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SEXUAL HEALTH

Let's talk about U=U: seizing a valuable opportunity to better support adolescents living with HIV

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ABSTRACT

The clinical knowledge that people living with HIV who maintain an undetectable viral load and therefore cannot transmit HIV sexually, known as Undetectable equals Untransmittable (U=U), has reached a critical mass of adults, but it is relatively silenced within adolescent HIV care and support. We argue that understanding the full range of opportunities enabled by viral suppression, including the elimination of transmission risk, could transform adolescents' understanding of living with HIV, incentivise optimal treatment engagement and support and sustain their positive mental health. However, the reluctance to discuss U=U with adolescents means that we are not providing them with adequate access to the information and tools that would help them to succeed. We need to recognise, value, and invest in the mediating role of building viral load literacy, illustrated by conveying U=U in ways that are meaningful for adolescents, to accelerate viral suppression. Rather than protect, rationing access to information on U=U only increases their vulnerability and risk to poor HIV and mental health outcomes.

Keywords: Africa, community interventions, HIV/AIDS, HIV literacy, living with HIV, mental health, wellbeing, youth.

Introduction

HIV can be suppressed with effective treatment to become undetectable, thereby preventing onward transmission and preserving good health. This has prompted a radical recalibration of what it means to live with HIV.[1–4] The clinical knowledge that people living with HIV who achieve and maintain an undetectable viral load cannot transmit HIV sexually, known as Undetectable equals Untransmittable (U=U),[1,2,5,6] has reached a critical mass of adults since the 2016 consensus statement was endorsed.

However, it is relatively silenced within adolescent HIV care and support. What being virally supressed can achieve for adolescents, including in supporting their mental health, is often left unsaid in conversations around adherence. Explanations of the eliminated risk of onward transmission when the virus is undetectable tends to be withheld until an individual reaches young adulthood.

An influential trend in the global HIV response has been the increased recognition of the role of mental health in mediating treatment engagement and virological outcomes, especially for adolescents.[7,8] Despite this, there are commonly significant gaps in the support and information that is provided to them.[9] We argue that understanding the full range of opportunities enabled by viral suppression, including the elimination of transmission risk, could transform adolescents' understanding of living with HIV, incentivise optimal treatment engagement and support and sustain their positive mental health. Given the comparatively poorer outcomes across the HIV cascade among this age group (10–24 years), failure to provide developmentally appropriate messages on viral suppression, including U=U, within routine HIV service delivery and psychosocial care squanders a valuable opportunity (and right) for this group to benefit from this clinical understanding.

In our reluctance to share optimistic messages about viral suppression and U=U, we risk failing those navigating their emerging sexuality by not providing them with access

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to information to contest the shame and stigma so often experienced by adolescents living with HIV. We are similarly falling short in supporting younger adolescents by withholding information that might ignite alternate imaginings of their future.

Discussion

The transformative effect of U=U: what it can do

Where U=U has been widely promoted, predominantly among adult sexual minority men in high-income settings, improvements in mental health, self-acceptance, and enhanced engagement in care have been promising.[10] Recent trials in Southern Africa are having similarly positive results.[11,12] Awareness of the U=U message, combined with engagement in regular viral load monitoring, can alleviate anxiety and fear of onward transmission, which can have a positive effect on sexual pleasure, reduce self-stigma and improve well-being.[13] Yet, although there is an emerging recognition of the opportunities of the U=U message to influence stigma,[14–18] we have not yet invested in explaining and supporting the development of viral load literacy across a wide-range of populations and age groups. How U=U is represented, if at all, in provider–client conversations has been shown to be heavily influenced by providers' stigmatising attitudes towards some groups.[19] As such, there is a call for U=U to be discussed in all routine clinical interactions between healthcare professionals and all people living with HIV.[10,20,21]

Why access to U=U information is so critical for adolescents

Adherence is situated within a complex knot of concerns within an adolescent's life and is often subsumed by other priorities.[22–25] We argue that adherence support should explicitly orientate towards realising the benefits of viral suppression. These discussions should align with adolescents' concerns, by explaining what being virally suppressed would mean for their energy levels, sporting ability, skin, growth and height, school attendance, relationships, and transmissibility to partners and future children, all of which coalesce to enhance the possibility of a fulfilling present and future life. The prospect of viral suppression, even before it is achieved or sustained, can have a profound effect on how an individual imagines the consequences of their condition: potentially alleviating the pressures on their mental health and operating as an accelerating agent in incentivising adherence as a mechanism to achieve suppression.

