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VIEWPOINT

A call for health systems to monitor the health-related quality of life of people living with HIV

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Abstract

Introduction: The World Health Organization's (WHO's) new global health strategy on HIV represents a major step toward a broader conceptualization of HIV care. It recognizes the importance of addressing chronic care more fully and–for the first time ever–the health-related quality of life (HRQoL) of people living with HIV (PLHIV).

Methods: A thorough literature review was conducted in order to analyse how the WHO strategy on HIV for 2022-2030 addresses the monitoring of the HRQoL of PLHIV for the next decade and compared it to that of other countries and health authorities.

Results: Unlike for other issues, the strategy does not include quantitative targets for 2030, thus falling short of committing to monitoring global progress in improving the long-term well-being of PLHIV.

Conclusions: We urge national health systems not to wait for WHO to lead on this issue. Seeking good HRQoL outcomes for PLHIV can confer far-reaching benefits on health systems. The feasibility of monitoring population-level HRQoL has been demonstrated through the use of simple tools like patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). Many countries can already set HRQoL monitoring targets, similar to those presented in this viewpoint, while we work toward an agreed minimum metric for use by all countries.

KEYWORDS

health policy, health-related quality of life, HIV, right to health, well-being

In May 2022, the World Health Assembly, which governs the World Health Organization (WHO), approved WHO's combined global health sector strategies on HIV, viral hepatitis and sexually transmitted infections for the period 2022–2030 [1]. With respect to HIV care, the new HIV strategy represents a major step forward since that presented by WHO in 2016.

HIV care has long been characterized by a primary focus on antiretroviral therapy use due to its role in bringing viral replication under control. There is now

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growing recognition of the importance of addressing non-communicable diseases as well, including mental health issues, and social well-being, in integrated person-centred service delivery models. Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are increasingly regarded as valuable tools in these efforts, with their use being implemented in diverse ways [2–4]. For example, the Swedish government established a goal of having 95% of people living with HIV (PLHIV) in Sweden complete a nine-item questionnaire annually, with indicators on physical, psychological and sexual health, medication adherence and satisfaction with care. The purpose of this was to guide interventions to improve individual patient outcomes (personal communication, Åsa Mellgren to Jeffrey V. Lazarus, 19 June 2022). Another example is the 2017 Positive Voices Survey in the UK, which collected data on PROMs and PREMs. It offered the opportunity to PLHIV in the UK to be heard, and provided evidence on the struggles this population still faces regarding stigma, discrimination, mental health issues and inequities. There is also growing interest around the world, though predominantly in high-income countries, in using existing validated PROMs such as EuroQoL, PROQOL-HIV and WHOQOL-HIV-BREF to measure the self-reported health-related quality of life (HRQoL) of PLHIV in clinical settings [3].

This broader conceptualization of HIV care is reflected in a key change in WHO's 2022–2030 HIV strategy: unlike that in the previous strategy, the HIV service cascade presented in the document mentions chronic care and HRQoL (Figure 1).

The 2022–2030 HIV strategy also draws attention to a range of issues that are pertinent to the goal of achieving good HRQoL outcomes. It emphasizes the importance of people-centred health services and includes an action calling for the stronger integration of communicable and non-communicable disease services. It also highlights the need for actions that recognize the significance of stigma and discrimination, mental health, disability and rehabilitation in the lives of PLHIV [1]. Finally, it underpins the significance of addressing the intersectional needs of key, vulnerable populations such as men who have sex with men, people who inject drugs, transgender people, sex workers, people in prisons and other closed settings, migrants and people living in humanitarian settings (i.e., due to conflict and civil unrest).

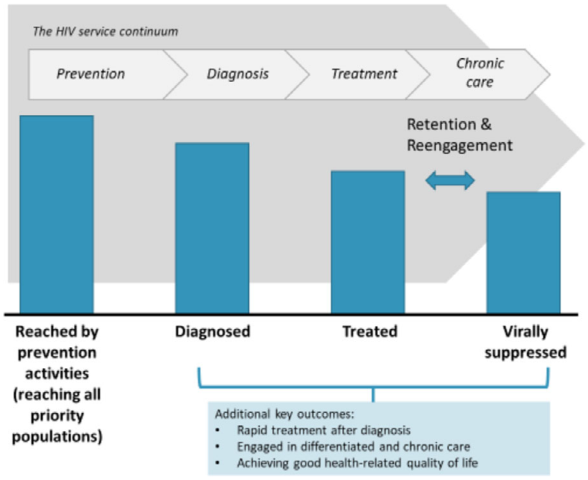

FIGURE 1 The World Health Organization HIV services cascade

WHO's decision to include HRQoL as a key outcome in the HIV service cascade, alongside diagnosis, treatment and viral suppression, will doubtlessly accelerate the paradigm shift that is underway in health system approaches to HIV care [5–8]. However, it is worth noting that HRQoL is not addressed in any of the 14 quantitative targets that WHO's 2022–2030 HIV strategy identifies for assessing impact and service coverage [1]. Thus, the strategy falls short of committing to monitoring global progress toward improving HRQoL outcomes in PLHIV.

