

# Retention in elimination of mother-to-child transmission of HIV [eMTCT] care: an evolutionary concept analysis: *Review Article*

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## Introduction

Control of the HIV & AIDS pandemic, which has lasted for more than 34 years, has been underpinned on antiretroviral therapy (ART) which is offered in five steps called the HIV treatment cascade. The steps are: HIV diagnosis, linkage to care, retention in care, receipt of antiretroviral therapy and plasma viral suppression [1]. The elimination of mother-to-child transmission of HIV (eMTCT) program is instrumental in the elimination of HIV by year 2030 [2]. EMTCT interventions are offered in another series of steps called the PMTCT cascade. The steps involve access to antenatal care, HIV testing and enrolment into care, initiating ART, follow up, access to postnatal care, testing the child and their enrolment into care, initiating the child on ART and follow up. Under the PMTCT option B+ the step of determining eligibility for ART is eliminated since all ART-naïve HIV-positive pregnant women receive ART while those already on ART continue ART [3]. The success of all the steps is mainly based on retention in PMTCT [4]. ART has proven to be efficacious as such, more than 15 million people living with HIV & AIDS are on ART [5]. For ART to be effective, 100% retention in HIV Care is required. Otherwise, the virus may develop resistance against current drugs and more people living with HIV & AIDS will become ill and die.

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## ABSTRACT

**Objectives:** Retention-in-care is a crucial process in HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immune Deficiency Syndrome) and eMTCT (elimination of mother-to-child transmission of HIV). Despite a lot of finance and effort to improve retention-in-care, the term remains without a standard definition resulting in different reports about the concept. The objective of the article was to define, explain and clarify the concept of retention in the eMTCT program.

**Methods:** A concept analysis, using Rodgers' evolutionary frameworks was done. Eight articles were systematically reviewed to produce a definition of retention-in-care.

**Results:** Attributes of retention-in-care include the following: the patient should be alive, attend all scheduled visits, participate in prescribed activities and the resultant retention can be objectively measured continuously, at death or when the mother gets transferred from the eMTCT program to routine adult HIV care. The suggested definition of Retention-in-eMTCT care can facilitate standardization, hence, uniform measurement and reporting of retention-in-care in clinical care and research.

**Conclusion:** Despite the dynamic nature of retention in care, the provided definition of retention in eMTCT may facilitate a clearer understanding and standard measurement and reporting of the concept. Multiple measures which capture the different dimensions of retention need to be considered when reporting retention in the eMTCT programme.

**KEY WORDS:** Elimination of mother-to-child transmission of HIV [eMTCT]  
Human Immunodeficiency Virus  
Retention-in-care  
Concept analysis

Retention-in-care has such an impact in the success of the elimination of HIV & AIDS that a lot of funding and attention is directed towards it [6]. With most eligible people already on ART, retention-in-care is crucial in the global response to the Acquired immunodeficiency syndrome (AIDS). The World Health Organization has defined retention-in-care as the continuous engagement of HIV of an HIV positive person, from the time of diagnosis to life-long care, in a package of preventive, curative, supportive and care services [7, 8].

The term retention in PMTCT has been used in several studies, yet it remains unclearly defined and understood [9,10]. That results in lexical inconsistencies in measuring and reporting retention-in-care. Retention in eMTCT is different from retention in HIV. In HIV care, it is a stage in the HIV care cascade which follows after linkage to care while in PMTCT retention-in-care is needed in all the stages of the PMTCT cascade. By virtue of that, there is inconsistency in measuring and reporting retention in eMTCT. There is need for a standardised definition of retention-in-care to facilitate quality monitoring, consistent research, surveillance and reporting of the HIV treatment and eMTCT program. Implementation of eMTCT Option B plus needs clear definition of retention in care since the program introduces pregnant women into life-long ART [11]. The etymological roots of the word retention and the dynamic use of the term retention in care warrants the use of evolutionary concept analysis [12]. The aim of this article is to provide a concept analysis of retention in eMTCT based on Rodgers' evolutionary framework. A concept is a mental abstraction which can be expressed in unique terms and whose attributes can be derived from reality [13]. Evolutionary concept analysis is a way of clarifying, describing and explaining concepts through analysing the way the concept would have been used in different disciplines. The steps of Rodgers' evolutionary concept analysis include: identifying a concept of interest, identifying surrogate terms, identifying a sample for data collection, antecedents, consequences, related concepts, model case and ultimately synthesizing the data [12]. The evolutionary methodology was chosen for its strengths in being systematic, logical and propensity towards interdisciplinary analysis and unambiguous definition of concepts [12].

