HEALTH SYSTEMS RESEARCH UNIT

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Understanding the literature on Adherence Clubs: An annotated bibliography

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COMMISSIONER

Ms Charlyn D Goliath, Office of the Chief Director: Metro District Health Services, Western Cape Government: Health

TASK: A quick scoping of literature of adherence clubs

This annotated bibliography has been prepared for the Western Cape Department of Health (WCDOH), as a first stage in further discussions towards a rapid evidence synthesis.

The search was conducted to assist Ms Goliath explore literature on adherence clubs. We present a summary of a rapid scoping of literature on adherence clubs. In addition, we present an annotated bibliography of possible studies for her consideration. A more comprehensive and focused search may follow upon further discussions with the Ms Goliath and her colleagues.

SYNTHESIS TEAM

Synthesis conducted by: Hlengiwe Moloi, with support from Karen Daniels (Principal Investigator) and Willem Odendaal (Project Manager).

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Problem as identified by the knowledge user

Ms Goliath from WCDOH seeks to better understand ART adherence clubs and the possibility of integrating ART adherence clubs with TB and other non-communicable disease (NCDs).

She is interested in literature that can assist her in answering the following questions (not an exhaustive list):

- What are adherence clubs and how do the work?
- What type of client should be recruited into an adherence club, with a focus on clients with HIV clients, TB and/or NCDs?
- How do health providers determine the readiness of clients (HIV, TB and NCDs) to go into adherence clubs?
- Should adherence clubs be integrated across diseases – TB, NCD and/or HIV? What will the impact of such integration, be on clients?
- In integrated adherence clubs, what works in terms of:
    - Staffing (facilitators/lay health workers /peers/formal staff)
    - Structure
    - Content of the health promotion

Abbreviations

ART	-	**Antiretroviral therapy**
HIV	-	**Human Immunodeficiency Virus**
MSF	-	**Medécins Sans Frontières**
NCDs	-	**Non- communicable disease**
TB	-	**Tuberculosis**
WCDOH	-	**Western Cape Department of Health**
WHO	-	**World Health Organization**

Background

The acceleration of ART expansion has represented substantial hurdle for the adherence of some patients on ART (World Health Organization 2012). Various strategies have been proposed to facilitate this expansion and improve retention in care (Bemelmans et al. 2014). One of the proposed care model are adherence clubs, which operate by recruiting patients into groups that are offered in the community or in the health facilities (Bemelmans et al. 2014)(Wilkinson 2013).

Adherence clubs are designed both to reduce attrition and decongest local primary health care facilities (Decroo et al. 2013). Adherence clubs encourages long-term adherence to medication and retention in care, by decreasing the frequency and intensity of club members visits to the healthcare centre, and by providing club members with peer psychological and emotional support (Tsondai et al. 2017).

Adherence clubs also create opportunities for group members to form friendships, potentially leading to peer support. In addition, adherence clubs can empower members to self-manage their health. The clubs can ensure continued access to clinical care and support through a suitable referral mechanism, which can lead to better care, and thus improve retention in care and viral outcomes for their members. Furthermore, adherence clubs aim to free-up clinicians to treat the highest-need patients. Thus, potentially taking some of the pressure off the health system (Decroo et al. 2013).

Medécins Sans Frontières (MSF) with support from the WCDOH and the Treatment Action Campaign piloted adherence clubs in Ubuntu community centre, which is a large ART community health centre in Khayelitsa, Cape Town (Luque-Fernandez et al. 2013). The pilot project, which appears to have been the first in the world, produced positive results, resulting in the WCDOH adopting adherence clubs for a phased roll-out in the Cape Town Metro health district (Wilkinson 2013).

In 2011, the Western Cape Department of Health (WCDOH) rolled-out ART adherence clubs in the Cape Town Metro as a way of improving retention in care for stable patients on ART (Wilkinson 2013). By March 2015, more than 1308 ART clubs were established in Cape Town, providing ART care to over 32 425 patients (Wilkinson et al. 2016).

Methods

Search strategy
To find relevant literature, a search strategy was developed using key words related to adherence clubs. As this is a rapid scoping of the literate the search strategy was not limited to any population, disease and/or setting.

