

Management of HIV/AIDS Care and Treatment Interventions: A Case for Antiretroviral Treatment (ART) Monitoring Within the Nairobi City Council

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Abstract: Background: High rates of defaulting and loss to follow-up (LTFU) are undermining antiretroviral treatment (ART) services in Kenya, with Nairobi City Council being no exception. Scale-up of treatment for HIV/AIDS requires long-term relationship with the patient, accurate and accessible records of each patient's history and methods to track his/her progress. Logical decision making may be compromised if right patient information is not available when needed. Objective: To improve quality by training on Quality Management concepts while at the same time developing and implementing an electronic medical database system that can be used in an ART programme to maintain and improve data quality and reduce multiple patient registration and loss of patients to follow-up. Methodology: The author and the City Council health management worked together to continuously improve care while keeping track of the care recipients. In order to achieve this, care givers were offered on-the-job training on quality management concepts while at the same time initiating and implementing a health information system (HIS) for HIV/AIDS treatment monitoring to support quality intervention outcomes within the care continuum. Results: A web-based Quality Management system developed and tested on internet protocol <http://41.84.132.90> that demonstrated ability to improve quality of patient data including tracking patient identities and detecting duplicate records; accurately track patient outcomes; enablement of effective patient follow-up; improved drug supply management/accountability and ability to generate real-time reports for host institution, project management and funding agencies. Conclusion: Implementation of the project introduced evidence-based decision making in HIV care and treatment continuum within the Nairobi City Council health facilities. If similar information can be collected from all ARV treatment units in the country, it can easily be collated and used for six-monthly and annual country reports. Such data will enable the Ministry of Health to assess the effectiveness of ARV treatment in Kenya.

Keywords: Loss to follow-up, Quality Management, Health Information System (HIS)

1. Introduction and Background

High rates of defaulting and loss to follow-up (LTFU) are undermining rapidly expanding antiretroviral treatment (ART) services in Kenya, with the Nairobi City Council being no exception. The scale-up of treatment for HIV/AIDS in Kenya and many other developing countries requires a long-term relationship with the patient, accurate and accessible records of each patient's history and methods to track his/her progress. Logical decision making may be compromised if right patient information is not available when needed. This project therefore sought to introduce Quality Management concepts among health care workers at the City Council of Nairobi while at the same time initiating a health information system (HIS) for HIV/AIDS treatment defaulters and patient follow-up.

Over 20% of patients on antiretroviral (ARV) treatment have missed appointments¹ or been lost to follow-up² in 1 year in some major HIV projects in Africa, with one study reporting 59% loss to follow-up over 4 years³. These patients are at great risk of dying or developing drug resistance if their antiretroviral therapy is interrupted. Determining who has missed follow-up appointments in a group of almost 11000 patients in nine clinics in rural Haiti was virtually impossible with paper records alone. At least nine patient lists (each with about 1000 entries, frequent corrections, and additions) would have to be brought together in one room and cross-checked¹⁰. If one of the lists was lost, vital data would be gone and patient confidentiality put at risk. In Eldoret, Western Kenya, an EMR system was developed and deployed in 2002 to document primary care clinic visits¹¹. A new version of this system, the Academic Model for the

Prevention and Treatment of HIV/AIDS (AMPATH) medical record system (AMRS), was implemented to support HIV treatment¹². The AMRS is used to track patients who miss clinic appointments, and an outreach team is sent to follow them up and ensure they receive treatment. The managerial team carries out a retrospective analysis of the reasons why patients fail to return for treatment and take measures to eliminate the major barriers identified.

Using such a system within Nairobi city council, authorized personnel will track patients who fail to turn up for scheduled ART treatment appointments, monitor their health information, and coordinate their care even across multiple facilities and provide data to the management upon which logical management decisions will be made.

2. Statement of the problem

The essential task of management is to arrange organizational conditions and methods of operation so that people can achieve their own goals best by directing their own efforts toward organizational objectives. This is a process primarily of creating opportunities, releasing potential, removing obstacles, encouraging growth and providing guidance. While many hospital and health systems have already implemented evidence-based medicine and processes of care, there are still several challenges Chief Medical Officers will have to face, ranging from full updates of evidence, technology and support from hospital and other clinical leadership. Consequently, the author held several consultative meetings with the Starehe District Health Management Team (DHMT) to establish priority areas in HIV/AIDS care and treatment services within the City

