Promoting paediatric ART adherence and retention: Outcomes of children receiving ART in family ART adherence clubs in Khayelitsha, South Africa



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Introduction

Community models of care for ART delivery supporting long term retention are relevant not only for adult ART populations but also for children.

Family ART adherence clubs (FCs) adjusted Médecins Sans Frontières' ART adherence club model for family units.

Fifteen children stable on ART and their caregivers meet at the clinic every 2 months, receive support and ART supply in their club. Not all caregivers have to be ART patients to join but caregivers on ART must be stable on treatment. Children's age is assessed to ensure enrolment into a FC with a similar age range for age appropriate progressive disclosure to take place. Child disclosure forms a key part of group discussions. Children have their viral load (VL) taken at least once a year with a follow-up clinical consultation. When a child has a raised VL, requires regular clinical follow-up, or neither child nor caregiver attends their scheduled club visit, they return to mainstream care, including enhanced adherence support.

For further detail see MSF FC toolkit:

http://samumsf.org/documents/2015/06/family-art-clubs.pdf

Aim

This study evaluated the retention and virological outcomes of children who had enrolled in the FC model.

Methods

Paediatric patients enrolled in FCs from March 2011–September 2013 and who were not reported to have transferred care elsewhere were included.

Patient baseline characteristics; longitudinal VL data, retention in care outcomes and child disclosure status were collected from clinic records on 30 November 2014.

Patients with no recorded clinic or FC visit for more than three months prior to collection date were counted as lost to follow-up (LTFU).

Results

146 children and 71 caregivers on ART enrolled in FCs in the study period. 7 children were reported to have transferred care and were excluded from the study cohort.

45% (65) of children were female and median age was 9.1 years (IQR 6.8-11.3). Median time on ART prior to FC enrolment was 5.3 years (IQR 3.6-6.4) and time in FCs was 2.7 years (IQR 1.7-3.5).

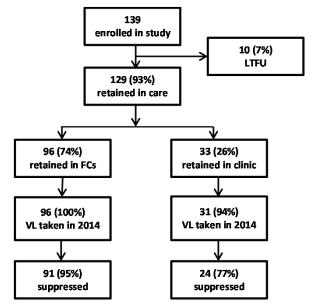
Retention and virological outcomes are reflected in flowchart.

Of those children retained in clinic care, 15 (45%) exited the FC due to a high VL while the remaining 17 (55%) were suppressed at exit and left the FC due to missing their scheduled club visit or for other clinical reasons.

Median time in a FC until exit was 1.9 years (IQR 1.3-3.3).

Of those children retained in FC care, 16 (100%) 7-10 year olds achieved partial disclosure and 57 (79%) older than 10 years of age achieved full disclosure at the time of assessment.









Conclusions

FCs ensure quick access to ART for children and their caregivers stable on ART, supporting high rates of paediatric retention and adherence.

FCs allow for family-centered HIV care with less interruption of daily family activities; promotion of school attendance; and an optimal setting for empowering caregivers to manage child disclosure.

Children struggle more than adults¹ to maintain good adherence throughout childhood years. Effective referral pathways between the FCs and routine clinic care are shown to be necessary to ensure clinician-led individual management of a child when indicated. Ease of transition between these two models of care supported overall retention.

FCs show that existing community models of care for ART delivery can easily be adapted to meet the needs of specific patient populations.

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Site B Ubuntu ART clinic staff Caregivers & children in care at Ubuntu clinic, Khayelitsha