Search terms
"Community adherence clubs" OR "Community adherence groups" OR "Community adherence" OR "Adherence" OR "Community models of care" OR "Community-based adherence clubs".

Databases searched
The initial search was conducted on the Cochrane and PDQ databases to find systematic review evidence applicable to adherence clubs. No relevant systematic reviews were found. The search was expanded to the Pubmed database so as to further search for systematic reviews as well as include primary studies.

Outcome of the search
The Cochrane database search found 365 systematic reviews, the PQD search reveled 39 systematic reviews. One reviewer screened the titles and abstracts of these systematic reviews to check for relevance. None of the systematic reviews were found to be relevant to adherence clubs.

The Pubmed search found 702 articles. One reviewer screened the titles and abstracts, and 12 studies were deemed relevant to adherence clubs and included in the summarized literature below.

Summary of the literature

ART Adherence Clubs

Currently, most studies define ART adherence clubs using the MSF standard operating procedure and toolkit. This definition is similar to the one used by WCDOH and other international organisms such as UNAIDS.

Citations

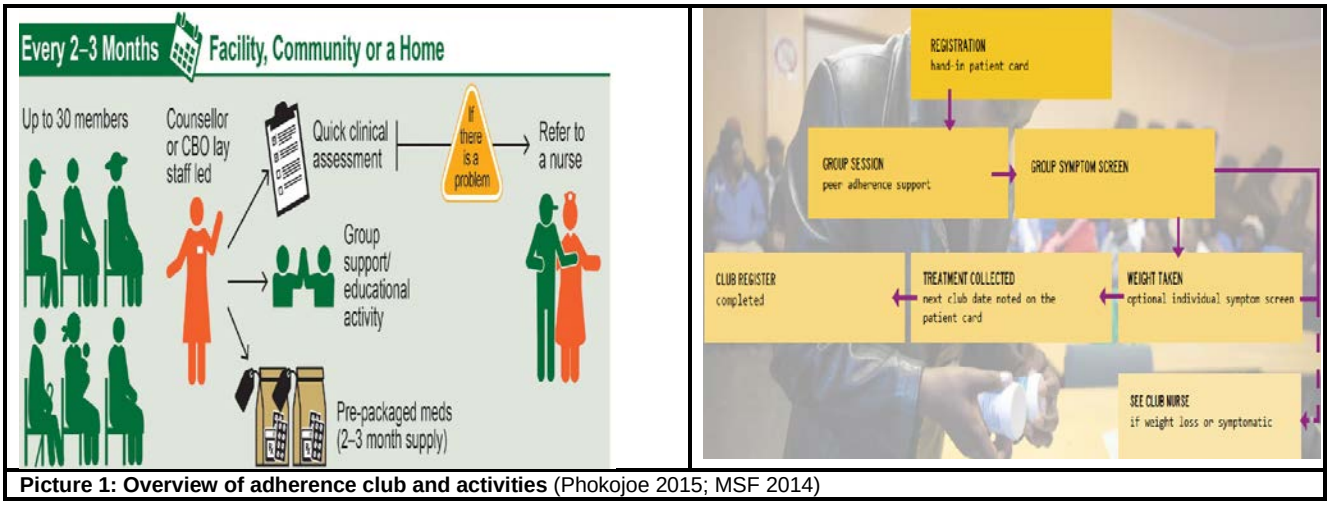
1. MSF. 2014. "Art Adherence Club Report and Toolkit." *Doctors Without Borders*, October:1–40. https://www.msf.org.za/about-us/publications/reports/art-adherence-club-report-and-toolkit.

2. Phokojoe, Mokgadi. 2015. "national adherence guidelines for HIV, TB and non-communicable disease" In *SA AIDS Conference Durban*. http://www.differentiatedcare.org/Portals/0/adam/Content/_YiT3_-qmECUkmkpQvZAIA/File/SOP A5 booklet 20-05-2016.pdf.

What are ART adherence clubs?

Adherence club

Adherence club members meet every 2 months. The club membership is limited to 25–30 patients. The club is facilitated by a lay counsellor or community health worker and overseen by a professional nurse (club nurse). In each session, there is group counselling, a brief symptom screening for each member and distribution of prepacked ART. Where necessary, patients with clinical complications are referred to a professional health provider. A club member can also send a patient-nominated treatment supporter or "buddy" to collect their ART at alternating adherence club meetings. *Please see the picture below for an overview of adherence clubs*.



