

Abstract

Optimal pediatric HIV disclosure impacts illness and developmental experiences while improving access to timely treatment. However, disclosure rates in high HIV prevalence countries remain low and there are limited data on best practices. We conducted a qualitative study of disclosure practices and interviewed healthcare providers from five pediatric HIV clinics in Kenya. We identified themes central to disclosure practices, rationale for approaches, barriers to implementing disclosure, and creative strategies to overcome challenges. We used these insights to develop a practice-based framework for disclosure that is sensitive to practical challenges. Overall, providers had limited training but extensive experience in disclosure, endorsed individualized disclosure practices, invested substantial time on disclosure despite clinical burden, and noted adverse outcomes associated with unplanned or abrupt disclosure. Providers advocated for an approach to disclosure that is child-centered but respects caregiver fears and values. Caregiver support was provided to enable caregivers to be the person who ultimately disclosed HIV status to children. Unplanned or abrupt disclosure to children was reported to have severe and persistent adverse impact and was a stimulus to accelerate disclosure in scenarios when providers believed children may be suspecting their diagnosis. Based on these expert insights, the framework we developed incorporates concurrent evaluation of child and caregiver readiness, identifies cues to prompt disclosure discussions, includes caregiver education and support, and utilizes a gradual approach of unveiling HIV diagnosis to the child.