

“Moving Fourth”: A Vision Toward Achieving Healthy Living with HIV Beyond Viral Suppression

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Abstract

Since HIV has evolved from being a fatal illness to a chronic condition, this brings new challenges relating to long-term health, as increasing numbers of people living with HIV (PLHIV) navigate their lives beyond viral suppression. This review presents the challenges facing patients and health-care providers managing HIV in Europe today. We highlight the challenges that the evolving landscape in HIV brings, including managing an aging and more diverse population of PLHIV; this requires a shift from managing disease to managing health and may best be achieved by multidisciplinary teams in the long term. We introduce the concept of “health goals for me:” an individualized approach to the management of HIV, and use this as the basis for a proposed framework for assessing health-related quality of life for PLHIV. Our framework comprises a continuous cycle of “ask and measure,” “feedback and discussion,” and “intervention,” based on collaboration between the health-care professional and patient. For improved long-term management of PLHIV, we consider that this framework should become an intrinsic part of HIV care in the future and that the “health goals for me” concept be used as a tool to facilitate healthy living for PLHIV beyond viral suppression. (AIDS Rev. 2019;21:135-142)

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Introduction

The 90-90-90 HIV treatment plan

Since the initial devastation caused by the global HIV pandemic in the 1980s, HIV has been transformed from

a life-threatening disease to a manageable chronic condition¹. In 2014, the Joint United Nations Programme on HIV/AIDS (UNAIDS) proposed the ambitious 90-90-90 treatment plan² to help end the AIDS epidemic: to diagnose 90% of all HIV-positive persons; provide antiretroviral therapy (ART) to 90% of those

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diagnosed; and to achieve viral suppression for 90% of those treated by 2020. Modeling suggests that achieving these targets by 2020 will enable the world to “end” the AIDS epidemic by 2030². The goal of ending the AIDS epidemic as a public threat by 2030 is linked to the World Health Organization (WHO) vision³ of having no new HIV infections, no HIV-related deaths and no HIV-related discrimination where people living with HIV (PLHIV) are able to live long and healthy lives. Recent data released by UNAIDS indicates that there are 37.9 million PLHIV globally, but only 19 countries are on track to ending the AIDS epidemic. There has been a 33% decrease in the number of AIDS-related deaths from 2010 to 2018; however, the rate of decline is slowing which will prevent the global mortality-reduction targets (< 500,000 deaths in 2020) from being achieved. Moreover, in 2018, there were 1.7 million new HIV infections globally which are far removed from the 2020 target of < 500,000 new infections annually. The UNAIDS report⁵ highlights that the global resources available for the AIDS response have declined for the first time since 2000 and asks for a strong collective effort from both governments and communities.

Prevention is another important area for further effort to meet the challenging 2020 targets and beyond. The aim includes both reducing sexual risks behaviors and expanding pre-exposure prophylaxis in those engaged in risky sexual activities. Existing guidelines^{6,7} include information on the use of pre-exposure prophylaxis; the benefits of patient education in such matters as safe sexual practices and abstinence should be part of public health strategies for stopping the spread of HIV and other sexually transmitted infections⁸.

The “fourth 90” concept

The 90-90-90 UNAIDS targets do not cover other HIV-related health challenges that PLHIV face such as associated mental and physical comorbidities, mental health issues, financial stresses, and potential HIV-related stigma. Subsequently, Lazarus et al.⁹ proposed a “fourth 90” target that 90% of the patients with viral load suppression should have good health-related quality of life (QoL); this was later updated to include all PLHIV¹⁰. This publication⁹ did not define “good” health-related QoL for PLHIV but suggested that it encompasses two main areas, successful management of comorbidities and improved self-perceived QoL and that these could be achieved by health systems becoming more integrated and centered around people.