Given the relative absence of discussions about U=U with adolescents within programmatic care and support, there is unsurprisingly scant evidence exploring this hypothesis. However, in a World Health Organization (WHO) global consultation, led by the authors, with 388 adolescents living with HIV (aged 10–24 years) from 45 countries, the influence of fuller knowledge about viral suppression, including U=U, was shown to have a profound effect on individuals' well-being and the management of their HIV status, including internalised stigma. This was a mixed methods consultation, integrating quantitative and qualitative data collection and analysis approaches. A structured questionnaire with 36 fixed and open text questions was administered online and available in five languages (English, French, Spanish, Portuguese and Russian) to capture a wide range of opinions of adolescents living with HIV from across different settings, regions, and target groups.

We drew on a well-established and extensive network of organisations working with adolescents and young people living with HIV to facilitate a broad reach across regions to ensure that the perspectives of young people from different communities were heard. Specifically, but not exclusively, this included collaborating with Y+ Global, Zvandiri and Paediatric - Adolescent Treatment Africa (PATA), as well as the WHO's Adolescent Service Delivery Working Group, to ensure that the online questionnaire was disseminated widely and actively within their networks of young people.

Responses were translated into English where required and both the quantitative and qualitative data were analysed inductively and deductively using thematic content analysis. Nine focus group discussions (FGDs) were also conducted with 61 of the survey respondents aged 14–24 years. Flexible topic guides were developed from preliminary analysis of the online questionnaire data. Due to the coronavirus disease 2019 (COVID-19) physical distancing restrictions in many settings at the time, these discussions were primarily conducted online, with a small number conducted face-to-face. The FGDs were recorded, transcribed, translated, and thematically analysed to generate insights into the diverse values and preferences of participants from a range of settings. The broad themes of this consultation have been represented in two short films, accessible online.[26,27]

The consultation highlighted that participants tended to have very low viral load literacy and lacked awareness of the effects of viral suppression, including on transmissibility.[6,28] Young people argued that if elevated viral loads are caused by suboptimal adherence behaviour, then viral load testing needs to be used deliberately to enable, support, and sustain behaviour change. For this behavioural effect to occur, young people need to have a foundational understanding of what viral load results indicate. This includes being provided with the information necessary for them to accurately grasp the meaning of viral suppression and being 'undetectable'. Most of the young people's experience of viral load counselling and support is currently uneven or even thin in standard of care, as an indicative quote from a young person from India shows:

> They are not provided counselling or information about their results. Instead, they are just handed results and

the healthcare worker says there is 'no problem' and so they misinterpret what suppression means.

Although rare within this cohort, there were a few young people who had encountered more comprehensive information about viral suppression and U=U. They described the powerful effect it had on them personally, suggesting that it had shifted the narrative and meaning of what it meant to live with HIV. A young person in Zimbabwe described the power of understanding viral load results for him and other young people. He described how this knowledge can be harnessed to incentivise improved and sustained adherence behaviour to achieve the goal of viral suppression:

> That sense of owning it, having a full sense of control of the virus. If he gets a suppressed viral load, it gives a sense of victory over the virus. Though it is in my body, l can still control it. If one is aiming for an undetectable viral load, it will be a goal and with motivation one feels that they can achieve it and the adolescent will really work hard to achieve the goal knowing that the virus, though it's in my blood, it can never control me.

The response from a young man in Chile illuminates the transformative potential of understanding U=U, as he reflects on how this knoweldge affected him:

> Happiness, I think. When they told me and explained to me what it meant (being undetectable), my mind was dancing (laughs). I was very happy.

The sense of relief, joy, and empowerment expressed in this quote demonstrates what was unlocked by access to this message. However, he only found out once in his early 20s. It begs the question, what impact would earlier access to this message have on how adolescents grow up with HIV?

Why are adolescents not told?

Three major intersecting factors influence the absence of U=U in conversations with adolescents. First, the long-standing and pervasive denial of adolescent sexuality in most settings silences the preventive health measures designed to limit risk. Comprehensive sexual health education, including affirmative consent, is commonly restricted for fear that access to information would encourage adolescent sexuality.[29] It is likely that promoting discussion about U=U with adolescents is attracting resistance for similar reasons.

Second, there is an implicit lack of trust in adolescents to use sexual health education information responsibly. In the case of U=U, the possibility that, in the context of wavering or intermittent adherence, seropositive adolescents will abandon other preventive options introduces an element of risk, adding further reticence to an existing reluctance. This echoes examples of healthcare providers withholding U=U messaging from their adult clients due to their own judgemental attitudes about some groups.[19] When similar paternalistic concerns have been voiced previously, such as fears that treatment as prevention (TasP) and pre-exposure prophylaxis (PrEP) would cause complacency among men who have sex with men, these have not eventuated. Although there is a need for caution, we argue it should not impede adolescents' right to access vital clinical information to better understand their condition. Rather than rationing information, we should invest in the provision of consistent viral load monitoring and development of viral load literacy, the continued promotion of combination approaches to HIV prevention, as well as tailored psychosocial support to optimise adherence.

