

## **FORUM**

# **ART adherence clubs: A long-term** retention strategy for clinically stable patients receiving antiretroviral therapy

L S Wilkinson, BA, LLB

Médecins Sans Frontières Khayelitsha, Cape Town, South Africa

Corresponding author: L Wilkinson (msfocb-khayelitsha-coord@brussels.msf.org)

The ART-adherence club model described here provides patient-friendly access to antiretroviral therapy (ART) for clinically stable patients. It reduces the burden that stable patients place on healthcare facilities, increasing clinical human resources for new patients, and those clinically unstable and at risk of failing treatment. In the model, 30 patients are allocated to an ART club. The group meets either at a facility or community venue for less than an hour every 2 months. Group meetings are facilitated by a lay club facilitator who provides a quick clinical assessment, referral where necessary, and dispenses pre-packed ART. From January 2011 to December 2012, after adoption for phased rollout by the Western Cape Government, more than 600 ART clubs were established in Cape Town, providing ART care to over 16 000 patients. This extensive, rapid rollout demonstrates active buy-in from patients and facility staff. South Africa should consider a similar model for national rollout.

S Afr J HIV Med 2013;14(2):48-50. DOI:10.7196/SAJHIVMED.924



South Africa (SA)'s National Strategic Plan 2012 - 2016 aims to ensure that 80% of all HIV-positive patients who are eligible for antiretroviral therapy (ART), estimated at more than 3 million, are initiated on such treatment

by 2016. It further aims to retain 70% of these patients in care 5 years after treatment initiation. By early 2013, 1.9 million people in SA were initiated on ART, with studies estimating retention to be <70% after 3 years of commencing treatment.[1,2]

The growing numbers of patients attending healthcare facilities place increasing pressure on already stretched humanresource capacity, impacting the time taken to deliver services and the quality of care provided. In turn, the cost to patients of having to return to facilities regularly, the long waiting times at facilities, competing demands on time, including work and family responsibilities, and dissatisfaction with the quality of care, all affect long-term retention.[3]

Effective long-term retention models of care are needed that offer quick, inexpensive and patient-friendly access to treatment and care for stable ART patients.<sup>[4]</sup> Such models should also aim to decrease the burden that stable patients place on healthcare facilities, thereby increasing human resources for new patients and those who are clinically unstable and at risk of failing treatment. The ART-adherence clubs piloted by Médecins Sans Frontières (MSF) in Khayelitsha, SA, represent one such model.

#### ART-adherence clubs

ART-adherence clubs are an option for rapid service delivery; 30 patients are allocated to a group and meet either at a facility or community venue for less than an hour every 2 months. These group meetings are facilitated by a lay club facilitator who provides a quick clinical assessment, with referral to a clinician, where necessary, and dispenses pre-packed ART. Club members establish a positive group dynamic over time, which renders much-needed peer support for adherence to lifelong treatment.

Club facilitators refer any patient reporting symptoms or ill health, or who recorded weight loss since their last club visitation. The club is supported by a facility nurse who is available to see patients referred by the facilitator, immediately after a club session. All club patients receive annual blood tests, with scheduling aligned and blood samples taken at the same session. Two months later, all members are seen by the club nurse for their annual clinical consultation and repeat prescriptions of ART.

Patients qualify for ART club membership if they have been on the same ART regimen for longer than 12 months, have two consecutive undetectable viral loads, and do not have any clinical conditions that require regular follow-up. While in the clinic waiting room, patients are encouraged to request their clinician to assess them for club recruitment.

Club patients are entitled to send a 'buddy' to collect their treatment from their ART club. However, patients themselves must attend every second club session, including the annual blood investigation and annual clinical consultation sessions. Patients can be removed from club care and returned to mainstream care when more intensive clinical or adherence follow-up is required. A patient exits the club when he/she misses a mandatory club session and fails to attend the clinic within 5 days. Patients determined by the club nurse to require more regular follow-up and those with elevated viral loads are also returned to mainstream care.

Club patients are monitored by completion of a simple register by the facilitator. Attendance is then captured as club



Fig. 2. Patients at an ART adherence club meeting.

plus clinic attendance in the clinic's electronic database by the clinic data capturer. ART clubs are considered part of the ART service at a facility and are managed by a facilitybased nurse (called the 'clubs manager') who is responsible for the scheduling of club dates, the smooth running of clubs, clinical governance and club reporting requirements.