Achieving the “fourth 90”

We believe that an individualized treatment approach for PLHIV would help achieve the all-important “fourth 90.” Individualized patient care in other disease areas has been shown to be beneficial in terms of improving adherence to drug treatment and health behaviors^{11,12}. Within the scope of HIV, this type of approach requires an adjustment in the objectives for treatment of each PLHIV as they face longer life expectancies, regardless of their socioeconomic status or geography. Ideally, this should encompass a collaborative and proactive approach to the assessment of health and therapeutic decision-making, to establish mutual responsibility and shared goals between the health-care provider (HCP) and patient.

Objectives

The aim of this publication is to define healthy living for PLHIV beyond viral suppression. Subsequently, we propose the “health goals for me” concept as a tool to provide an individualized treatment approach.

Evolving challenges for long-term healthy living with HIV

Increasing diversity in the PLHIV population

As a result of advances in HIV management, life expectancy of PLHIV is now close to that of the general population¹³. An HIV-positive male in the UK starting ART at age 35 years has an expected life expectancy of 73 years, compared with 78 years in the general population¹⁴. Nonetheless, multiple factors can compromise the possibility of living healthily in the long-term: HIV itself; choice of a treatment regimen; and the occurrence of comorbidities which could partly be due to the individual’s own lifestyle choices¹⁵⁻¹⁸. For example, in a large study of HIV-infected individuals on ART for at least 1 year in Europe and North America, 60% of PLHIV were smokers, and smoking was found to be associated with a two-fold increase in mortality¹⁹. Thus, PLHIV need to be health conscious to an even greater extent than HIV-negative individuals do to improve longevity and morbidity.

With more people with HIV living longer²⁰, diversity is increasing in the patient population. This is not only reflected in the range of comorbidities that peo-

ple experience and the complexity of treatment regimens but also includes age, socioeconomic status, access to medical care, sexuality, sexual and reproductive health, mental health problems or HIV-related stigma²⁰⁻²².

Patient versus physician perspectives

Often, PLHIV has concerns and priorities that differ from those anticipated by the HCP²³⁻²⁵. A recent qualitative analysis of interviews with patients and HCPs demonstrated some disparity in the perceived level of importance of factors influencing decision-making in HIV care²⁵. A clear difference was observed in the ranking of long-term treatment side effects. For example, while patients named depression or feeling very sad as most important, nausea and diarrhea topped the ranking for HCPs, with mental health perceived as less important²⁵. This study also showed great variability among and between providers and patients in the level of patient involvement expected in shared decision-making^{25,26}. There is, therefore, a need to support HCPs in identifying each individual's personal concerns and priorities so that the needs of all PLHIV can be adequately addressed⁶.

Considerations for managing HIV in the long term

Despite improvements in mortality rates, the long-term health of PLHIV beyond viral suppression has not improved at the same rate²⁷; this includes the burden of harmful health behaviors, the role of HIV itself and associated inflammation, treatment side effects, levels of psychological distress, and the burden of comorbidities. Treatment guidelines place the emphasis on achieving viral suppression, management of comorbidities, and drug–drug interactions^{6,26}. However, there is little guidance on aspects such as evaluating and improving health-related QoL, management of polypharmacy, use of technology in HIV care, sexual and mental health or dealing with HIV-related stigma^{6,26}. The authors advocate that international guidelines for the treatment of HIV-positive patients should include health-related QoL as the measure of success of the treatment²⁸.

In our experience, sub-optimal well-being is regarded as “normal” for PLHIV in many cases, and it is possible that the HCP does not know what questions to ask to get a full picture of an individual's health

status. To manage the treatment for PLHIV beyond viral suppression, it is necessary to gain a good understanding of the various issues that this population may experience at an earlier age than the general population²⁷, including issues such as HIV itself and related stigma. To gain an understanding of these issues requires a focus that includes the patients' perceived health concerns, rather than solely considering the side effects of drug treatment, while acknowledging that it can be difficult to distinguish if an issue is related to ART, or an effect of HIV, comorbidity treatment, or part of the natural aging process.

