









REVIEW ARTICLE

Why we need to re-define long-term success for people living with HIV

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Funding information

Gilead Sciences

Abstract

Over the past few decades, the life expectancy of people living with HIV has markedly improved due to the advances in HIV diagnosis, linkage to care, and treatment. However, with these advances, a new set of challenges has emerged that must be addressed to ensure the long-term well-being of people living with HIV. In this article, as part of a wider journal supplement, we explore the unmet needs and challenges across the HIV continuum of care and re-define what long-term success looks like to support the healthy ageing of all people affected by HIV.

KEYWORDS

AIDS, antiretroviral therapy, health-related quality of life, HIV, person-centred health systems, stigma, well-being

Globally, approximately 38 million people are living with HIV, and an estimated 1.5 million new infections occur each year [1]. This translates to 4000 new HIV infections every day [1]. Despite a substantial reduction in the number

of new annual infections from a peak of 3.2 million in 1996 [1], the number of people living longer with HIV has been increasing due to the successful scale-up of antiretroviral therapy (ART) and subsequent gains in life expectancy [2].

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Since the discovery in the 1980s that HIV causes AIDS, a global multidisciplinary effort has led to the development of novel and effective HIV treatments and preventive strategies [3–5]. This effort has resulted in over 30 antiretroviral drugs being approved by regulatory authorities [5] and has paved the way for a new era of effective combination therapies [6]. ARTs can achieve long-term treatment success by durably maintaining reductions in viral load, often to undetectable levels [6], offering people living with HIV the potential for improved life expectancy approximating that of the general population [7]. The development of such effective treatments, alongside the ability to rapidly diagnose people living with HIV, has transformed the HIV management landscape and provided hope for those affected. As such, HIV infection has become a chronic, medically manageable condition for most people who have access to ART [8]. However, with these advancements, new challenges have emerged that need to be addressed if the sustained well-being of people living with HIV is to be achieved.

A substantial proportion of people living with HIV do not consistently receive ART, despite programmes that support global access to these medications [1]. As of 2021, it was estimated that 9.7 million people living with HIV worldwide were not receiving ART [1]. The structural and societal barriers that persist across the HIV continuum of care have continued to impede access, uptake, and maintenance of ART and have thus affected the ability of people living with HIV to achieve and sustain undetectable viral loads [9]. Individuals who are not receiving ART remain at higher risk of opportunistic conditions and premature death than those benefitting from ready access to ART [10]. To maintain and achieve epidemic control, universal access to ART must become the global standard for treating people living with HIV [11].

Among those with access to effective HIV therapies, durable viral suppression, and the longevity it offers, has meant that addressing new and perennial challenges to well-being is now essential. Compared with the general population, people living with HIV have a greater risk of multimorbidity, including physical and mental health conditions, which can impact their health-related quality of life (HRQoL) [12]. Many conditions associated with ageing, such as cardiovascular disease, fatty liver disease, central nervous system disorders, fracture risk, and osteoporosis, are more common in people living with HIV than in the general population [13, 14]. The synergistic effects of ageing with HIV can promote progression to states of frailty that reduce the HRQoL of people affected by HIV [15]. As such, in addition to viraemic control, the prevention and management of comorbidities has become a priority objective for most healthcare professionals (HCPs) caring for people living with HIV where ART is freely accessible. Much of the discourse on HIV-

associated comorbidities has focussed on organ systems, with less attention paid to the substantial impact of mental health conditions, which are disproportionately prevalent among people living with HIV [16]. Often, mental health conditions are undetected and remain untreated [16–19], and this has been further exacerbated by the COVID-19 pandemic [20]. As a result, mental health conditions persist as obstacles to engagement in care and healthy ageing [16].

