Ageing with HIV: toward a lifecycle approach
Brief Summary Report

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Executive summary

The Ageing with HIV project sheds light on the challenges that emerge from the increasing number of people living longer with HIV, facing new and poorly understood issues that still require further research and policy dialogue. Overarching themes identified by all stakeholders include mental health, stigma, and discrimination, especially toward key and vulnerable populations. Some of the general issues include multi- and co-morbidity, poly-pharmacy and the need to switch service delivery from a single disease to a holistic model. For adolescents, key concerns include disclosure, family dynamics and the inability for adolescents to access HIV testing, sexual and mental health services, drug treatment and harm reduction and PrEP without parental consent. Meanwhile, for PWHIV over 50 years old, comorbidities related to mental

health, drug abuse and increased suicide risk seem to be the most pressing issues for research, service delivery and policy dialogue.

In addition to providing a better understanding of this new set of challenging issues, the project highlighted the need to allocate more resources for further consultation and continued funding to allow long-term follow-ups of cohorts ageing with HIV. Further consultation building on community expertise in HIV and ageing and multi-morbidity is underway, with the ultimate goal to enact a shared research agenda informed by the project and to inform a review of international guidelines and clinical practice.

The project

This brief summary report provides an overview of the key issues highlighted during the proceedings of the Ageing with HIV project, led by the European Aids Treatment Group (EATG)[1] between 2015 and 2018. The initiative aimed at better understanding the current needs of people living and ageing with HIV, as well as assessing how to contribute to the development of more focused responses for this population. The project addressed the challenges and unmet needs of people living with HIV (PLHIV) *from a life cycle perspective*, looking at different age groups from children and youth to the elderly.

How ageing and HIV are related is an area we are just beginning to understand. Thus, to address this new emerging issue and mostly uncharted territory, three face-to-face conferences were organized within the framework of the project. The three events took place in different European cities, followed by thematic webinars and social media interactions (messages via Twitter and Facebook). A dedicated website https://www.ageingwithhiv.com/ was also established.

Overall, 286 participants from 30 countries took part in three face-to-face consultations; ,each focused on a different age group, 1) PLHIV aged 50+, 2) children and adolescents aged 0-25, and 3) people aged 18-50 living with HIV for at least ten years. An additional 37,900 people engaged through the website and social media. The target audience of all these events was a mix of community, researchers, healthcare providers, and other key stakeholders.

Background

For a long time, the history of HIV has been that of young people dying at their prime and children born with an infection that will prevent them from reaching adulthood. After the introduction of Highly Active Antiretroviral Therapy (HAART) in the late 1990s and especially after the massive scale up that took place during the following decade, long-term survival has become part of a

[1] EATG is a member-led network of more than 180 volunteer activists, most of them living themselves with HIV, and based in 47 countries across Europe and Central Asia, has been at the front of activism in Europe for the past 25 years in collaboration with many European and international partners

new picture in which the demographic profile of people living with HIV is shifting to even older ages.

According to the latest UNAIDS data[2], 5.8 million people living with HIV, accounting to 16% of the 36.7 million people living with HIV worldwide, are aged 50 or older. This is a sharp increase from 2014, when 4.2 million people, accounting to 13% of the adult population living with HIV, were aged 50 or older[3].

As more people living with HIV become older, their needs and concerns are gradually shifting from HIV to mental health, sexual health, hepatitis B or C, TB and other long-term diseases, including heart, lung, bone, and skin conditions. Ironically, the pill burden that decreased dramatically since the introduction of HAART is likely to increase again to respond to age-related co-morbidities (e.g., statins for high cholesterol and angiotensin-converting enzyme inhibitors for high blood pressure). This represents just one of many emerging issues affecting an ageing population of people living with HIV.

Ageing and HIV – key elements

Evidence presented during the project outlined that the increasing elderly population living with HIV in Europe belong to two main groups: those diagnosed early in the history of the disease who are now ageing with HIV as a chronic condition and those diagnosed with HIV in older age.

This is resulting in an increasing population of people living with HIV who are experiencing co-morbidities and co-infections. Some are a direct consequence of HIV, while others are related to natural ageing or the ageing-related social and psychosocial barriers due to stigma and social exclusion.