Adopting a multidisciplinary approach to patient care

A patient's treatment plan may be best managed by multiple HCPs and this has been linked to improved clinical outcomes²⁹. The treatment approach should consider whether the patient is more effectively managed within primary or secondary care, and whether to utilize one specialist or many who work together in a network. Another consideration would be the emotional needs of patients who may wish to have one principal HCP to whom they divulge sensitive information. Various HCPs may be involved in managing comorbidities, sexual or reproductive health issues, and psychosocial health such as insomnia and depression, or experiences with HIV-related stigma³⁰. This requires coordination of the treatment plan and cross-specialty working, with open channels of communication.

Improving patient engagement

Given the increasingly restricted nature of health-care systems, both in term of finances and consultation time, patients should be encouraged to participate fully in their own treatment plans. Moreover, better patient engagement has been shown to have a beneficial impact on treatment adherence leading to improved clinical outcomes³¹, and many patients themselves desire active engagement in their care³². Further investigation is required to better understand the needs of PLHIV and to support a change in their behavior so that individuals are engaged, educated, and empowered to achieve long-term healthy living with HIV for themselves³³. Many patients may be regarded as experts in their own condition, and their knowledge has been used in hospital clinics, thus strengthening the working relationship between the PLHIV and the HCPs³⁴.

A vision toward achieving long-term healthy living with HIV

Individualized approach to patient care

Our vision is based on a personalized approach to the treatment of each individual living with HIV, regardless of socioeconomic status or geography. Current guidelines allow for some individual treatment choices, for example, the EACS guidelines⁶ include a section on assessing HIV-positive persons' readiness to start and maintain ART. Advances in ART enable the use of research evidence and clinical expertise to guide individualized care toward long-term healthy living with HIV^{6,26}. In addition, HCPs require information about each patient's circumstances, goals, values, and priorities to gain a full understanding of the objectives for each PLHIV as they live longer and more fulfilled lives. We suggest adopting a collaborative and proactive approach to health assessment and therapeutic decision-making, underpinned by mutual responsibility and understanding between the HCP and patient.

The “health goals for me” concept

Our “health goals for me” concept is an expansion of the WHO's perception of “healthy aging,” described as the process of developing and maintaining the functional ability that enables well-being into older age³⁵. Although the concept is primarily focused on healthy aging, it is also applicable to younger PLHIV with issues that include many social and psychological factors, sex, HIV disclosure, risk/harm reduction with “chem-sex,” and HIV-related stigma as well as the prevention of multi-morbidity and diseases related to aging.

Our vision goes beyond the “goal for all” (once viral suppression is achieved), to the long-term goal of healthy living with HIV (i.e., the “health goals for me” concept; Fig. 1). The “health goals for me” concept is seen as part of the solution to meeting the “fourth 90” target for achieving a good QoL for 90% of PLHIV and encompasses all relevant health-related issues. To achieve this, we suggest a framework for assessing health-related QoL for PLHIV which is aimed at managing health rather than just disease.

Proposed framework for the assessment of health-related QoL for PLHIV

Our framework is designed to facilitate HCPs and patients working together, encouraging shared respon-

sibility, and ensuring that the objectives of both parties are considered in a continuous cycle of: (1) ask and measure; (2) feedback and discussion; and (3) intervention (Fig. 2).

Asking the right questions and measuring health data

This initial step comprises multiple elements in addition to the basic measurement of health data.

Engage the patient

A proactive approach is required from the HCP to engage the patient in this process. For example, some patients highly rate their medications but may, at the same time, experience many other health-related problems or concerns. In our experience, we have come across patients who have been taking the same medications for a very long time, but who are unaware that there may be a problem directly or indirectly related to their current medications. On the other hand, the patient may not have any problems with their medications, but the HCP still needs to engage him/her in the clinical visit and the “ask and measure” phase. It is the responsibility of the PLHIV and the HCP to work as a team to uncover and explore these issues. Levels of engagement will vary depending on the individual; therefore, it is important that flexible and adaptable mechanisms are in place to collect this type of information.