Council of Nairobi. It came out clearly that there was no tracing mechanism for clients on ARVs. As a result, Ngaira dispensary and STC Casino dispensary had recorded up to 180 and 155 ARV defaulters respectively in the previous five years prior to initiation of this project. The number could however be more than this since the council health care documentation system at the facilities is manual. The defaulters are not known where they are, whether alive or dead or whether continuing with ARVs from other facilities. At the same time, multiple registrations for ARVs were reported to be rampant for interests best known to the clients. Some arguments were that some clients would register in more than one clinic for purposes of receiving incentives like food supplements or they would do so in order to get extra drugs which they would later sell to their "patients". It is also worth noting that an estimated 7% of eligible pregnant mothers are getting access to Zidovudine or Azidothymidine (AZT) within Starehe district. This low figure however is attributed to poor documentation among other factors. In view of the foregoing scenario, the DHMT felt that there was an urgent need to improve its CCCs patient data quality and documentation system. It's on this background that the author chose to approach this challenge as an opportunity to innovate hence the designing of this project.

3. Project Objectives

3.1 Goal

To improve quality of the management approaches by training on Quality Management concepts while at the same time developing and implementing an electronic medical database system that can be used in an ART programme to maintain and improve data quality and reduce multiple patient registration and loss of patients to follow-up in view to improving health outcomes in the scale-up of care and treatment for HIV.

3.2 Purpose

The project sought to build capacity in Quality Management while at the same time initiating and implementing an electronic health records information system within the City Council of Nairobi's Comprehensive Care Centers in order to track patients with HIV, ensuring they are promptly started on high quality care, reducing multiple registration and loss to follow-up.

3.3 Deliverables, outputs or specific objectives:

1. Detect patients registering in more than one comprehensive care centre.
2. Improve quality of patient information within the City Council's health care facilities.
3. Train City Council of Nairobi health care providers on Quality Management concepts and how to use of electronic health recording.
4. Guide future implementation and evaluation of e-health recording at policy-making level.

3.4 Justification/ Significance

The best medications and clinical expertise are of limited use if large numbers of patients default from treatment or are lost to the health care system. It equally applies for patients who register in multiple facilities for ARVs while not being considerate of the fact that health care workers in these facilities have to be accountable for the drugs they dispense. It is disturbing to find out that those who register for ARVs in several clinics at the same time eventually distorts the national tally of Kenyan population on medication due to double counting. Inaccurate information on the amount of drugs dispensed will also be presented to the concerned authorities and stakeholders in the fight against HIV/AIDS.

Missing just a few days of ART can cause the loss of ART efficacy, and most people in developing settings have access to one regimen of drugs. A systematic review of patients who initiated antiretroviral therapy across sub-Saharan Africa found that approximately 25% were no longer in care one year after initiation, a figure rising to 40% after two years¹³. This challenge combined with the need for strict adherence to medications for HIV and other chronic diseases make the use of technologies to monitor and improve adherence a much needed effort. Frequent antiretroviral therapy adherence monitoring could detect incomplete adherence before viral rebound develops and thus potentially prevent treatment failure.

There are many critical steps that lead to successful long-term HIV treatment. At each step, the patient may be lost from the treatment process unless there are good systems in place to track his/her status. This process is complicated by several factors among them the fact that the treatment process is spread over a wide geographic area. A patient may be tested and treated at different health institutions either because he/she moves between clinics or is referred to the ARV clinic. Laboratories may be far from the clinic, especially for CD4 counts. The general infrastructure and systems are usually poor, resulting in a high risk that samples or test results may be lost not forgetting that staff is likely to be overworked and thus lack time to check for missing patients each month. In other cases, it is difficult to contact patients because of poor specificity of the patient's physical address due to absence of street names and house numbers. Creating a central database of core information can allow clinical and administrative staff to track individual patients as well as monitor the care of the patient population as a whole.

Although the cost of the application shall be high in the beginning, it will drop in the long run due to the benefits accrued as a result. Improved inventory control through real time tracking will reduce costs by preventing over or under purchasing of medical supplies. Clinicians will be in a position to tell the number of patients seen in a particular period of time, drugs they have consumed and what is remaining in store. This is essential for accountability and general planning of health care services. Improved quality of life of the patient, better time management, reduced loss of patient data by going paperless and effective and efficient customer service shall be positively affected by the system, making its benefits outweigh the costs.

