



Independent observer  
of the Global Fund

## ADDRESSING LOW RETENTION-IN-CARE RATES AMONG PEOPLE LIVING WITH HIV IN WEST AND CENTRAL AFRICA – A LITERATURE REVIEW

The United Nations has set a three-fold target ('90-90-90') for the HIV response by 2020: 90% of people living with HIV are tested and aware of their status, 90% of those have entered care, of which 90% (73% of people living with HIV) have an undetectable viral load. Many African countries are trying to achieve these goals. A recent publication by the [Global Burden of Disease group](#) indicates that out of a total of 195 countries, only 54 countries, including 10 in Africa, are expected to have 81% of PLHIV on antiretroviral treatment (ART) by 2020, and 12 countries will reach 90% on ART by 2030.

By the end of 2018, [around 8 out of 10 people living with HIV \(PLHIV\) knew their HIV status](#), 78% (69–82%) of them were on antiretroviral treatment and 86% of these had a viral load under 1000 cp/ml. These figures, which are encouraging, also reveal that 47% of PLHIV (nearly 18 million people) are not having their viral load monitored, and 8 million of these are unaware of their HIV status. This is particularly an issue in French-speaking West and Central Africa. Although we have made very significant progress, we are far from reaching the 2020 targets.

Strategies to retain patients in care

Various [articles](#) highlight that access to treatment can be facilitated if various strategies are put in place to reduce the loss of patients between detection and treatment initiation, and during treatment, in low-income countries. These include immediate CD4 tests and treatment initiation, and supportive interventions, such as phone reminders, treatment literacy and support groups. These interventions can go a long way to meeting the second and third 90% targets. Decreasing the number of medical consultations and receiving relevant support from health-care staff and peers may help, but this has not yet been well [documented](#). Providing a small transport allowance and nutritional support can help retain PLHIV in the care system, but support of this kind, modest as it may be, is not considered sustainable. It also creates equity issues with regard to patients with other health conditions.

Around 24 million people have had access to antiretrovirals, which is very encouraging given the situation in 2005. However, this figure represents those who have had at least initial contact with the antiretroviral distribution system and does little to demonstrate the actual number of people adhering to treatment or the number still being monitored at 6, 12 and 24 months, or for a longer period.

The third 90% target, which relates to viral load, requires good adherence and continued care. National and international programs focus a lot on this third area, which also includes a very attractive component for donors and programs: the provision of point of care (POC) diagnostic and prognostic services for CD4 counts and measuring viral load. It is often easier and more “attractive” to buy new equipment for facilities than committing resources to transport costs, for example, or to telephone costs to call patients and remind them about their appointments. It makes it possible to equip laboratories and account for budgets, but POC management, like all laboratory equipment, creates issues around training personnel, supplying commodities (including running water and electricity) and maintaining equipment.

To a certain extent, this approach constitutes placing trust in technological advances rather than it being a pragmatic response to real problems. However, enabling treatment literacy, for example, is fundamental to patient monitoring and should be included in the provision of care. This costs less but it plays an important role in terms of adherence and retention in care. It also makes it possible to better connect PLHIV with healthcare teams in charge of their care, provided that it is not limited to receiving orders or drug prescriptions.

Retention in care can be lower than 50% at 24 months among patients in large African cities. In order to remedy this, it is necessary to assess why people stop taking their treatment and the extent to which stopping treatment is the reason for leaving care compared to other factors (death, work or personal reasons for relocation). Studies show a very high proportion of patients [lost to follow-up](#) and a much lower proportion of deaths at 5 years: 42% and 6% respectively.

[A study carried out in Côte d'Ivoire](#) in 2000, before there was widespread access to antiretroviral treatment, revealed that specific procedures to investigate the status of registered patients (home visits, telephone contact with relatives, or reading funeral notices published in the newspaper) corrected the mortality rates of the cohort by 11%, 23%, and 30% at the end of the first, second and third years of follow-up. [A study on mortality](#) in 2008 at 11 African treatment sites that have introduced measures to correct

declared mortality found similar, sometimes even higher figures, with mortality increasing by 1.2 to 8 times depending on the site.

## Reasons for discontinuing care

Since the introduction of large-scale antiretroviral treatment programs in Africa, [studies](#) have been able to show that where mortality represents a substantial component of those “lost to follow-up”, it did not correspond to all of those not followed-up. After the first year on antiretroviral therapy, the proportion of deaths among those lost to follow-up declines, replaced by undocumented transfers to other treatment centers and treatment dropouts. In this study, home visits were more effective than telephone calls to identify the circumstances of PLHIV lost to follow-up.

Discontinuing care can arise from [multiple factors](#): poor treatment at health facilities, unplanned absences of health-care staff involved in other activities (this mainly relates to doctors and can be reduced through task shifting), and the chronic nature of the condition, which requires medical practices that differ from the prevailing model in Africa.

Stigma and self-stigma are major reasons for both not starting and leaving care. Even though health care staff and program managers may think that stigma has decreased, it is not the case for many PLHIV. They are still afraid of being identified as HIV positive and therefore hide their status, depriving themselves of support from family and friends, and preferring to give up on their treatment rather than being identified. In addition, traditional healers, and religious leaders in particular, sometimes ban the use of antiretrovirals. This has been seen in [the Democratic Republic of Congo where people living with HIV use prayer](#) and do not return to seek care until a very advanced stage of illness.

Finally, despite the fact that antiretroviral treatment is free in most countries, the cost of transport, laboratory tests and drugs for opportunistic diseases are real obstacles to accessing care, particularly for the poorest and most vulnerable PLHIV. Furthermore, some people are not even aware that antiretroviral drugs are available free of charge, as free treatment is not the norm in African health systems. There is also a reluctance to devote scarce resources to patients who are wrongly considered to be terminally ill, especially when the disease is at a very advanced stage.

What solutions exist to stop people discontinuing care?

[Decentralization of care appears to be a good strategy](#) to reduce the number of patients lost to follow up. However, there are limitations to this approach. The most effective model appears to be initiation of treatment following testing in a health-care setting with monitoring and distribution at community level. This allows people living with HIV to have access to treatment near where they work or live. However, [the best solution is probably to have multiple methods of distributing treatment](#) and monitoring PLHIV –

hospital consultations, community distribution points, patient clubs, etc. In this way, PLHIV could more easily decide to stay in care without fear of stigma and identification.

Ultimately, there is a need for greater understanding of retention in care and the factors that facilitate it or make it difficult, through qualitative research and operational studies.

Finally, for the last few years, prevention and testing have been targeted at 'key populations' that play an important role in the epidemic. However, over the last ten or fifteen years, the general population has lacked information on how the HIV and AIDS epidemic is evolving. If we want to meet targets around testing and retention in care for PLHIV, it is necessary, through massive information campaigns, to reach all of the adult population in Africa, as we did in the days when AIDS was a costly and deadly disease. Today the situation has changed, and we need to convince people to be able to reduce fear, stigma and exclusion from healthcare, enabling us to meet the United Nations targets.

Philippe Msellati, MD, PhD, works as a research director in TransVIHMI, Institute of Research and Development from France, as an epidemiologist. Dr Msellati worked for the past 30 years mainly on transmission of HIV from mother to infant and its prevention, paediatric HIV infection and access to antiretroviral drugs in Africa.

This article [originally appeared in French](#), in the Observateur du Fonds Mondial, numéro 95 (23 January 2020).

[Read More](#)

---