Third, healthcare providers working within over-burdened health systems are constrained by time, confidence, and capacity, which may coalesce with an existing reticence, due to the two factors described above, to initiate such conversations with adolescents. We are not investing in listening and talking with adolescents, including about viral suppression. As it is not being prioritised, such vital omissions persist, often unnoticed.

Equipping adolescents to succeed

The absence of discussion of U=U reflects a paradox in how HIV is often communicated to adolescents. They are often charged with an enormous moral responsibility to manage their own treatment and the social and relational aspects of their condition (e.g. complex expectations around disclosure). Yet, illogically, they are not trusted to use information about the elimination of transmissibility wisely because they are commonly cast as inherently 'irresponsible'.

The transition during adolescence towards greater individual responsibility is recognised as contributing significantly to adolescents' poor mental health.[9] Developing knowledge about the condition one is living with, and tasked with managing, facilitates the necessary agency and empowerment for adolescents to live well.[30] Fulfilling their right to access critical information, including U=U, can support this transition towards primary responsibility, with subsequent positive effects on mental health.

An enormous opportunity created through viral suppression, and U=U, is recognising an individual's capacity to effectively manage their HIV so that it barely constrains their lives and choices. Explaining viral suppression can reinforce the value of sustained treatment engagement, which in turn supports ongoing positive mental health, positioning them to embrace multiple positive consequences so that they can flourish even with an HIV-positive status, as this young man from Chile describes:

> [Viral suppression is] a symbol of wellbeing, but not only a medical wellbeing but also a moment where you're happy and you can share that happiness and you feel encouraged

to feel even better about other things. So, you think, "okay, now I'll stop smoking, or I'll start eating better". When you see that the treatment works, when you start gaining weight and looking and feeling better, and when people tell you that you look better and healthier, it's a very nice feeling.

Tailoring the U=U message to meet adolescents' concerns and priorities

Global HIV policy continues to prioritise achieving sustained viral suppression (targeting 95% of those on HIV treatment). Yet, the inadequacy of current viral load counselling and support for adolescents, as highlighted within the WHO global consultation, suggests that we have overlooked the value of investing in viral load literacy.

U=U, when tailored to the needs and concerns of individual adults' circumstances and relationships, has been shown to have a hugely motivating effect, as well as reducing fear and stigma.[10] It is a fair assumption that this information, delivered responsively to meet an adolescent's needs and concerns, would have a similarly positive effect. The opportunity to further address stigma by shifting the narrative surrounding what it means to live with HIV should motivate us to find ways to share this message widely, to young people who are living with, and without, HIV.

Explaining viral suppression and U=U to adolescents should not look the same as it does for adults. Rather, we are calling for a more expansive and integrated approach within existing youth-led programming, which locates U=U within a trajectory of learning about HIV throughout childhood and adolescence. This should be responsive to their individual developmental needs and priorities, as we have successfully done to support disclosure and treatment adherence. We have begun this work by drawing on the WHO consultation findings to create accessible visual reources that can be used to develop adolescent's viral load literacy.[31,32]

Recent WHO global guidelines on adolescent HIV service delivery strongly recommend that psychosocial support be an integral component of standard HIV care for adolescents.[26] Explaining viral suppression in ways that resonate with their physical, social, and relational priorities within standardised HIV psychosocial support and counselling during clinic visits will provide opportunities for these catalytic conversations. Articulating and celebrating the opportunities offered by widespread and sustained viral suppression is potentially one of our most effective weapons to shift harmful narratives circulating within communities that fuel self-stigma, which can be so detrimental to accepting and managing one's positive HIV status.[10,13,20]

Conclusion

Understanding the opportunities enabled by being virally suppressed is a game-changer for those living with HIV and we argue has specific potential to improve adolescents' health outcomes. The WHO consultation illustrated rare moments where knowledge about viral suppression and U=U radically reoriented a young person's perspective and relationship with what it means to live with HIV. These moments were few and far between, and were often the result of incidental exposure to U=U messaging. We must ensure that knowledge about U=U is delivered deliberately and intentionally. Community-based youth-led HIV support programs have been vital in improving HIV literacy among young people and their families, and in so doing have been integral to combatting the HIV stigma that so often perpetuates adherence challenges. These spaces, which are built on principles of youth-centred differentiated care and acceptance, are the obvious place to extend conversations about U=U as a means to improve treatment adherence and reduce stigma and to celebrate the opportunities that it affords.

We need to recognise, value, and invest in the mediating role of building viral load literacy, illustrated by conveying U=U in ways that are meaningful for adolescents, to accelerate viral suppression. We must acknowledge and address the reluctance to discuss U=U with adolescents. It represents a potentially harmful withholding of a crucial piece of information that has shown to be transformative, not only among adult populations, but also among those young people with whom it has been shared. Rather than protect, rationing access to information on U=U only increases their vulnerability and risk to poor HIV and mental health outcomes.

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