The physical and mental health issues that people living with HIV encounter as they age can be compounded by societal forces, such as stigma and discrimination [21]. HIV-related stigma is a complex phenomenon with diverse manifestations and intersections, occurring at different levels, such as institutional, organizational, community, interpersonal, and intrapersonal levels [22]. Both stigmatization of HIV and discrimination against those who live with HIV have a significant impact on HRQoL and health outcomes, including increased rates of depression and reduced levels of adherence to treatment [21]. Internalized stigma (i.e., felt or self-stigma) is particularly prevalent among people living with and at risk for HIV and can compromise HIV prevention, care, and treatment as well as HRQoL [23]. In addition to their direct impact on the individual, stigma and discrimination can also be barriers at each point along the HIV care continuum, from testing and linkage to care to viral suppression and beyond [24]. Although attitudes are changing, stigma and discrimination can still occur from a variety of sources, ranging from healthcare workers and employers to friends and family [25]. For example, in The People Living with HIV Stigma Index survey, conducted in over 50 countries, one in eight people living with HIV reported having been denied access to healthcare services due to their HIV status [26]. In addition, at least 68 countries have laws that specifically criminalize HIV non-disclosure, exposure, or transmission [27].

Alongside these sources of stigma and discrimination, structural factors, including poverty and isolation, can further challenge the well-being of people living with HIV [12]. Circumstances of poverty, such as food insecurity and unstable housing, are highly prevalent among people living with HIV, particularly as they age [28–30]. Evidence suggests that the presence of poverty impedes even the most ambitious efforts to end the HIV epidemic [31]. Social isolation and exclusion, often experienced by people living with HIV, also lead to health inequities [32] and can have a negative impact on physical and mental health [33]. This demands a need for the scale-up of novel approaches that recognize and address structural drivers of health and social disparities.

The COVID-19 pandemic has exacerbated many of the threats to the well-being of people living with HIV. Mitigation strategies, including mass physical distancing

and social isolation, led to increased social isolation and loneliness, which are already epidemic among people living with HIV [34]. Policies also designed to reduce SARS-CoV-2 transmission restricted access to clinics and care, resulting in an increase in online services as an alternative approach to in-person HIV care [35]. While the benefits and barriers of these services have been noted, as we emerge from the pandemic, consideration of patient preference will be key to ensuring a person-centred approach and avoid a digital divide in which some key populations are less able to access the care they need [35]. With ongoing financial, political, and climate crises, it is critical that people living with HIV are specifically considered in any governmental or organizational interventions to protect them from further health consequences.

Another barrier key to addressing the myriad of existing challenges to living long and well with HIV is the fact that HIV care is not always integrated with other care needs and services [36]. HCPs and people living with HIV note a lack of continuity of healthcare service provision between primary and speciality care [37, 38]. Poorly integrated care can be time consuming, waste resources, result in conflicting advice and, ultimately, reduced adherence to treatment and loss of engagement in care [37, 39, 40]. Multidisciplinary teams currently face several communication and coordination-related challenges that can impede the efficiency and consistency of services. For example, some people may lack confidence that other HCPs adequately understand the complexities and challenges of HIV and may also be uncertain about where to find support for managing their long-term conditions [37]. Implementing an integrated approach, one that is sensitive to the diverse needs of people living with HIV, can help improve long-term health [41].

In 2014, in response to the shift in approach for HIV management, the Joint United Nations Programme on HIV/AIDS (UNAIDS) developed a series of ambitious targets to end the AIDS epidemic by 2030. The UNAIDS 90-90-90 treatment targets aimed for 90% of people living with HIV to know their HIV status, 90% of people living with HIV to be receiving ART, and 90% of people receiving ART to achieve viral suppression [42]. Recent figures indicate that the viral suppression target is close to being achieved, with an estimated 88% of people living with HIV globally and receiving ART having already reached this goal [11]. A set of interim targets for 2025 were subsequently developed, which maintain the same overall approach but adopt a more ambitious target of 95% for each of the steps of the cascade [11]. These targets also align with the World Health Organization's (WHO) 2022–2030 global health sector strategy for HIV, which calls for a more focused effort, including a wide range of targets, on reaching those most affected and at risk for HIV in order to address inequities [43].