3.5 Project Implementation Methods and Management Plan

One of the biggest challenges that the City Council of Nairobi was facing before initiation of this project was serving HIV positive patients with antiretroviral drugs while maintaining accurate information on those accessing treatment, their health outcomes while maintaining quality, safety and the patient confidence. The council therefore, in partnership with the University of Nairobi's Institute of Tropical and Infectious Diseases (UNITID) worked towards creating efficiency while being ever mindful that quality outcomes, patient safety and the patient experience cannot be sacrificed. To do this, the author and the council health management team worked as a multidisciplinary team and asked those in direct care of patients (nurses, clinicians etc) to make quality management-oriented changes to continuously improve care while keeping track of the care recipients.

In order to achieve the foregoing with resultant improvement in the management and work efficiency at the city council of Nairobi's health care system, this project sought to build capacity on quality management concepts to the council staff (through on-the-job training) while at the same time initiating and implementing a health information system (HIS) for HIV/AIDS treatment monitoring to support quality intervention outcomes within the care continuum.

The routinely generated list of patients who miss visits would be given to the Council's Outreach Team for follow up. Thus, each HIV positive patient who presented at Ngaira Health Center for comprehensive care services would be registered and given a unique and universal identifying number while the patient's demographic, clinical and treatment module information is entered in a computer program.

Without such an HIS, the City Council's health facilities will forever rely on multitudes of paper registers to mine data related to patient visits, double registration and loss to follow-up. This will call for clinicians and data management personnel spend more time recording patient data in registries while manually collating statistics on patient monitoring and loss to follow-up. Such manual data may be, as it has been, very minimal or not available at all.

Data entered in the system included patient demographics, clinical assessment, laboratory investigations done, medication protocol started and social circumstances based on the paper form (MOH 257) the council has always used for several years in its Comprehensive Care Centers. Only staff related to the direct care of patients or who are involved with monitoring and evaluation would have access to the records. A log-in system was provided by the systems administrator to only authorized persons.

All patients who start ARV therapy while being captured by the system during one full quarter (i.e. 1st April to 30th June) form the fixed cohort for this period. Treatment outcome and drug adherence rates for the last month of that quarter are documented soon after the quarter has finished. Every three months, the outcome data in this particular cohort are

analyzed. In this way, new events occurring in patients in that cohort are monitored over time, as outcome data will change as patients die, default, transfer-out or stop treatment. The patients who start ARV treatment between 1st July and 30th September form the next cohort of patients, and they are followed-up in a similar way every three months. These cohorts then increase in number as more patients over time are started on ARV therapy, and each cohort shall be analyzed as a separate entity. The impact of the system will then be observed for purposes of guiding future implementation and probable wider roll out within the City Council of Nairobi and even across the country.

4. Results

A web-based Quality Management system was developed and tested on internet protocol (IP) <http://41.84.132.90> that demonstrated the ability to improve quality of patient data with following Quality Management capabilities:

- 1) The ability to track patient identities and detect duplicate records;
- 2) The ability to accurately track patient outcomes;
- 3) The enablement of more effective patient follow-up;
- 4) Improved drug supply management/accountability;
- 5) The ability to generate reports (real-time) for host institution, project management and funding agencies.

5. Conclusion

In line with the foregoing managerial capabilities of the project, and in view of the long term impact of the same, it was envisaged that information routinely collected from the quarterly cohort analysis of enrolled patients should be an invaluable method of assessing whether ARV programme performance is improving or deteriorating:

- 1) Allow comparisons of treatment outcomes of cohorts recruited in diverse years.
- 2) Increasing rates of switching from first-to second-line regimens or increasing mortality would point to the development of drug resistance to the first-line regimen.
- 3) The individual quarterly cohort analysis allows the city council to assess trends over time, e.g. the annual death rate in discrete groups of patients.
- 4) Decreasing rates of death or default would point to improved management of ARV treatment.
- 5) The cumulative ARV quarterly analysis shall allow for regular up to date information on:
 - a) Number of patients ever started on ARV drugs since the programme began.
 - b) Number of patients alive and currently taking ARV drugs (which can be further subdivided into those on first-line regimen, alternative first-line regimens and second-line regimen).
 - c) Number of adults on the first-line regimen with drug adherence rates greater than 95%.
 - d) Number of patients who have died, defaulted, stopped ARV drugs or who were transferred out to another treatment facility since the programme began.

6. Recommendation

The author hereby recommends the Nairobi County Health Management to embrace the project for better decision

making and work towards up-scaling it to all facilities within Nairobi. If such similar information can potentially be collected from all ARV treatment units in the country, it can easily be collated and used for six-monthly and annual country reports. Such data will enable the Ministry of Health to assess the effectiveness of ARV treatment in Kenya, and will allow HIV/AIDS officers to identify problems and institute appropriate measures to overcome them.

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