### Materials and Methods

We searched for the concept of retention-in-care using the PubMed database. PubMed covers a broad range of health sciences including medicine, nursing, dentistry, veterinary medicine, health care systems, pre-clinical sciences such as molecular biology and chemistry. It is not only linked to journals but also libraries and sequencing centres. We did a preliminary search for the terms retention in PMTCT, retention in PMTCT care, engagement in PMTCT care using

the Boolean terms "AND" and "OR". We searched for articles published between 2012 to 2015. We chose the year 2012 since it was the year WHO gave a technical update on PMTCT which recommended Option B Plus [14]. Articles which had a definition of retention or retention-in-care, attributes and measurement of retention were included. The search yielded 437 journal articles. After reading the abstracts and considering manuscripts which emphasized on definition and measurement of retention in PMTCT or HIV care the search results narrowed to 18 journal articles. The other 12 journal articles were then left out because they either were written before 2012 or did not have the required components namely: a definition of retention-in-care, attributes or clear measurement of retention-in-care. Consideration of grey literature yielded an extra 2 relevant journal manuscripts. In total, 8 journal manuscripts were utilized.

### Results

The articles were mainly from research in Sub-Saharan Africa which has the largest burden of HIV & AIDS. Other articles were written in the United States of America which finances most of the research in HIV. A systematic review article, Plazy, et al, was also included. Table 1 shows the results of the literature search.

### Identification of retention in care/ Concept analysis

The word retention originated from the Latin "retentionem or "retentio" means to hold back. The power thesaurus has 140 synonyms and 79 antonyms for the word. The synonyms for retention include memory, holding, keeping, maintenance, confinement, engagement, conservation, reserve, adhesiveness, grip, persistence, firm hold and total recall. Antonyms of the word include attrition, discharge, abandonment, breakup, discharge, dumping, escape, release and separation. The term retention has been used in English poetry, news, literary quotations, science medical practice albeit with a similar meaning of keeping something which is either abstract or concrete in a certain place. Interdisciplinary disparities of the word stem from inevitable enculturation in disciplines [12].

The terms retention and retention in care have been used interchangeably in caring medical or paramedical disciplines in caring for individuals with chronic conditions. The advent of antiretroviral therapy necessitated retention of individuals in HIV care and eMTCT care.

**Table 1.** Results of literature search.

Num-ber	Authors	Year	Sample Size	Population
1	Assefa et al [15]	2012	55 Health facilities	People on ART, Ethiopia
2	Rasschaert et al [16]	2012	21 725 patients on ART	Buhera, Zimbabwe and Tyolo, Malawi
3	du Toit [17]	2014	872 HIV infected patients	Community study of HIV-positive males and females in pre-ART care in the Western Cape Province, South Africa
4	Rollins et al [18]	2014	No sample	Concept paper concerning pregnant women on ART in Zimbabwe, Nigeria and Malawi
5	Mekuria, et al [19]	2015	836 patients on ART	Patients on HIV treatment; Addis Ababa, Ethiopia
6	Plazy, et al [20]	2015	10 research articles and 2 abstracts	Systematic review, people in pre-ART care, Sub Saharan Africa
7	Reveles et al [11]	2015	8 845 HIV-infected patients	Patients on HIV care at Veterans Health Administration clinics in USA
8	Yehia et al [21]	2015	17 140 HIV-infected patients	Patients on antiretroviral therapy, North-eastern, Southern, Western and Mid-western parts of United States of America

Retention in eMTCT care evolved as options of care changed: from Option A through Option B to the currently recommended Option B plus. However, there is still no standard definition of the term resulting in different measurement and reporting of the concept. The dynamic and context-driven nature of retention in eMTCT warrants Rogers' evolutionary concept analysis [12].

