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Editorial

Follow-up losses of people with HIV infection: A weak point in the continuum of care[☆]



Las pérdidas de seguimiento de las personas con infección por VIH: un punto débil en el continuo de cuidados

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At a time when people living with HIV (PLHIV) can expect quality of life and survival similar to uninfected people, it has become a priority to identify any obstacle which prevents them from accessing and benefiting from the healthcare that provides these benefits, including antiretroviral treatment. The most important goal is sustained viral replication control. This means that, after being diagnosed with HIV, people need to engage with the health service, be retained in care, start antiretroviral treatment and, ultimately, adhere to it. These multiple stages were first outlined in 2011¹ by Gardner et al., in what they called the continuum (or cascade) of HIV care, and identified the proportion of people who did not overcome all of the obstacles and were not therefore able to achieve the ultimate goal of undetectable viral load. Strikingly, according to their estimates, only 19% of patients in the United States with HIV had undetectable viral load.

The continuum of care proposed by Gardner had wide resonance and acceptance, and countries around the world have been working to estimate the values in each of the stages of the cascade. Importantly, it served as the basis for establishing the World Health Organisation's 90-90-90 strategy,² which has the following goals: by 2020, 90% of people with HIV are diagnosed; by 2020, 90% of those diagnosed are on antiretroviral treatment; and by 2020, 90% of people on treatment have fully suppressed viral load. The six stages of the initial proposal are therefore condensed into just three. However, summarising the stages to such an extent could lead to some of the hugely important intermediate barriers being ignored. Between diagnosis and the indication of antiretroviral treatment in particular is the period of engagement with and retention in the healthcare system. In some countries, including Spain, these stages have been a weak point of care, limiting overall success. It is important to have as accurate an idea as possible of how well each of the partial objectives are met so measures can

be established to help improve the situation when deficiencies are detected.

The article by Teira et al. is particularly relevant in this context.³ They examine the people who are retained in the healthcare system after they have made contact, one of the least assessed areas within the PLHIV care cascade. The proportion of people seen in an HIV clinic who are lost to follow-up is a hugely important area. In the original article by Gardner et al., approximately one third of the people diagnosed and engaging with healthcare services were not retained in the system¹, contributing significantly to the poor figures for people achieving undetectable viral load.

According to the figures for the Spanish hospitals participating in the VACH cohort included in the study by Teira et al., 15% of the patients seen were lost to follow-up in the study period from 2012 to 2014. This finding is better than figures reported by studies in neighbouring countries^{4–6} and consistent with other Spanish studies.⁷ However, it should be noted that comparing studies may not be reliable given the different definitions used. There is actually no standard definition for “lost to follow-up” in healthcare. However, for our setting, the definition we used in this project (less than one visit over a one-year period) is appropriate and reliably transmits the idea of patients who fail to adhere to the number of visits currently considered minimal for adequate follow-up.

There are two main reasons for the interest in the lost to follow-up figures. The first is that it determines the minimum number of patients who are not receiving antiretroviral treatment. However, there is a lack of consensus when it comes to assessing the consequences of loss to follow-up in our region. The most recent update of the care cascade in Spain suggests that 92–96% of all diagnosed patients are receiving antiretroviral treatment.⁸ This apparent inconsistency is difficult to explain, given that the estimate of 15% of patients lost to follow-up in this article is in the low range, but still much higher than the estimated proportion of diagnosed people who are not on antiretroviral treatment (only 4–8%).

The other reason for the interest is the fact that identifying factors associated with loss to follow-up could help us to design strategies to improve the situation. On this subject, a number of factors identified by Teira et al. merit discussion. It is particularly relevant that it is sociodemographic factors which largely

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determine loss to follow-up. Being unemployed, being an immigrant or belonging to a low social stratum are all associated with a lower rate of retention in healthcare. If the aim is to reduce loss to follow-up, extra attention will have to be paid to patients in these categories, especially if they are young (being younger has also been associated with a higher rate of loss). In an ideal scenario, yet-to-be-designed mechanisms should be implemented with these people that would guarantee attendance at clinic appointments. Social workers could certainly provide additional help in this regard. Although not consistent across all the published studies, the size of the hospital has been identified as a factor in the rate of patients with adequate follow-up, with better figures found in larger hospitals (>1000 beds). This is an interesting finding and, if confirmed, may be related to the greater experience and degree of specialisation in large hospitals where more people with HIV are treated.

The subject we are analysing is no minor issue. Each of the components of the PLHIV care cascade needs to be examined, to detect potential failings and provide solutions. For obvious reasons, the focus up to now has been on measuring and improving the first stage of the cascade, i.e. to reduce the proportion of people who remain undiagnosed, currently estimated at 18% in Spain.⁹ At the other end of the cascade, adherence to medication in patients on antiretroviral treatment has been a constant focus of interest and, to a large extent, remarkable successes have been achieved in this area. We must not, however, forget the intermediate stages. One clear improvement that needs to be made is to ensure that patients who initially engage with the clinic are retained and adhere to the recommended follow-up. Our healthcare system has to respond

to this challenge, but we are sure that, once again, it will do so successfully.

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