Researchers consulted during the Ageing with HIV project demonstrated how this is likely to increase the complexity of care management, demanding a change in the delivery of existing services. **There should be a shift from a single disease management model into a multi-dimensional approach to care**. Many of the project participants emphasized how differing health and social care systems complicate the new issues faced by an ageing population of PLHIV.

Long-term survivors of HIV have been through the traumatic early days of death, stigma, social exclusion and discrimination. To a different extent, they are all dealing with post-traumatic stress, including self-internalized stigma. Living longer comes with additional stress and potential consequences such as multi-morbidities and uncertain future care options from health and social care providers.

[2] 2017 Global HIV statistics, UNAIDS

[3] GAP Report 2014, UNAIDS

Depression, anxiety and other associated mental health conditions are common co-morbidities of all chronic illnesses including HIV infection. All of these conditions imply particular challenges to clinical care for all groups with HIV, and are linked to medication adherence, drug abuse, ability to engage in self-care, quality of life issues and biomedical outcomes with an increased risk of suicide (particularly with men having sex with men (MSM) and transgender).

Some of the potential solutions to address these challenges include integrated health and social care systems, community based peer-support services that inform clinicians, social care and other key actors working on the needs and rights of PLHIV as they age- regardless of their gender, ethnicity or sexuality. Arrangements for housing and employment for those who are left without and mental health support for those needing it are also key elements in addressing the needs of ageing PLHIV.

Clinicians participating in the Ageing with HIV project demonstrated that a thorough use of assessment tools, preventive interventions and rehabilitation techniques could improve the quality of life for those over 50 and ageing with HIV. **Information and training are also of key importance**. As the history of the epidemic has taught us, educated and empowered PLHIV are more likely to take responsibility in significantly reducing the risk factors for co-morbidities that are likely to affect their quality of life and mental wellness such as smoking, obesity, drug and alcohol abuse. In addition, educated and empowered PLHIV are more likely to become equal partners in the various models of care.

According to some, given that we now have a good range of treatment options that succeed to suppress viral load and with less side effects, spending resources on finding new treatment may be unnecessary and therefore it is better to invest in cure research. Others suggest that ageing is substantially different among people living with HIV and that there are important issues impacting adherence and the quality of life of PLHIV. This offers unique opportunities for **new scientific and clinical research** that might potentially provide important insights into the broader phenomenon of ageing.

Growing up with HIV

Young people living with HIV highlighted the difficulty of dealing with their sexual health. For many the trauma of rejection due to disclosure to partners makes it hard for young people to form relationships. All participants emphasized how an open and honest interaction with children and adolescents from the moment of diagnosis is essential to empower children and young people to self-manage their care. In turn, this will lead to adherence to medications and self-acceptance. HIV is part of the story of these children and young people but does not represent the whole picture. Psychosocial, mental health and general well-being issues are equally important. Access to support throughout the transition into adult services affects a young person's long-term health and well-being.

Among the recommendations to policymakers is the need to engage young people in the design of guidelines and repeal laws that affect their rights. This includes parental consent to prevention measures such as access to needle and syringe programs, sexual health and other services that still require parental consent. While parents need to be educated and adequately supported, all possible measures should be put in place to avoid situations in which they can potentially become a barrier to the right to self-management and self-determination of those living with HIV, irrespective of their age.

This means striking a balance between protecting young people from harm while they develop the ability to take full responsibility for their actions, decisions and their right to self-determination.

Key populations living with HIV

The projects covered a number of issues relating to groups and populations living and ageing with HIV that do not fit the stereotypical image of HIV and are still grossly under-researched.

Transgender people, in particular, present higher risks of poor physical health, disability, depression and perceived stress compared to their LGB counterparts. Trans people globally are amongst the most brutalized of all marginalized communities with a few countries outlawing transgender men and women altogether. Many communities endure systemic transphobia and health and social systems are often poorly tailored to meet their needs.

Criminalisation and discrimination of sex workers in Europe remain key issues with many countries imposing laws on prostitution based on the Swedish model that makes it illegal to buy sex, but not to sell the use of one's own body for such services. In the Netherlands and Turkey, sex work is legalized but in Turkey, only cis[4] women can work in brothels whilst all the other groups are criminalized. Many are discriminated in health settings and are unable to access treatment.