## **Pilot: Experience** from Khayelitsha

MSF began with a pilot project of 20 clubs at the Ubuntu clinic, Site B, Khayelitsha in 2007. A retrospective observational evaluation found that retention in clinic care after 40 months was 97% for club patients compared with 85% among those who qualified for clubs but continued to be managed outside of the club model. Club participants were also 67% less likely to experience virological rebound, indicating better adherence in clubs than in mainstream care.[5]

The club model was adapted both during and after the completion of the initial pilot. At first, clubs allowed membership in excess of 50 patients, but this was later limited to 30 patients after lay club facilitators struggled to manage club sessions and it was felt that smaller groups would improve peer support among members. Eligibility criteria were also amended from >18 months on ART to >12 months on ART, at the time when routine viral load testing changed from every 6 months to annually after the first year of ART.

To obtain buy-in upfront from the facility manager and improve staff participation in the club model, a formalised ART club staff organogram was introduced, with clearly defined roles and responsibilities for each

team member. Most importantly, the clubs manager required the requisite delegated authority from the facility manager to ensure the effective implementation and smooth running of the clubs. While the clubs manager has, in the past, also taken on the role of the full-time club nurse, placing the responsibility entirely on a single clinician, this led to a parallel service with limited capacity to expand. Daily rotation of the club nurse function within a facility ensures collective responsibility for the management of club

The implementation of clubs and their expansion within a facility is dependent on the clinic pharmacist, as the club model relies on the pre-packing of ART. While supplying club patients with pre-packed ART adds no additional burden to supplying the same patients as facility patients, the club model does not alleviate overall pharmacy burden. Furthermore, the benefits of not seeing each individual patient at the pharmacy window can be overlooked.

Space limitations can create an obstacle to club implementation or expansion beyond one club a day within a facility. While full decentralisation into the community is the goal, community venues close to the clinic can be utilised without requiring additional logistical support. The Ubuntu clinic utilises a room at the local library, approximately 500 metres from the facility, where half of its day clubs meet. It has also started evening clubs at 18h00, utilising extended hours. This has allowed for 3 club meetings a day. Allocating patients to a club designated for a specific feeder area makes it easier to move clubs into the community at a later stage.

Overall, there has been widespread buy-in and participation by clinic staff and patients in the ART clubs in Khayelitsha. There is a continued, high demand for more ART clubs in facilities where club rollout has slowed or stopped.

Further detail on how to establish clubs, the ART club staff organogram, lessons learnt through the Khayelitsha implementation experience and tools utilised in the ART club model, are available online (http://www.msf. org.za/publication/art-club-toolkit).

## **Implementation** beyond the pilot

In early 2011, the ART club model was adopted by the Western Cape Government (WCG) Department of Health (DoH) for phased rollout initially in the Cape Town Metro. A partnership was formed between the WCG DoH, City Health (City of Cape Town), MSF and the Institute for Health Improvement (IHI), to support implementation.[6]

Fig. 1 illustrates the implementation strategy adopted by the partnership. First, a steering committee with representatives from each partner was formed and HIV/AIDS, sexually transmitted infections (STIs) and tuberculosis (TB) (HAST) managers or facility-based doctors were identified to become club mentors. The club mentors were trained on the ART club model and were tasked with supporting the implementation of ART clubs in 1 - 3 pilot facilities. Facilities with the highest patient load were prioritised. The next phase was to invite 10 - 12 facility club teams (including the clubs manager, club nurse, club facilitator(s), clinic pharmacist and clinic data capturer) to attend a learning session where they were trained by the steering committee and club mentors and supported in making an implementation plan. The facility club mentor supported the team at the facility intensively at first and with routine support visits thereafter. Six months later, the same facility club teams attended a second learning session where they reported back on progress. Any challenges experienced were discussed with other facilities and the steering committee allowed for the sharing of possible solutions. Where club implementation at these pilot facilities continued to face obstacles, a third learning session could be convened. In general, for this process to be successful, it is important to have buy-in and active support from facility management and sub-district management throughout the implementation process.

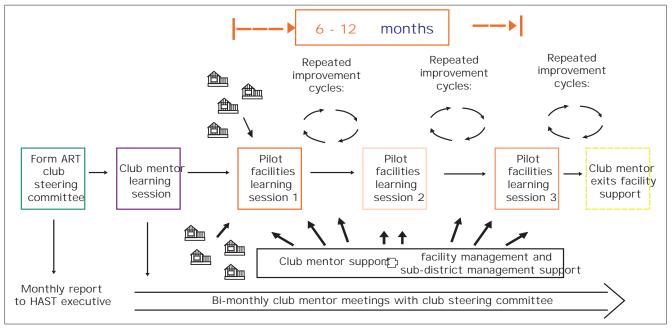


Fig. 1. Schema for the implementation of ART adherence clubs. HAST = HIV/AIDS, sexually transmitted infections (STIs) and tuberculosis (TB).