Picture 1: Overview of adherence club and activities (Phokojoe 2015; MSF 2014)

ART Adherence clubs staffing

The adherence club requires several staff:

- A facility manager who is responsible for the activities necessary for the club to run smoothly;
- A club nurse to oversee the activities of the club and who is also responsible for members that are referred to the clinic for assessment;

- A pharmacist to prepack the medication;
- A club facilitator who is a lay health worker, prepares and runs the club session. The facilitator also provides a basic clinical assessment of the patients (e.g. blood pressure checks), performs pill checks, provides emotional and psychosocial support;
- A data capturer transfers records from club membership attendance registers, into facility electronic registers.

Please see the picture below for club staffing.

Picture 2: Adherence club organogram (MSF 2014)

What type of patients should be recruited into ART adherence clubs?

For HIV adherence clubs, only consulting health professionals can recruit patients to the ART adherence club. HIV positive patients have to meet all the following to criteria to be eligible for recruitment:

- 18 years or older;
- Have been on the same ARV regime for at least 12 months;
- Their two most recent consecutive viral loads undetectable;
- No active opportunistic infections and have no medical conditions that require regular clinical consultations more than once a year.

Adherence clubs program theory

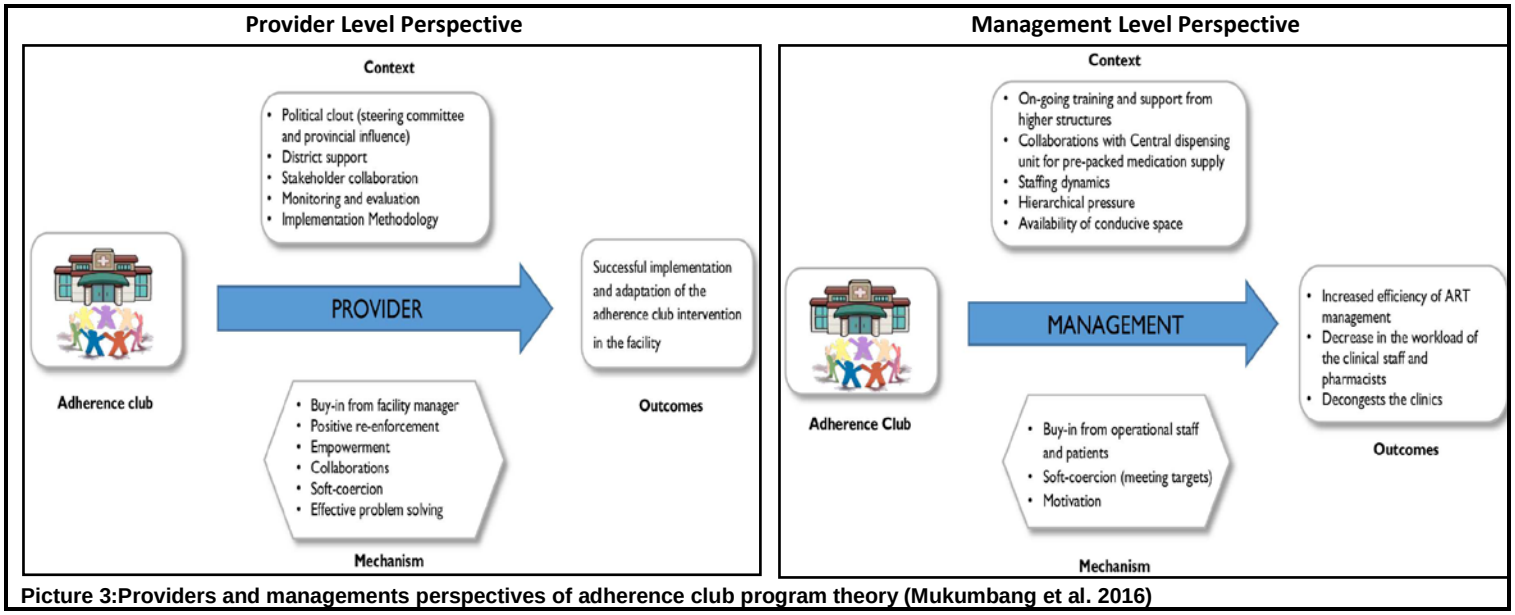
Ferdinand Mukumbang and colleagues aimed to produce a program theory for adherence clubs using realist evaluation methods (Mukumbang et al. 2016, 2017a, 2017b). To achieve this objective, the authors conducted three individual studies, detailed below.