Use appropriate questioning

Asking appropriate questions will facilitate the assessment of each PLHIV's health and lead to effective therapeutic decision-making. The HCP should record all symptoms and concerns experienced by the patient, in addition to their medication and any other factors that may be affecting their well-being. A multi-dimensional approach should be taken, including the consideration of all aspects of the patient's life. In conjunction with disease parameters such as CD4+ cell count and viral load, the patient's mental health, social and sexual relations, experiences of HIV-related stigma, and any other aspect that the patient considers relevant should be considered to build an overall picture of their full health status. In some cases, there are validated questionnaires in place to record this type of information.

Where there are multiple issues to address, patients and HCPs should work together to determine a mutu-

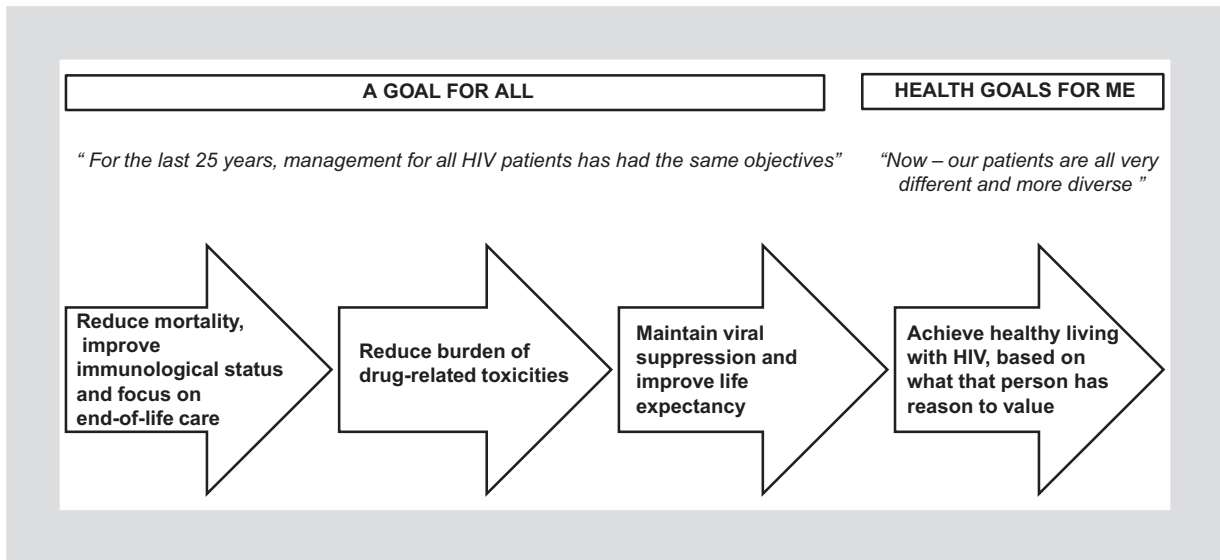


Figure 1. Healthy living with HIV: “Goal for all, health goals for me” concept.

