



The Perceived Impact of Disclosure of Pediatric HIV Status on Pediatric Antiretroviral Therapy Adherence, Child Well-Being, and Social Relationships in a Resource-Limited Setting

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Abstract:

In resource-limited settings, beliefs about disclosing a child's HIV status and the subsequent impacts of disclosure have not been well studied. We sought to describe how parents and guardians of HIV-infected children view the impact of disclosing a child's HIV status, particularly for children's antiretroviral therapy (ART) adherence. A qualitative study was

conducted using involving focus groups and interviews with parents and guardians of HIV-infected children receiving ART in western Kenya. Interviews covered multiple aspects of the experience of having children take medicines. Transcribed interview dialogues were coded for analysis. Data were collected from 120 parents and guardians caring for children 0–14 years (mean 6.8 years, standard deviation [SD] 6.4); 118 of 120 had not told the children they had HIV. Children’s caregivers (parents and guardians) described their views on disclosure to children and to others, including how this information-sharing impacted pediatric ART adherence, children’s well-being, and their social relationships. Caregivers believed that disclosure might have benefits such as improved ART adherence, especially for older children, and better engagement of a helping social network. They also feared, however, that disclosure might have both negative psychological effects for children and negative social effects for their families, including discrimination. In western Kenya, caregivers’ views on the risks and benefits to disclosing children’s HIV status emerged a key theme related to a family’s experience with HIV medications, even for families who had not disclosed the child’s status. Assessing caregivers’ views of disclosure is important to understanding and monitoring pediatric ART.

Description:

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