1. **An empirical qualitative study to explore and identify the assumptions of the programme designers and health service managers on how and why adherence club work.**

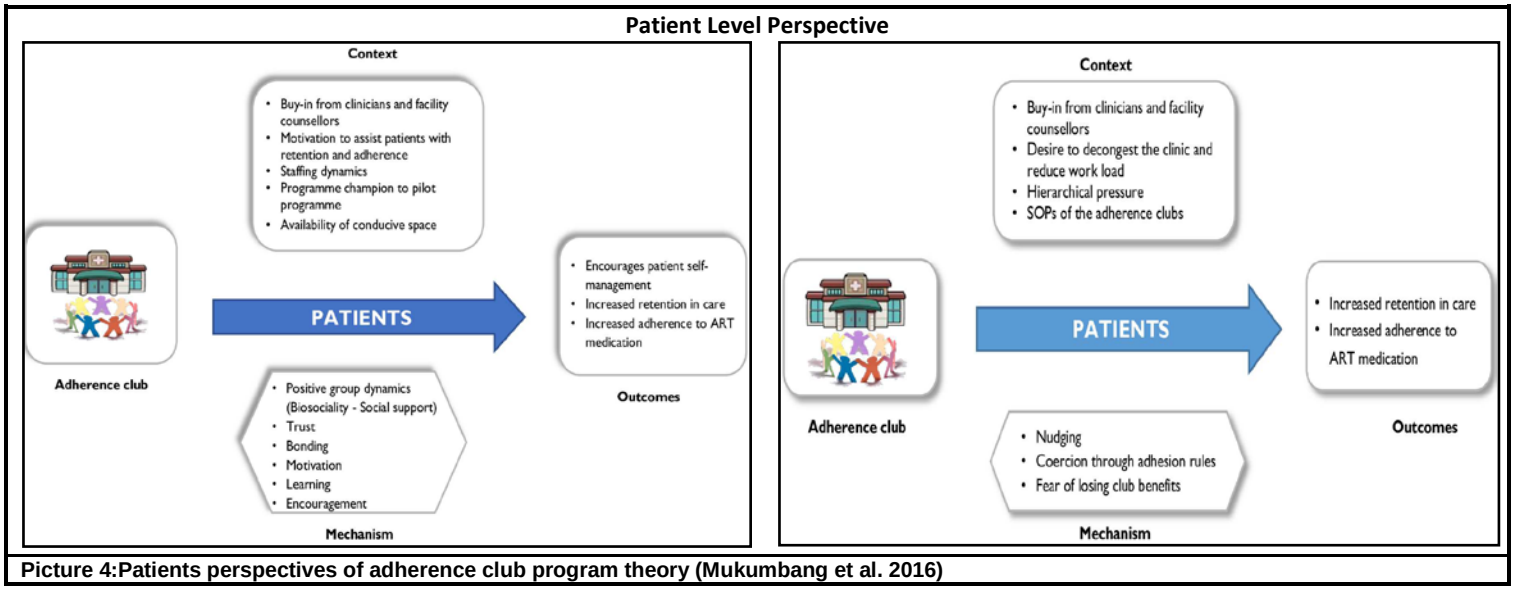
The study aimed to develop an initial programmme theory of how adherence clubs are expected to be implemented in order to achieve the goals low attrition, high retention to care and decrease in clinic

decongestion.

Mukumbang et al. 2016, conducted a document review and interviewed purposively selected programme designers and managers on their assumptions and perceptions of how and why adherence club are expected to achieve its goals; and how have adherence clubs achieved or not achieved these goals. The analysis of the collected data lead to an initial program theory that explains adherence from the perspective of frontline provider, management and patient (the patient perspective level has two rival theories). The initial program theory shows contexts that are likely to lead to the adopting of adherence club and the mechanism that promote adherence club. *The picture below illustrates three perspectives of adherence clubs program theory.*



Picture 3:Providers and managements perspectives of adherence club program theory (Mukumbang et al. 2016)



Picture 4:Patients perspectives of adherence club program theory (Mukumbang et al. 2016)

2. **A scoping review of theories on ART adherence to identify potential mechanisms provided by ART interventions.**

The focus of Mukumbang and colleagues' scoping review was to identify theories and potential mechanisms which can be used to explain why individual patients either adhere to or default from treatment. According to the authors, these explanations can be used to produce programme theories of group-based adherence interventions such as the adherence clubs.