While sustained viral suppression is essential to improving life expectancy for people living with HIV [7, 11], reducing secondary transmission [44] and meeting UNAIDS and WHO targets [42, 43], controlling viraemia alone is not a sufficient defining point for achieving long-term success (LTS) for people living with HIV. As discussed, it has become evident that all people affected by HIV still must confront both persisting and new challenges to their HRQoL and overall well-being. Therefore, there is a need for HCPs, policymakers, and commissioners of HIV services and treatments to adjust their focus from viral suppression alone to a broader vision that considers control of viraemia as a minimum and essential contributor to LTS. With this in mind, Lazarus and colleagues proposed a fourth target to complement the three aforementioned UNAIDS targets [45]. This additional target aims for 90% of people living with HIV to have good HRQoL and is directed at three key domains focussing on multimorbidity, self-perceived QoL, and stigma and discrimination [12].

With the threat of progression to AIDS largely removed, the communities of HCPs and people living with HIV are challenged to co-produce strategies that support every person living with HIV being able to live their best life. Creating the conditions for successful long-term medical management will move us past laboratory metrics as measures of treatment success to recognizing the aforementioned determinates of healthy living and ageing with HIV. Given the complexity of the experience of living with HIV, a multidisciplinary, integrated, person-centred approach with active patient participation that reflects the major concerns of people living with HIV is increasingly being adopted in HIV management. With this approach, the HIV clinical care perspective is widened to integrate overall well-being and healthy ageing in a supportive environment. As a complement to the traditional management and monitoring of HIV, more person-centred, self-reported assessments of health and well-being (e.g., patient-reported outcomes) should be harnessed to help identify priority issues that could then be addressed [46, 47]. This holistic approach recognizes HIV treatment as one part of a larger vision that defines LTS in living and thriving with HIV. In our subsequent article, we detail a new framework developed to help guide clinical practice, incorporating elements of holistic care alongside effective treatments, and establishing LTS as a new goal in the next phase of HIV management. Reaching this goal will require the HIV community and wider society to work together to make LTS a reality for everyone living with HIV.

AUTHOR CONTRIBUTIONS

All authors were part of the expert panel mentioned in this supplement. All authors contributed to the concept of this supplement and in drafting and revising the text. All authors read and approved the final version for publication.

ACKNOWLEDGEMENTS

The authors thank Shannon Gunn, Kelly Rooke, PhD, and Langland Health Communications Agency for editorial support.


FUNDING INFORMATION

Financial support was provided by Gilead Science Europe Ltd for editorial services in accordance with Good Publication Practice (GPP3) guidelines. Authors did not receive any honoraria for the supplement but were compensated for their participation in two virtual workshops that helped co-create the LTS framework.

CONFLICT OF INTEREST STATEMENT

MJF has received consultancy fees from Gilead Sciences, Janssen, MSD, ViiV Healthcare, GSK, and Theratechnologies and has received payments for lectures or educational presentations from Gilead Sciences, Janssen, MSD, and ViiV Healthcare. DW has received research grants and fees for advisory boards and lectures from Gilead Sciences, MSD, Janssen, ViiV Healthcare, and Theratechnologies. MC has received consultancy fees from Gilead Sciences and ViiV Healthcare. GG has received study grants and attended advisory boards for ViiV Healthcare, Gilead Sciences, Janssen, and Merck. JR has received honoraria for participating in advisory boards and speaking at educational events from Gilead Sciences, Janssen, Merck, Theratechnologies, and ViiV Healthcare. MH has received consultancy and speaker fees from Gilead Sciences and ViiV Healthcare. BR has received grant income and has served as an advisory consultant for Gilead Sciences and ViiV Healthcare, as well as grants and fee-for-service income from Janssen and Merck. GB has received payments from Gilead Sciences as a speaker, advisory board member and as an educational grant, and has also received compensation from ViiV Healthcare as part of a working group. JVL has received speaker fees from AbbVie, Gilead Sciences, Janssen, MSD, Novo Nordisk, and ViiV Healthcare and grants to his institution from AbbVie, Gilead Sciences, MSD, and ViiV Healthcare.


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How to cite this article:

Fuster-RuizdeApodaca MJ, Wohl DA, Cascio M, et al. Why we need to re-define long-term success for people living with HIV. *HIV Med*. 2023; 24(Suppl. 2):3-7. doi:10.1111/hiv.13461