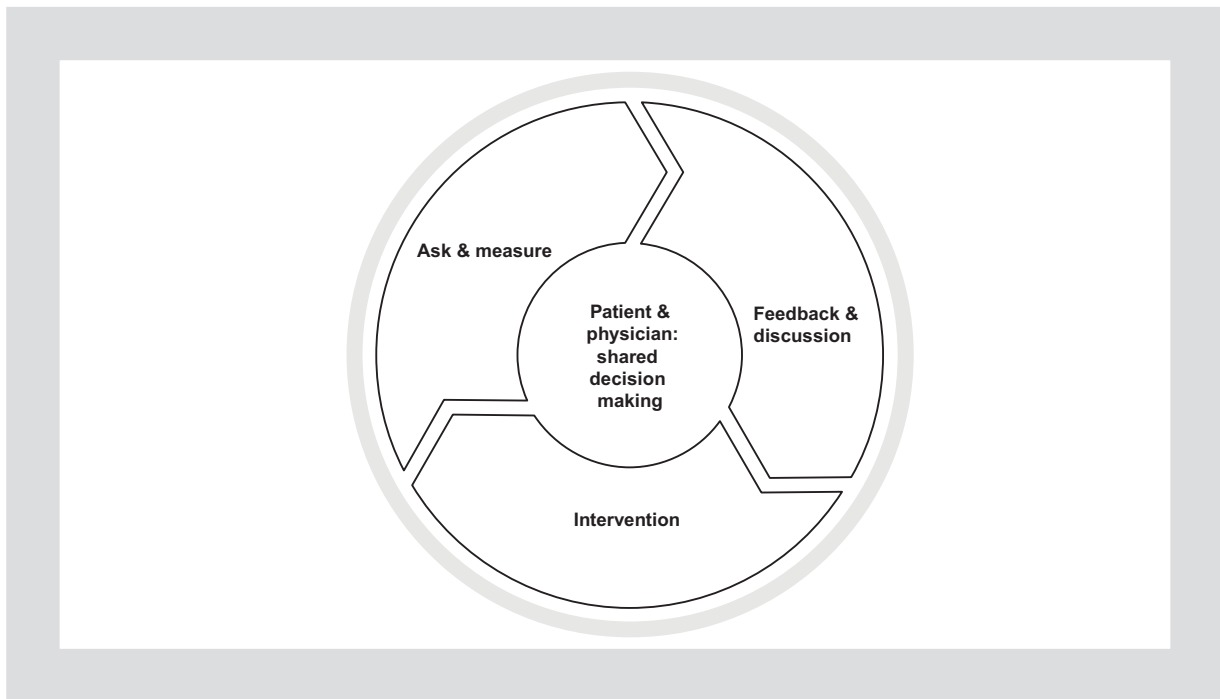


Figure 2. The proposed “health goals for me” tool is a continuous cycle involving the patient and the physician at all stages of the process.

ally agreed hierarchy for addressing the patient’s needs, with understanding on both sides of how this may impact therapeutic decision-making.

PLHIV and physician preparation for the consultation

Patients should be encouraged to bring information to the consultation that would otherwise not be available to the HCP. At present, additional information may

include new symptoms and ART or additional medications prescribed by other HCPs. It may also encompass changes in the importance of symptoms since their last appointment; for example, increasing concern with reproductive or sexual health, or recent experience of HIV-related stigma. Not all patients will have the same experiences with such issues, and therefore cultural, social and health-care system issues should be taken into account as part of this pre-consultation assessment. The ideal broader scope should include

social circumstances, financial problems, psychological stresses, and any other relevant information which may not normally be covered in regular consultation. It is recommended that this information is gathered at least annually by the individual and recorded in clinical practice by the HCP. Information can be effectively collected by completion of a pre-consultation questionnaire. The role of technology and e-health should be considered to facilitate this process and empower patients, as some health-care systems become increasingly digitised³⁶. Some initiatives are already available that empower patients to manage aspects of their own care alongside their physicians (e.g., My Smart Age with HIV [<https://www.mysmartage.org/>]; the Happi App [<https://happiapp.eu>]). It is essential that processes are put in place to ensure the privacy of personal health data³⁷ and information governance should be addressed.

In addition to the patient preparing for a consultation, ideally, the HCP should also review the responses to any pre-consultation questionnaire before the clinic visit to understand the potential complexity of the consultation. In the interests of time, a summary report of the patient's answers may be prepared for the HCP to review at the start of the consultation. This will enable the HCP to identify the most appropriate questions to ask during their assessment of the individual's health status and to select the appropriate therapeutic instruments before meeting the patient.