People who use drugs are by far one of the most criminalized and stigmatized communities, facing unnecessary incarceration for victimless non-violent offenses, police brutality and widespread violations to their right to health, including the failure to provide them with adequate drug dependence treatment and essential medicines for pain relief. This situation has led to the marginalization and social exclusion of people who use drugs, pushing them away from jobs, education and other health and social services. The prevalence of HIV and other blood- borne diseases, such as tuberculosis and viral hepatitis, is particularly severe among people who use drugs.

[4] Cisgender: people whose gender identity matches the sex that they were assigned at birth

The absolute number of women living with HIV is also increasing in Europe. However, there are no studies in Europe on the effect of menopause and HIV. Yet, women can expect to live 40% of their lives post-menopause and may spend 10% of their lives with menopausal symptoms. Of particular concern is the invisibility of older women in migration. The almost complete lack of understanding about their experience and their needs increases their isolation and vulnerability with some women experiencing gender-based violence and sexual abuse.

Conclusions

While death rates have gone down with AIDS, deaths from cancer, coronary heart disease, and other co-morbidities are on the rise. The incidence of liver disease rapidly goes down in the over 70s age range, but liver damage from hepatitis C worsens with ageing. Some ARVs have an impact on the liver, and other medicines interact with drugs associated with age (DAAs, statins, proton pump inhibitors, anti-depressants, cardiovascular drugs). Due to these multiple co-morbidities, significant risks as people age are polypharmacy, drug-drug interactions and drug toxicity, which in turn affect pharmacokinetics and pharmacodynamics.

The Ageing with HIV project showed how complex and challenging the intersection between ageing and HIV is, emphasizing the need for a more coherent community-led and community-informed research agenda. According to participants and experts participating in the project, countries should be encouraged to develop quality of life outcome indicators that go beyond viral suppression while placing PLHIV in control of the long-term management of HIV and co-morbidities associated with ageing and HIV.

A more holistic and person-centred approach to care that integrates health and social systems, peer support services and up to date technology will be essential for developing a lifecycle approach to HIV. This new approach should obviously take into account biomedical markers, but also the impact of poverty, homelessness, gender-based discrimination, social exclusion, and isolation. If we are serious in reforming health systems towards person/patient centred care, then policy-makers, those designing health professional trainings and medical professional will need to collaborate with PLHIV.

ANNEX

Indicative recommendations from EATG Ageing with HIV project 2015-2019

This annex brings together the recommendations that emerged from the EATG Ageing with HIV project stakeholders' consultations, needs assessment and collection of best practices performed via three conferences, a series of webinars and a community focus group from 2015 to the end of March 2019. The project took a life cycle approach by investigating the issues faced by PLHIV at different periods of their lives: 1) people living with HIV/AIDS aged 50+, 2) children and adolescents (aged 0-25) and 3) people who have lived with HIV/AIDS for at least 10 years (aged 18 to 50). The list of recommendations is organized per stakeholders and the recommendations outlined are indicative – i.e. these do not constitute the position of EATG per se.

1. Recommendations to all stakeholders

a. Address mental health and psycho-social issues of isolation and depression
b. Address stigma and discrimination in healthcare and in general
c. Share information the message of the Undetectable=Untransmissible paradigm
d. Adopt a 'holistic' view on health and a multidisciplinary approach to care provision and addressing non-medical/ social aspects of quality of life
e. Address the specific needs of key populations, including groups that are not well served by the health system
f. Involve communities in design, implementation and evaluation of programmes, reform process

2. Recommendations to PLHIV, Community and civil society organisations

a. Get involved in or even lead discussions on delivery of HIV long-term care
b. Provide input into the design of patient reported outcomes measures (PROMs)
c. Organize for peer support in care management and navigation across the health system
d. Include key populations as peer mentors
e. Collect evidence on how the benefits peer-to-peer approach for improved health outcomes
f. Developing tools for enhancing patient health/treatment literacy on comorbidities prevention, treatment and management, polypharmacy's impact, drug-drug interactions, toxicities
g. Support adherence, long-term HIV management literacy among young people, support of women during perinatal and antenatal care, preconception and transition into adult care
h. Educate and inform professionals and peers on PrEP, PEP and other preventative methods and press for implementation of guidance.

