Supporting HIV disclosure to infected children and adolescents: The experience of Médecins Sans Frontières

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Background: WHO recommends that HIV-positive children between the age of 6 and 12 years should be told their HIV status. Disclosure can be a challenge for caretakers who may fear emotional consequences for the child or that the child will disclose their HIV status within the community. Médecins Sans Frontières (MSF) supports caretakers in disclosure by offering partial disclosure sessions in which children are given information about what is happening in their body without naming the disease. After a preparation session, caretakers can choose to name HIV to the child at home or with the help of a counsellor at the clinic. A full disclosure session is offered at the clinic to finalise the process, explaining the infection and ways of transmission. Full disclosure should be reached before the age of 12. Professional and lay counsellors have been trained on this task. We reviewed the disclosure status of children and young adolescents enrolled on ART in 5 MSF programs in Guinea-Conakry, Kenya, Malawi, Mozambique and South Africa to evaluate the intervention.

Methods: A retrospective folder review recording the degree of disclosure (nil, partial, full) was carried out in children and young adolescents between 6 and 14 years of age on ART and retained in care between August 2012 – April 2013.

Results: 14.5% (95% CI 11.7-17.3) of children between 6 and 9 years were recorded as being partially disclosed, whilst 32.9% (95% CI 28.8-37.0) of adolescents aged 10 to 14 years were fully disclosed. Rates of disclosure ranged from 2% to 46% and from 17% to 59% in children aged 6-9 and 10-14 respectively. Projects where disclosure counselling is not task-shifted to lay counsellors, and those without a standardised disclosure approach, had lower rates of disclosure. A shift from motivating caretakers to disclose towards actively supporting caretakers in disclosure improved rates of full disclosure for young adolescents from 37% to 59% in one site.

Conclusions: Increased investment in active disclosure support has lead to better disclosure outcomes but an unacceptably high number of children still remain undisclosed by adolescence. This has psychosocial and behavioural implications and may worsen adherence to antiretroviral therapy. Several health centre related barriers to disclosure have been identified such as lack of task-shifting and training of lay counsellors, delayed provision of disclosure support and resistance of counsellors to take an active role in disclosure. Caretaker related barriers are ongoing refusal to disclose and children having multiple caregivers. Future interventions should focus on addressing these barriers and balancing

between caregiver-driven and health care worker-driven models of disclosure. Routine and structured disclosure support should be offered earlier and counsellors are to be further trained in supporting disclosure.