### Definitions

The definition by Mekuria, et al is the most cited in HIV and eMTCT literature [19]. There is a need for the individual to be alive and still receiving HIV-related care. The attribute of continuing to receive medical care is implicitly accentuated in other literature. Another important dimension of retention-in-care is presence at scheduled visits which are between 60 and 90 days apart. For a woman to be considered as retained-in-care, she should also come for the eMTCT visit at 12 months after being enrolled into the program, with an allowance of a 2 week early visit or delay [11;15;17-20;22]. Apparent weakness in these definitions include the fact that retention is a continuous process and not a one-time event and that the eMTCT program does not end at 12 months. The program is not arbitrarily time-framed but endpoints are determined by cessation of breastfeeding or attainment of 18 months of age by the child at which time the mother and baby, if diagnosed as HIV-positive, are transferred from the eMTCT programme to routine HIV care [3]. The mother may also be transferred from

the eMTCT program if the child dies [23]. On the other hand, just focusing on facility attendance warrants intention to treat analysis as the mother or mother-baby-pair may not utilise the offered services; for instance, they may not regularly take ARV medicines. Alternatively, having a CD4 count at the prescribed time also indicates retention-in-care [20]. Lastly, regularity of scheduled visits is not all. There is also need for HIV related care per rising need even when not scheduled by the health care worker. Some definitions of retention-in-care, including the medical specialty context in which the articles were written, are shown in Table 2.

### Discussion

Rodgers evolutionary concept analysis involves the use of surrogate terms, related concepts, attributes, antecedents, consequences and model cases to clarify a concept. Surrogate terms are alternative words which can be used to express the concept, other than the term selected by the researcher. Thus, surrogate terms are similar to the concept of interest, unlike related concepts.

Related concepts have some relationships with the concept of interest but do not share the same attributes. Attributes are basically the characteristics of the concept. One of the main goals of evolutionary concept analysis is to identify attributes of a concept. Concepts are preceded by situations which called antecedents. Situations which occur after a concept are the consequences of the concept.

**Table 2.** Some definitions of retention-in-care.

Number	Author	Specialty area of corresponding author or journal	Definition
1	Assefa et al [15]	Public Health	All patients who are not lost to follow up [LTFU] or dead. LTFU meant not reporting for scheduled visit at HIV health facility within 3 months after last visit. Levels included cohort retention, current retention and cumulative retention
2	Rasschaert et al [16]	Tropical medicine	Being alive on antiretroviral drugs or transferred out.
3	du Toit [17]	Medicine	People on ART who reported having collected HIV medicine in the previous 3 months. People not yet on ART who had a CD4 count checked in the past 6 months
4	Rollins et al [18]	Maternal, new born, child and adolescent Health	Zimbabwe - Attendance in month 11 or 12 plus at least once every 2 months, within 2 weeks of the scheduled time in the period 0-10 months after starting PMTCT. Nigeria – 3 PMTCT visits in the first 6 months and 5 visits in 12 months [full Retention-in-care = 70% of the time, partial RIC = 35-70% attendance and no RIC = less than 35% attendance] Malawi – attendance at the 12 month plus getting all the ART supplies
5	Mekuria, et al [19]	Medical psychology	Alive and known to be receiving medical care; includes individuals who stop taking ARV medication
6	Plazy, et al [20]	HIV medicine	Kenya, Malawi, Zambia – not missing an appointment for more than 6 months South Africa – having a repeat CD4 count check at delivery Kenya – not being more than 60 days late for an HIV-related appointment Nigeria – not missing a scheduled HIV related appointment
7	Reveles et al [11]	Medicine	At least 2 appointments 60 to 90 days apart
8	Yehia, et al [21]	Medicine	Two or more HIV medical visits at least 90 days apart

Finally, model cases are the exemplary cases of the concept under study. Since this study suggests a definition of retention-in-care, a fictitious model case with all attributes of retention-in-care will be used [12;13].

