

Abstract

Indonesia is ranked third highest in the world for the number of children living with HIV, following only India and China. Although the government of Indonesia has responded with a policy package for HIV management, the focus is on adults with HIV, while children with HIV receive little attention. The aim of this thesis is to explore the subjective experiences and perspectives of children with HIV, their families, and healthcare professionals; and to generate a substantive grounded theory on HIV care for children and their families across the continuum in the Indonesian context.

A qualitative constructivist grounded theory design was used to guide the research. Semi-structured interviews were conducted with children with HIV aged 8-18 years and their family carers, and health professionals across eight different healthcare settings, including five Public Health Centres (PHCs) and three hospitals in Surabaya, in the East Java Province of Indonesia. The participants were recruited using purposive sampling, and the data were analysed according to grounded theory methods. This study purposively sampled 12 children with HIV, 8 parents or family members, and 23 health professionals.

The coding analysis constructed three major categories, namely maintaining the health of the child, living with fear and stigma, and predisposing factors for ineffective healthcare. Children with HIV and their families experience financial and other challenges, such as discrimination and marginalisation that negatively affect their care. However, families are motivated to maintain their children's health through developing family caregiving responsibilities to sustain the uptake of Antiretroviral (ARV) treatment while continuing to promote the child's growth and development. Children with HIV and their families experience fragmentation of care due to the absence of child-centred care, inadequate healthcare system support, and their social determinants of health. In this study, the integration of the categories constructed the core category, 'The need for comprehensive care'. The resulting model was structured on child-centred care and social support to address the fragmentation of care.

Exploring the perspectives of children with HIV, their families, and health professionals has revealed the need to enhance the delivery of comprehensive care. These perspectives will inform policy-makers, health professionals, nursing educators, and researchers to improve care across the continuum for these children and their families in Indonesia.