Mukumbang et al. 2017b, found three major sets of theories; Information-Motivation-Behavior, Social Action Theory and Health Behaviour Model. These theories offered possible underlying social drivers of behavior that could be used to explain patients' adherence behaviour to ART and other chronic medications" (Mukumbang et al. 2017b, p.11). Using these theories, the authors identified potential candidate mechanisms under two major themes: "psychological mechanisms (motivation, self-efficacy, empowerment, perceived threat and benefits) and relational mechanisms (perceived social support)" (Mukumbang et al. 2017b, p.11).

3. **A systematic review assessing the evidence on theories of how and why group-based ART adherence interventions work.**

Mukumbang et al. 2017a, conducted a systematic review to identify literature on causal mechanisms of group-based ART models in Sub-Saharan Africa. The authors deemed this a necessary step in developing programme theories that explain how and why ART adherence clubs work, for which HIV positive populations they work, and under what circumstances.

The systematic review included qualitative studies, quantitative studies and mixed methods studies. The analyses of these studies, revealed that quantitative studies do not clearly identify the characteristics of the context and mechanisms that work to trigger the outcomes of group-based models. Qualitative and mixed methods studies were found to identify some aspects of the context and mechanisms that could trigger the outcomes of group-based ART models. However, these studies did not fully explain the relationship(s) between the context and mechanism interact to produce the group-based models' outcomes. As a result, the authors were not able to use this information to guide the development of programme theories underlying interventions for ART adherence clubs.

<u>Citations</u>

1. Mukumbang Ferdinand C, Sara Van Belle, Bruno Marchal, and Brian Van Wyk. 2016. "Towards Developing an Initial Programme Theory: Programme Designers and Managers Assumptions on the Antiretroviral Treatment Adherence Club Programme in Primary Health Care Facilities in the Metropolitan Area of Western Cape Province, South Africa." *PloS One*, 1–31.

2. Mukumbang Ferdinand C, Sara Van Belle, Bruno Marchal, and Brian Van Wyk. 2017. "Exploring 'Generative Mechanisms ' of the Antiretroviral Adherence Club Intervention Using the Realist Approach : A Scoping Review of Research-Based Antiretroviral Treatment Adherence Theories." *BMC Public Health*, 1–14.

3. Mukumbang Ferdinand C, Sara Van Belle, Bruno Marchal, and Brian Van Wyk. 2017. "An Exploration of Group-Based HIV / AIDS Treatment and Care Models in Sub-Saharan Africa Using a Realist Evaluation Outcome Heuristic Tool: A Systematic Review." *Implementation Science: IS*. Implementation Science.

Implementation of ART Adherence clubs

Wilkinson et al. 2016, described the implementation of different adherence club models across the Metro health district, Cape Town, South Africa, between January 2011 and March 2015. The table below, copied from Wilkinson et al. 2016, shows the different adherence club components that were adapted to better suit different context and resources. The study concluded that to continue the expansion of adherence clubs without compromising quality of care, the adherence club models need their own dedicated funding instead of leveraging existing Department of Health HIV resources.

Table 2 Adherence Club model components that can be adapted and adaptations that were made by implementing sites

Components of the AC model that can be adapted	Types of adaptations made by sites when implementing the AC model
Eligibility criteria	Duration of time of ART required
	Inclusion of patients on second line ART
	Number of suppressed viral loads required
	Inclusion of patients with co-morbidities
Location of AC meetings	Within ART facility
	Community venue close to facility
	Community venue close to club member's home
	Home of Club member
Cadre of staff facilitating the AC	Lay counsellor
	Community health worker
	Nurse (professional or auxiliary)
	Pharmacy assistant
	Club member
ART dispensing strategy	Pre-packed at central dispensing unit
	Pre-packed at health facility
Integrated services provided	Condom distribution
	Family planning
	Hypertension/diabetic drug supply
Patient population	General adult population
	Families
	Youth
	Men
	High risk (experienced viral rebound in the past)

AC, Adherence Clubs; ART, antiretroviral therapy.

