"If I'm not in the club, I have to move from one chair to another."

A qualitative evaluation of patient experiences of adherence clubs In Khayelitsha and Gugulethu, South Africa

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Background

Quantitative outcomes of ART adherence clubs have been well described both for pilot and scaled implementation in South Africa, but to date there has been no qualitative evaluation of the model of care from the perspective of patients.

Adherence clubs are made of 15-30 ART patients who meet five times a year either at a facility or at a venue in their local community. Pre-packed ART is distributed to club members by a lay health-care worker. Patients must meet certain clinician-assessed criteria which classifies them as 'stable' in order to join a club. They are referred-out of clubs to clinician-led facility-based 'routine' care if they miss appointments by more than 5 days, experience virological rebound or become clinically unstable requiring more regular clinical follow-up.

We explored perceptions of clubs amongst members and non-members in two sites in Cape Town, South Africa.

Image 2. Community venue based ART adherence club, Khayelitsha

Methods

- A qualitative study was conducted in 2015-2016 in Khayelitsha and Gugulethu, two high HIV prevalence communities in peri-urban South Africa

11 focus group discussions with 85 participants who were all current club members

43 individual in-depth interviews with eligible patients who had never joined a club and club members who had been returned to routine care.

- Interviews and FGDs were conducted in isiXhosa by a local research assistant
- Audio-recordings were transcribed and translated into English
- Transcripts were entered into NVivo and coded
- Thematic analysis was used. Codes explored people's perceptions and experiences of clubs, including benefits and challenges of membership.

Image 1: Khayelitsha, a high- HIV-prevalence settlement in Cape Town, South Africa

You become interested to be in the club through hearing people say that in the club people do not take long; you get there, take your pills and get a date to come back. Even people who work there as counsellors tell us that anyone who misses a date will be taken out: that encourages us to know our date so that you are not taken out.

I feel so bad. I do not like it at all. I wish they could send me back to the club just the way I was. I do not like staying at the clinic the whole day.

Patient from Gugulethu, referred out of club due to virological failure

If you can stay away for a month, that means you don't care about your life. That shows that you don't care because you cannot make the mistake of going back to the clinic whilst already in the club. It means you don't care if you allow yourself to go back [to the clinic] while you are in the club.

Club member, Khayelitsha

I took my medication the way they told me to, but I was given this one pill instead. When they looked at my folder they noticed that the one who changed me didn't write down that she had changed me to this one pill in my folder. Everything showed that I was still on the old medication. They said it's them who gave me wrong medication and that's why I had to go back to [routine care].
I felt very bad. I even wanted to quit my medication.

Patient from Khayelitsha referred back to clinical care

Results

✓ Adherence clubs saved patients time and money through fewer clinic visits and longer periods between refills, and created peer-support networks.

✓ Patients viewed club membership as an achievement and a privilege. Members believed in the need to follow certain 'rules' to continue being a member.

✓ Specifically valued club processes included allowing ART refills to be collected up to 5 days late or by a 'buddy' were also appreciated.

✓ Removal from clubs for missed appointments or virological rebound were acceptable rules to those in clubs, but perceived as unfair by those referred-out.

✓ Eligible patients who were not enrolled understood the broad concept and benefits of clubs. They most commonly learned about clubs from waiting room talks by peer-educators.

☒ Being returned to regular clinical care was considered a 'failure' by patients, and there was limited appreciation for the increased clinical support provided after losing club benefits.

☒ Moving between clubs and routine care created frustration, and led to a breakdown of trust in the health-care system and relationships with health-care providers.

☒ Patients attributed external factors for their referral out, often blaming health-care workers. Reasons provided by clients for referral out included being given incorrect/no appointment dates or an ineffective drug regimen which caused virological failure.

☒ Stable patients who were not club members knew about clubs, but did not feel sufficiently empowered to request enrolment if it was not offered by a clinician. Clinicians did not systematically discuss or offer enrolment, perceived by patients due to time constraints.

Conclusions

- The club model was considered **acceptable** by patients, including those who were no longer in clubs. The **flexibility around ART refill collections** offered to members was particularly **valued**.
- **Stronger eligibility and enrolment follow-up** is required **from clinicians** during consultations.
- **Improved patient understanding of** the following **model components is essential** to build relationships with health-care workers and trust in the overall health-care system:
  - criteria for club eligibility and referral out; and
  - the value of increased clinical oversight given upon referral out.
- **Further research** should determine **in which circumstances club removal is warranted**, compared with increased adherence or clinical management within or alongside continued AC membership.

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