Sharing feedback and discussion of management options

The second part of the continuous cycle relates to sharing feedback and discussing the available management options. The HCP is encouraged to share information with the patient, while continuing to encourage the patient to share any relevant information, thereby empowering the patient and helping them understand its relevance to the most appropriate choice of intervention. A PLHIV may be uneasy about divulging information about their situation and may not understand the importance of making changes to their lifestyle or their therapeutic regimen. The process of asking the right questions, measuring the individual's health data and then feeding back to the patient should be continuous throughout long-term care. This is an important part of the cyclical nature of the framework since, as PLHIV become more aware of their own health data and see the impact it has, they are more likely to share it with their HCP and

make meaningful changes to their lives. Thus, this second step of the "health goals for me" framework is achieved by shared collaboration and is designed to empower the patient.

Intervening to achieve long-term healthy living

Finally, the intervention step of the continuous cycle will enable the HCP and PLHIV to agree on common goals and the hierarchy of interventions, to achieve long-term healthy living with HIV, based on the questions, measurements, and feedback provided. The HCP should lead discussions about what has been measured and the reasons why to allow the patient to be involved in the choice of intervention. It is envisaged that the patient will have greater input regarding the lifestyle changes that they can manage, while the HCP would advise on potential interventions including treatment change, lifestyle adaptation, counseling, and specialist referral. Some patients will naturally feel more empowered and confident than others in this process; however, it is the role of the HCP to understand the extent to which the patient is willing and able to be involved and to subsequently identify how to support them to live healthily with HIV. The end result should be a balance between the patient's perspective based on personal experience and the HCPs knowledge leading to effective decision-making.

Future perspectives

Further work is needed to implement this framework in the real-world setting and to make this vision of long-term healthy living with HIV a reality. This includes defining good health-related QoL for PLHIV, ideally in both an objective and subjective manner to know what to measure, identifying which areas to assess an individual's health status beyond viral suppression, and designing patient-reported outcome questionnaires or other tools to address each of these areas. A strategy to implement such tools may enable a shift away from the slowing or "plateauing" seen in the rate of decline of the global AIDS epidemic. Any such tools should be validated in PLHIV and should incorporate flexibility by taking into account an individual's age or other factors. The use of e-health to facilitate long-term healthy living with HIV may be advantageous, and new technologies may be utilized for capturing patient-reported outcomes, which may be of particular use in resource-limited

settings in both developed and developing countries³⁶. Empowering the patient in this way may help relieve the time and resource constraints on health-care systems. Ideally, any further work should be adopted globally to help guarantee access to treatment and long-term disease management for every HIV-positive person.

Conclusion

We present a vision for the future of HIV care which is focused on achieving the “fourth 90,” a target relating to achieving a good health-related QoL for 90% of PLHIV. Our vision recognizes the increasing diversity and aging of the HIV-positive population and emphasizes the need for a shift from focusing on HIV disease only, to centering on long-term health. The authors advocate adopting a multidisciplinary approach to improve patient care for PLHIV. Importantly, it is critical to empower HCPs and PLHIV to collaborate and mutually agree on individual objectives for care based on a continuous cycle of sharing information. In support of this approach, we present the “health goals for me” framework as a useful tool to move forth toward achieving long-term health and well-being of PLHIV globally.

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Conflicts of interest

Dr. Giovanni Guaraldi reports personal fees from Janssen, grants and personal fees from Merck, grants and personal fees from Gilead, grants, and personal fees from ViiV Healthcare; Dr. Joop Arends reports advisory board fees from Gilead, Janssen, ViiV Healthcare, and MSD, outside the submitted work; Dr. Thomas Buhk has nothing to disclose; Dr. Mario Cascio reports personal fees from Janssen; Dr. Adrian Curran reports personal fees from Janssen; Dr. Eugenio Teofilo has nothing to disclose; Dr. Guido van den Berk has nothing to disclose; and Dr. Christian Verger has nothing to disclose.

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