By 31 December 2012, the Cape Town Metro had implemented over 600 clubs with more than 16 000 stable ART patients accessing care and treatment accordingly. This amounts to approximately 15% of ART patients in care in Cape Town. The partnership won a 2012 Platinum Award from the prestigious Impumelelo Social Innovations Centre for adopting and implementing this innovative approach to managing large numbers of patients receiving ART.

### Resources to operate adherence clubs

Each facility running ART clubs requires a club team. The role of the clubs manager is part time, but does require sufficient time to carry out club-management responsibilities. At least one full-time lay club facilitator is required per 40 ART clubs. In addition, a facility nurse needs to be allocated as the club nurse on the clinic roster for each day on which a club session takes places. The nurse can usually continue to see clinic patients as he/she is infrequently required to see a club patient after a club session, other than the annual blood investigation and annual clinical consultation sessions.

In the Cape Town Metro, club facilitation has been included in the job profile of facility counsellors. Additional counsellor posts have been allocated to facilities - one for facilities with more than 15 clubs and two for facilities with more than 40 clubs. Where clubs are run in the community, community-care workers could serve as club facilitators. In addition, resources may be spared by adapting the ART club-visit schedule and associated ART supply from 2- to 3-monthly.

Pharmacy-related bottlenecks to club rollout can be pre-empted by allocating an additional pharmacy assistant where the number of facility clubs exceeds 15, or alternatively, by utilising a central dispensing service for pre-packing ART as demonstrated in the Cape Town Metro. Access to fixed-dose combinations (FDCs) is imperative to support accelerated ART club rollout. In addition to supporting long-term adherence, FDCs reduce the pre-packing burden on pharmacy staff and make it logistically simpler to transport pre-packed ART drugs to ART club locations.

### Conclusion

The ART-adherence club model improves adherence and long-term retention in care among clinically stable ART patients, while optimising health resources to manage new ART patients and patients at risk of failing treatment. The impressively extensive and quick rollout in the Cape Town Metro demonstrates active buy-in from patients and facility staff by addressing the obvious need for quick, patient-friendly access to care and treatment for clinically stable ART patients. It is imperative that SA considers a similar model for national rollout.

Conflict of interest. The author contributed to the development of the club model and is the MSF representative on the WCG DoH ART club steering committee.

Acknowledgements. ART club steering committee: J Mouton (WCG DoH), K Jennings (City Health), M Youngleson (IHI), B Harley (City Health), C Cragg (WCG DoH), S Jacobs (WCG DoH), E Kriel (WCG DoH); and the Ubuntu, MSF and Treatment Action Campaign (TAC) Khayelitsha staff who contributed to the development of, and continue to support ART clubs.

#### References

- 1. Cornell M. Grimsrud A. Fairall L. et al. Temporal changes in programme outcomes among adult patients initiating antiretroviral therapy across South Africa, 2002 -2007. AIDS 2010;24:2263-2270
- 2. Fox MP, Rosen S. Patient retention in antiretroviral therapy programs up to three years on treatment in sub-Saharan Africa, 2007 - 2009: Systematic review. Trop Med Int Health. 2010;15(Suppl 1):1-15
- 3. Ware NC, Wyatt MA, Geng EH, et al. Toward an understanding of disengagement from HIV treatment and care in sub-Saharan Africa: A qualitative study. PLoS Med 2013;10(1):e1001369. [http://dx.doi.org/10.1371/journal.pmed.1001369]
- 4. Harries AD, Zachariah R, Lawn SD, Rosen S. Strategies to improve patient retention on antiretroviral therapy in sub-Saharan Africa. Trop Med Int Health 2010;15(Suppl 1):70-75. [http://dx.doi.org/10.1111/j.1365-3156.2010.02506.x]
- 5. Luque-Fernandez MA, Van Cutsem G, Goemaere E, et al. Effectiveness of patient adherence groups as a model of care for stable patients on antiretroviral therapy in Khavelitsha, Cape Town, South Africa, PLoS One 2013;8(2):e56088, [http://dx.doi. org/10.1371/journal.pone.0056088]
- 6. Institute for Healthcare Improvement. The Breakthrough Series: IHI's Collaborative Model for Achieving Breakthrough Improvement. IHI Innovation Series white paper. Boston: Institute for Healthcare Improvement, 2003.