### Surrogate terms

Terms which could be used interchangeably are called surrogate terms [12]. Surrogate terms for retention-in-care include retention [11;15;17-20;22], retention in services [24], viral suppression [18;19] engagement [25] and adherence [18]. However, viral suppression appears to be an outcome of retention in care rather than an equivalent of retention in care. Engagement entailed follow-up visiting by clients to their clinician [25]. Mugavero, Amico, Horn and Thompson cited three components of engagement as linkage to care, retention and re-engagement in care. Therefore, engagement cannot be equated to retention [11]. On the other hand, adherence was defined as the extent to which an individual's behaviour corresponds to prescribed diet, lifestyle and other medical recommendations [18]. The concept of adherence cannot be equated to retention in care. A person can be retained in care without being adherent and,

in praxis, also be adherent without being retained in care. Hence, adherence cannot be used as a proxy for retention in care [1].

### Related concepts

Related terms share some common attributes with the concept in question [12]. Terms related to retention in care were health care utilization, quality care [11] patient follow up [16] and attendance [18]. Health care utilization conveyed an element of partnership between the clinician and the client. Patient follow-up and quality care implied a passive role by the client. Above all, the terms were related to acceptable HIV and eMTCT care. The term attendance is part of retention in care; however, there is more than attendance in retention in care.

### Attributes

A universal attribute of retention in care in literature is that the individual has to be alive [11;15;17-21;25]. Another common characteristic of retention in care, though expressed in different terms, is coming for scheduled appointments. Nonetheless, presence for appointment is conceived

differently in literature. Some sources allow a specific number of missed visits as long as the client remains traceable and comes back in future, for instance, before or on the day of the end of the eMTCT program before transfer to the HIV treatment program [19]. In most literature sources, if an individual did not come on the scheduled date for HIV or eMTCT care it was still considered as adherence and retention-in-care. That is, if they came for the scheduled visit 2 weeks before or after the scheduled date, it would still count as adherence [18;22]. Practically, the scheduled appointments are better made on mutual agreement between the client and the clinician. According to Rasschaert et al, the retained client should not miss even a single scheduled appointment [16]. One important attribute is that clients who are regarded as retained in care should do what was prescribed during their HIV treatment visits to clinicians. These prescriptions include, but are not limited to, having CD4 count checks, viral load monitoring, collecting and taking ARV medicines as prescribed [17;20]. It is noteworthy to assert that retention in care is dynamic along a continuum as somebody can be lost to follow-up but later on become re-engaged and retained in care [19]. Retention in care can be objectively measured either formatively or summatively within either the HIV care or eMTCT cascade as current and cumulative retention, respectively [15]. Retention in the eMTCT program can be measured during or at the end of the program when the mother-baby pair gets transferred to routine HIV care. Summative evaluation of retention in the HIV care program can be done when the individual dies or becomes lost to follow up. Measurement of retention in care can be effected directly by counting the frequency of obeying medical prescription or indirectly by measuring the known outcomes of retention in care such as viral load suppression [15;18].

### **Antecedents and consequences**

Identification of antecedents and consequences facilitate further clarification of the concept of retention in care [12]. The identified antecedents to retention in care include linkage to care following diagnosis of HIV infection and fulfilment of WHO criteria for commencement on ART [11;19;22]. Other cited antecedents include initiation of ART by the individual [16-18] and engagement of the person in HIV care [20].

Consequences of retention in care may be either direct or

indirect. Direct consequence of retention in care include viral suppression as indicated by a reduction in viral load to an acceptable threshold, a progressive increase in the clients' CD4 count [11;16-18;22] and improved adherence [15;16]. Indirect consequences of retention in care include reduction in the incidence of opportunistic infections, reduced hospitalization, improved survival and quality of life [11;15;17;19]. According to the systematic review, prevention of mother to child transmission of HIV is another consequence of retention in care [18]. Retention in care has also another effect of reducing loss to follow up [16].

