensive coverage of prevention of mother-to-child transmission of HIV (PMTCT) and a decline in new HIV infections of children nationally, challenges still exist with regard to the utilisation and retention of PMTCT services in Mpumalanga Province. The PMTCT research conducted previously in South Africa has been more programme and implementation-focused, therefore, there is a dearth of information on the intersecting narratives of PMTCT lived experiences among HIV positive women (who receive healthcare services), grandmothers (who support those receiving PMTCT services) and healthcare providers (who provide PMTCT services) in a rural context. It is not known how women in the rural communities of Mpumalanga Province make decisions regarding their participation in the PMTCT programme. The impact of family on the early participation in the PMTCT programme and on infant feeding is also not entirely known. Additionally, the cultural and linguistic barriers to PMTCT service provision in a rural setting are not documented. The aim of this study was to explore the intersecting narratives of PMTCT lived experiences among HIV positive women, grandmothers and HCPs in a rural South African context. Such narratives were obtained to assist in describing factors that facilitate and hinder HIV positive women's early participation in the PMTCT programme.

The sample for this study consisted of 66 participants who were divided into three groups: 29 HIV positive women, 32 grandmothers and 5 HCPs. A purposive sampling procedure was used to select study participants. A narrative qualitative research design was used to conduct the study. Data were collected using semi-structured interviews and focus group discussions. Additionally, data were analysed using thematic analysis and small story analysis framework. The social constructionism theory and the phenomenological approach were used to understand participants' lived experiences of the PMTCT programme.

This study provided a unique way of understanding the PMTCT lived experiences by demonstrating multiple perspectives of how PMTCT services are perceived by rural women. The findings revealed intersecting narratives of the lived experiences among the three groups of participants on factors that facilitate and hinder participation in the PMTCT programme. There

were seven key themes that emerged from the study, which include: 1) fear of stigma as a trigger for late antenatal care attendance, 2) HIV testing stgmatisation and fear of HIV burden, 3) fear of stigma and women disempowerment on infant feeding, 4) health services stigmatization and cultural stereo types affecting male involvement, 5) structural violence, tradition and healthcare system as PMTCT blockages, 6) fear as a factor affecting adherence to PMTCT processes and 7) enhancing PMTCT programme through health education, community participation, individual and health system change

This study revealed that PMTCT services non-utilisation stems from negative societal constructions of HIV. Findings revealed a high degree of dependency on "social selves" in relation to health-seeking reality. A pertinent finding of this study was that fear appeared to dominate every aspect of health-seeking behaviour for the HIV positive participants. Hence, factors inhibiting PMTCT utilisation in a rural context included multilevel stigma at the individual, community, and healthcare facility level. Other factors included: structural violence, cultural, traditional, psychosocial, health system and knowledge factors. The facilitators of PMTCT services utilisation were community mobilisation on social and cultural factors; health systems improvement; ongoing PMTCT education (relevant to rural context); HIV disclosure; peer counsellor involvement; family involvement (grandmothers and male partners); individual factors improvement (self-love; self-reliance) and improved language-use in PMTCT. These were suggested to be vital for the PMTCT service improvement. Data for the study generated new category of 'PMTCT shared small stories' and PMTCT affective small stories' which provided a unique way of understanding the context of lived experiences of the three groups of participants. The lack of knowledge, fear and lack of decision-making powers disempower women from adhering to PMTCT cascade processes. The findings of this study have informed implications for the HCPs and the Department of Health, to promote the effectiveness of the PMTCT programme in a rural context.

Key words: PMTCT, HIV, MTCT, healthcare provider, healthcare facility, narratives, small stories, narrative inquiry, women, lived experience, fear, community, thematic analysis, infant feeding, and women disempowrment.