i. Advocate legal and regulatory reform to remove barriers to prevention, treatment and care and build alliance across groups and sectors
j. Advocate for funding streaming including targeted actions to address the needs of key populations.
k. Campaign on TB as an overlooked condition with human rights implications and added complications
l. Build partnerships across Europe to seek access to Hepatitis B vaccines and treatment of Hepatitis C
m. Campaign to reduce stigma and discrimination for key populations and groups; targeting health and social care professionals especially dentists, nursing home care, care in the home (using evidence from Stigma Index, for example).
n. Inform and support community involvement in CURE and vaccine research
o. Build advocacy partnerships with patient groups in other disease areas to advance the patient-centred approach in health care
p. Engage with EACS and/or WHO on reviewing guidelines

3. Recommendations to health professionals and health services managers

a. Organize for doctor-patient dialogue and partnership on quality of life issues
b. Engage PLHIV and key populations in the design, implementation and evaluation of services to improve self-management and long-term care
c. Improve support to children transitioning in to adult care
d. Design and implement training on people-centered care in collaboration with the communities
e. Address comorbidity prevention, treatment and management in long-term HIV care beyond viral suppression
f. Implement Patient Reported Outcome Measures (PROMS) into clinical practice and research
g. Enhance knowledge on HIV in various specialities and in primary care
h. Improve communication between health specialists for integrated and patient-centred care
i. Increase rehabilitation to improve the functioning of older people with HIV, to address many different conditions such as heart disease, frailty, diabetes, etc
j. Educate and inform professionals and peers on PrEP, PEP & other preventative methods
k. Use technology where appropriate to give PLHIV greater control of the management of their health conditions and communication with clinicians
l. Increase awareness of and empowerment to address intimate partner violence (IPV) to reduce stigma, isolation and improve well-being

4. Recommendations to medical professionals and bodies issuing guidance (clinical societies, professional associations, WHO)

a. Increase comorbidity screening within PLHIV

b. Encourage TB screening using LAM tests and treat accordingly
c. Promote more targeted cervical and anal screening
d. Screen PLHIV for HPV who are beyond the age vaccination and treat pre-cancerous lesions to prevent progression to cancer
e. Improve screening and treatment on women and frailty / osteoporosis
f. Encourage HPV vaccination between 9 – 26 years of age to be gender neutral to reduce the risks of anal and cervical cancers
g. Update and consolidate guidelines: e.g. Eliminate dental fungal and bacterial infections or other diseases of the mouth associated with HIV, TB/HIV care
h. Professional associations to address stigma and discrimination by adequate information provision, training and monitoring of nursing/ home care

5. Recommendations to national authorities

a. See recommendations to guidance issuing bodies
b. Monitor health and social outcomes of PLHIV as well as quality of services
c. Support the development and implementation of integrated care models that bring together health professionals, social care and community and peer support services
d. Involve PLHIV and key populations in programme design, implementation and evaluation
e. Ensure that programmes respond to the specific needs of sex workers, people who inject drugs, gay men and other men who have sex with men, transgender people, migrants, refugees and people in detention
f. Remove policy and rregulatory barriers to universal access to prevention, testing and linkage to care.
g. Support community services /peer support programmes as part of the health system
h. Integrate testing for related infections as relevant
i. Integrate rehabilitation in HIV care
j. Support the development and provision of respite care for the elderly living with HIV
k. Support the development of suitable housing options for the elderly living with HIV where needed
l. Ensure access to HBV vaccination and HCV treatment

6. Recommendations to bodies commissioning research and researchers

a. Developing monitoring and screening tools targeted for ageing PLHIV
b. Include elderly PLHIV across key populations in clinical research
c. Address HIV and ageing related co-morbidities e.g. neurocognitive impairment, heart disease, frailty, diabetes
d. Address interconnection of mental wellbeing and health outcomes and implications
e. Examine drug-drug interactions – (prescribed drugs, over the counter medicines and recreational drugs)
f. Simplify pediatric treatments and create new and better options

g. Fund/support the conduct social research on different non-medical aspects of quality of life
h. Examine rehabilitation to improve the functioning of elderly people with HIV
i. Support community to be involved with vaccines and cure research