### **Model cases**

Rogers' evolutionary method of concept analysis needs a model case to clarify the concept in its totality [14, 15]. After synthesis of literature, the following is a description of a model case for retention in care:

A pregnant woman, diagnosed as HIV positive at antenatal care booking, gets enrolled in the eMTCT Option B plus program. The clinician prescribes CD4 count and viral load tests, cotrimoxazole prophylaxis and ART. The woman makes effort to eventually get the tests done on the same day of enrolment as baseline. She also begins to take all the medicine as prescribed from the day of enrolment. She is initially given a review date, 14 days afterwards. However, she develops side-effects in 5 days after starting the medicine. She decides to go back to her clinic for medical assistance. After the 14 days, she comes back as scheduled. She is given a refill of ARV medicines and a 2 monthly review dates. In between the review dates, she comes for her focused ANC visits. Every six months afterwards ARV medicines, she gets CD4 and viral load tests as prescribed. At delivery of her child, she breastfeeds her baby, exclusively, for 6 months. After weaning, she continues visiting her clinic until her child turns 2 years. She communicates and mutually agrees with her clinician on review dates to enable her to attend all prescribed visits and fulfil all medical prescriptions. This enables her to make social and medical visits without compromising on her eMTCT review dates, laboratory investigations and ART. Finally, she visits the clinic when her child turns 2 years and they both get transferred to the HIV care program.

### **Working definition of retention in care**

After critical appraisal of reviewed literature sources, a polished definition of retention in care is proposed. Retention



in eMTCT refers to documented regular participation of the pregnant woman, confirmed HIV positive, together with her child or children not yet confirmed as HIV-positive, in all prescribed activities aimed at preventing transmission of HIV from her to the child, and scheduled or unscheduled HIV-care related visits, measured during or at the end of care. It results in uninterrupted supply of ART. Thus, retention in care can be measured along a continuum spanning from not retained [which is equivalent to attrition] in one end and fully retained-in-care on the other extreme. For instance, individuals can be lost, moderately retained or fully retained-in-care. If the child becomes HIV-positive, the mother-baby-pair gets transferred to routine HIV-care.

### Implications

Analysis of reviewed works revealed conceptual and operational disparities in the definition, measurement and reporting of retention in care, as shown in Table I. It was, therefore inevitable to find disharmony among reports of retention in care. There is a need to use the refined definition of retention in care as stated in this article as part of monitoring of the program towards elimination of HIV by 2030 [2]. So far, reported retention in care is measured using the HRSR HAB [Health Resources and Services Administration HIV/AIDS Bureau] measure which regards retention as coming for at least two visits separated by at least 90 days. The tool may include parameters such as presence for scheduled appointments using missed visit and dichotomous missed visit count, measures of visit regularity such as visit adherence, 4-month constancy and 6-month gap, fulfilment of clinician's prescriptions, viral suppression and the HRSA HAB [Health Resources and Services Administration HIV/AIDS Bureau] performance measure, combined to complement the Kaplan Meier method shortcomings in measuring current retention [11;15;18]. The tool can be easier to use by nurses, physicians and other health workers involved in caring for eMTCT and people living with HIV & AIDS without having to master the rather intricate time-to-event analysis. Analysis of retention in care should not only be based on intention to treat but also per protocol analysis to enable appropriate interventions after determining risk density of attrition. Clinicians may also report retention in care quarterly, annually, and/or at the end of the program for eMTCT Option B plus. Above

all, policy should enable clinicians to self-monitor retention in care programs using simple statistics which capture all the elements of retention in care.

### Conclusion

Clinicians who care for clients in the eMTCT program and HIV care are well positioned to continually measure and improve retention in care. The definition presented in this article facilitates comprehension of retention in care. It may assist in standardisation of measurement and reporting of retention in care. Use of other measures of retention in care is encouraged to produce a clearer understanding of either cohort or calendar retention. Nonetheless, the concept of retention in the eMTCT care cascade continues to change.

### Conflict of Interest

We declare that we have no conflict of interest.

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