Picture 5: adherence club model components that can be adapted (L. Wilkinson et al. 2016)

A different smaller scale study by Grimsrud et al. 2015, described the implementation of community-based adherence clubs at a large, public-sector facility in Cape Town, South Africa. The study found that adherence clubs staff members could successfully work together despite having different line managers. Furthermore, the authors found that the success of the adherence programs was linked to health professionals trusting stable patients to take care of themselves. The authors also found that staff at Community Health Centres tended to forget that they were still responsible for community adherence clubs members, given that these staff did not often see these patients in the facility.

Citations

1. Wilkinson Lynne, Beth Harley, Joseph Sharp, Suhair Solomon, Shahieda Jacobs, Carol Cragg, Ebrahim Kriel, Neshaan Peton, Karen Jennings, and Anna Grimsrud. 2016. "Expansion of the Adherence Club Model for Stable Antiretroviral Therapy Patients in the Cape Metro, South Africa 2011 – 2015." *Tropical Medicine & International Health* 21 (6):743–49.

2. Grimsrud Anna, Joseph Sharp, Cathy Kalombo, Linda-Gail Bekker, Landon Myer. “Implementation of Community-Based Adherence Clubs for Stable Antiretroviral Therapy Patients in Cape Town, South Africa.” *Journal of the International AIDS Society* 18:1–8.

Perceptions and Experiences of ART adherence clubs

Two qualitative studies by Dudhia and Kagee 2016, and Mosikare et al. 2017, explored the perceptions and experiences of patients in ART adherence clubs and health professionals working with ART adherence clubs. The studies documented benefits such as reduction of time and cost of transportation fees associated with frequent clinic visits. Patients found value in meeting with other HIV positive people. However, there were concerns about the security of the areas where medication was distributed, the storage conditions for the medication, and transportation of the prepacked medication to the distribution sites. There were further concerns about some patients being lost-to-follow-up, and an increase in defaulters.

Citations

1. Dudhia Raashika, and Ashraf Kagee. 2016. “Experiences of Participating in an Antiretroviral Treatment Adherence Club.” *Psychol Health Med* 20 (4):488–94.

2. Mosikare Ofentse, Olufunke A Alaba, Keith Muloongo, and Peter S Nyasulu. 2017. “Acceptability of Community-Based Adherence Clubs among Health Facility Staff in South Africa: A Qualitative Study.” *Dove Press Journal* 11:1523–31.

Outcomes of ART adherence clubs

Three studies Grimsrud et al. 2016, Luque-Fernandez et al. 2013, and Tsondai et al. 2017, independently assessed the effectiveness of ART clubs in Cape Town. These studies found that patients using the adherence clubs showed better retention in care when compared to those who remained in standard care clinics.

Citations

1. Grimsrud Anna, Maia Lesosky, Cathy Kalombo, Linda-Gail Bekker, and Landon Myer. 2016. “Community-Based Adherence Clubs for the Management of Stable Antiretroviral Therapy Patients in Cape Town, South Africa: A Cohort Study.” *Acquir Immune Defic Syndr* 71 (1):16–23.

2. Miguel Angel Luque-Fernandez, Gilles Van Cutsem, Eric Goemaere, Katherine Hilderbrand, Michael Schomaker, et al. 2013. “Effectiveness of Patient Adherence Groups as a Model of Care for Stable Patients on Antiretroviral Therapy.” *PloS One* 8 (2).

3. Priscilla Ruvimbo Tsondai, Lynne Susan Wilkinson, Anna Grimsrud, Precious Thembekile Mdlalo, Angelica Ullauri, and Andrew Boulle. 2017. “High Rates of Retention and Viral Suppression in the Scale-up of Antiretroviral Therapy Adherence Clubs in.” *Journal of the International AIDS Society* 20 (5):51–57.