This omission may reflect the relative newness of addressing HRQoL outcomes in the monitoring of health system responses to HIV. In 2018, when European countries were asked to report to the European Centre for Disease Prevention and Control (ECDC) on whether or not their health systems evaluated HRQoL outcomes in PLHIV, only 5 of 48 responding countries answered affirmatively (personal communication, ECDC to Jeffrey V. Lazarus, 5 June 2018). In the United States, the 2022–2025 national HIV/AIDS strategy expresses a commitment to monitoring quality of life (QoL) for PLHIV. This follows work carried out to assess potential data sources and develop a suitable indicator, especially because no such indicator currently exists [9].

In the 2021 'Consensus statement on the role of health systems in advancing the long-term well-being of people living with HIV', a global panel of HIV experts noted: "self-reported HRQoL should be recognized as a core outcome in the clinical management of individual patients, and in the national and global monitoring of health system responses to HIV" [10]. This consensus statement was informed by studies observing lower HRQoL among PLHIV and the overall recognition that ongoing stigma and discrimination and the lifelong use of medication negatively impact HRQoL [11]. The absence of a WHO-defined HRQoL target, or a more general QoL target for the HIV field, raises the risk that many countries may not understand the repercussions of not reporting on the HRQoL of PLHIV. Furthermore, countries may be unsuitably resourced or ill-equipped to incorporate a HRQoL component of care and related monitoring into existing health service coverage for HIV.

We urge national health systems not to wait for WHO to lead on this issue. The feasibility of monitoring and implementing measures to improve population-level HRQoL has been convincingly demonstrated, including in the HIV field. An informative example comes from Australia where the explicit objective of improving the QoL of PLHIV was first included in the country's 2010–2013 national HIV strategy [12]. PLHIV and affected communities had called for this objective. They followed up by advocating for investment and community partnerships to develop a PROM that would be suitable for assessing national progress toward integrating a focus on QoL and well-being into health care for PLHIV [13].

Australia's 2018–2022 national HIV strategy, endorsed by all national, state and territorial health ministers, has the following among its nine targets: '75% of people with HIV report good quality of life' [14]. Progress in achieving this target is measured by administering a previously developed PROM, known as PozQoL, to nationally representative samples of PLHIV [13, 15]. In 2019, an Australian government-funded study found that 63% of study participants reported having a "good" quality of life [16]. New national data for this target are anticipated to be reported in late 2022.

At a time when health systems are facing intense challenges associated with the COVID-19 pandemic, global instability and large-scale population displacement, the justification for focusing on the HRQoL of a patient population that includes many clinically stable individuals may not be obvious to all stakeholders. This may be even truer in low-income settings with weaker health systems. However, seeking good HRQoL outcomes for PLHIV, who experience a larger overall burden of multi-morbidity than the general population, may confer far-reaching benefits. Poorer HRQoL outcomes predicted all-cause hospitalization in a large longitudinal cohort study of US PLHIV [17]. Studies in other patient populations have reported similar findings, as well as associations between poorer HRQoL and mortality [18, 19]. The effectiveness of interventions in improving HRQoL in various patient populations has been demonstrated [20, 21], and it is time to leverage such knowledge to achieve better population-level HRQoL outcomes for PLHIV. For this reason, we strongly recommend that WHO develops quantitative indicators to help facilitate the adoption of the aforementioned measures in countries with fewer healthcare resources. We also urge them to provide technical support for data collection and research development concerning the impact of inter alia socio-cultural factors on the QoL of PLHIV [22].

Importantly, certain subgroups of PLHIV have reported better HRQoL outcomes than others [23]. Health system monitoring of HRQoL in PLHIV with disaggregation for age, sex, ethnicity, migrant status and other characteristics is important in guiding resource allocation decisions, so that those who need the most support in this domain are prioritized. By recognizing the diversity of PLHIV and seeking to understand how their HRQoL-related needs may change under different circumstances and across time, health systems can help drive equitable progress toward broad health-related targets defined in the 2030 Agenda for Sustainable Development and ensure that no one is left behind.

AUTHOR CONTRIBUTIONS

JVL conceived the study and prepared the first draft. All the other authors have contributed equally to subsequent drafts and approved the final version.

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CONFLICT OF INTEREST

The authors have declared no competing interests.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analysed in this study.

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