



Disclosure of their HIV status to HIV-infected children participating in the ARROW trial in Entebbe, Uganda

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ISSUES

HIV-infected children depend upon adults for their HIV-related care.

It has been suggested that knowledge of HIV status among older children may improve adherence to anti-retroviral therapy (ART).

The Ugandan National ART guidelines recommend children aged ≥ 8 years be informed of their HIV status.

There are few documented experiences of disclosure of HIV status to children on ART.

DESCRIPTION

ARROW is a clinical trial evaluating monitoring strategies and first-line ART in HIV-infected children from Uganda and Zimbabwe.

Informed consent to participate in ARROW was given by the child's primary carer.

The trial counselors encourage carers of children ≥ 8 years to disclose to them their HIV status at home.

The counselors also offer the option of assisted disclosure in the clinic.



FINDINGS

189 children were recruited to ARROW -Entebbe

- median age 6.6 (IQR:3.7 -9.2); 88 boys/101 girls)
- None of them knew their HIV status at enrolment.

179 children are in active follow up

There are 96 children >8 years and the disclosure process has been started in 81 (84%) and is ongoing.

- Over the past two years,
 - **81 children (79/81 aged ≥ 8 years) have learnt their HIV status through assisted disclosure**

- **2 children aged 7 years were also informed of their status as both had been asking questions about tablet taking.**

50/81 (61.7%) carers were biological parents

- mostly on ART
- found disclosure easier than non-biological guardians who understood little about HIV.

Information supplied through guidance and support from counselors was central to the success of the assisted disclosure process.

Carers reported that information received during the disclosure process has helped improve children's adherence to ART.

LESSONS LEARNED and NEXT STEPS

- Disclosure of their HIV status to children on ART aged ≥ 8 years is an ongoing process which appears fundamental for maintaining adherence to ART.
- Carers, especially non-biological parents, frequently require professional support to disclose to the children their HIV status.
- Disclosure of a child's HIV status by all primary carers should be encouraged and be part of the training given to HIV health care workers.

COLLABORATORS and ACKNOWLEDGEMENTS

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