Integrated Adherence Clubs

In our search, we were only able to identify two studies Khabala et al. 2015 and Venables et al. 2016 on integrated adherence clubs, since the other studies only focused on HIV adherence clubs. These two studies are from Kenya, where the authors assessed the acceptability and feasibility of integrated

adherence clubs that include patients with HIV and other NCDs.

What are integrated adherence clubs?

Khabala et al. 2015, describes integrated adherence clubs as those with patients who are on either HIV and/or hypertension and/or diabetes mellitus medication. Adherence club members meet quarterly. The club is limited to 25–30 members. In each session, there is a brief focus on health promotion, then each member is quickly screened to ensure that they are still stable, after which they receive their prepacked medication. All club members must consult a clinician once a year for a full check-up. However, if a club members develops clinical complications they must be referred to a clinician for an immediate assessment.

Staffing for integrated adherence clubs?

The only information available on staffing is that the club is facilitated by a nurse.

What type of patients should be recruited into integrated adherence clubs?

For patients to be eligible for the clubs they must be 25 years or older, and have one or more of the following conditions: HIV, diabetes, and hypertension. Club members must also meet the following criteria:

Diabetes and hypertension patients

- Be on their medication for 6 months or more;
- diabetes patients must have glycated haemoglobin results that are less than 8%;
- hypertension patients must have a blood pressure of <150/100.

HIV patients

- Must have been on the same ART medication for at least a year;
- have a CD4 count of more than 200;
- have a undetectable viral load at their last test.

Once, recruited to the adherence club, each member must sign an informed consent form acknowledging that they understand that the adherence club would have patients with hypertension, diabetes mellitus and HIV, and that diagnosis disclosure is voluntary.

Feasibility of integrated adherence clubs

Khabala et al. 2015, conducted a descriptive study to assess the care received in integrated adherence clubs in primary healthcare centre in Nairobi, Kenya. In this study, integrated adherence clubs composed of patients with either HIV and/or hypertension and/or diabetes mellitus.

The study found that integrated adherence clubs reduced the burden of regular visits for stable patients. Hence, the authors concluded this study demonstrates the feasibility and early efficacy of integrated adherence clubs.

Citation
Khabala, Kelly B, Jeffrey K Edwards, Bienvenu Baruani, Martin Sirengo, Phylles Musembi, Rose J Kosgei,

Kizito Walter, et al. 2015. “Medication Adherence Clubs: A Potential Solution to Managing Large Numbers of Stable Patients with Multiple Chronic Diseases in Informal Settlements.” *Tropical Medicine & International Health* 20 (10):1265–70.

Acceptability of integrated adherence clubs

Venables et al. 2016 conducted a qualitative study to assess patient and health-care worker perceptions and experiences of adherence clubs in Kibera Kenya. The adherence clubs included both patients with a range of NCDs and those who have HIV. The study found that “some patients and health-care workers felt that the mixed adherence clubs reduced stigma for HIV positive patients by treating HIV as any other chronic condition. However, staff and patients reported challenges in recruiting patients into adherence clubs as some patients did not fully understanding the eligibility criteria for the adherence clubs” (Venables et al. 2016, p.2.).

Citation

Venables, Emilie, Jeffrey K Edwards, Saar Baert, William Etienne, Kelly Khabala, and Helen Bygrave. 2016. “They Just Come , Pick and Go .” The Acceptability of Integrated Medication Adherence Clubs for HIV and Non Communicable Disease (NCD) Patients.” *PloS One*, 1–12.

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Decroo, Tom, Freya Rasschaert, Barbara Telfer, Daniel Remartinez, Marie Laga, and Nathan Ford. 2013. “Community-Based Antiretroviral Therapy Programs Can Overcome Barriers to Retention of Patients and Decongest Health Services in Sub- Saharan Africa: A Systematic Review.” *International Health* 5 (3):169–79. https://doi.org/10.1093/inthealth/iht016.

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Tsondai, Priscilla Ruvimbo, Lynne Susan Wilkinson, Anna Grimsrud, Precious Thembekile Mdlalo, Angelica Ullauri, and Andrew Boulle. 2017. “High Rates of Retention and Viral Suppression in the Scale-up of Antiretroviral Therapy Adherence Clubs in.” *Journal of the International AIDS Society* 20 (5) : 51–57. https://doi.org/10.7448/IAS.20.5.21649.

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http://www.who.int/alliance-hpsr/en/