



# Prioritising pleasure and correcting misinformation in the era of U=U

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There is widespread unawareness and disbelief regarding the evidence-based conclusion that people who have a sustained undetectable HIV viral load cannot sexually transmit HIV—ie, undetectable=untransmittable (U=U). Long-standing, misguided fear about HIV transmission persists; consequently, so does the policing of sexual expression and the penalisation of pleasure faced by people with HIV. Many people with HIV with an undetectable viral load have unnecessarily abstained from condomless sex, avoided serodifferent partnering, and had anxiety about onward sexual transmission due to perceived HIV risk that is now known to be non-existent. Some health professionals have refrained from correcting this misinformation because of concerns that people with HIV will engage in more condomless sex or have more sexual partners upon learning of U=U. Withholding information about U=U is thus rooted in behavioural assumptions and is scientifically unfounded. Moreover, withholding such information violates medical ethics, perpetuates health inequities, and infringes on the sexual health and human rights of people with HIV. Health professionals and the broader public health community have an ethical responsibility to actively address misinformation about HIV transmission and disseminate the U=U message to all people.

## Introduction

WHO recognises pleasure as fundamental to sexual health for all people,<sup>1</sup> but fear surrounding HIV transmission has created behavioural, psychosocial, and structural barriers to sexual pleasure for people with HIV. Scientific advancements have the potential to reduce the fear surrounding HIV transmission. Analyses of data from more than 120 000 condomless sex acts reported by heterosexual and male same-sex serodifferent couples have conclusively shown that people with HIV who have a sustained undetectable viral load cannot sexually transmit the virus,<sup>2-5</sup> a concept referred to as undetectable=untransmittable (U=U). For people with HIV, awareness of U=U can enhance sexual pleasure by facilitating HIV-protected condomless sex, reducing anxiety about HIV transmission during sex, and—for those who have previously avoided serodifferent sexual partners for fear of HIV transmission—opening up new partnering possibilities. HIV-negative individuals might likewise derive sexual pleasure from U=U awareness through increased comfort with condomless sex, reduced HIV anxiety, and increased openness to serodifferent partnering. Similar to other biomedically-based HIV prevention strategies like the use of pre-exposure prophylaxis (PrEP), access to knowledge of U=U and the use of antiretroviral treatment to achieve an undetectable viral load can increase access to sexual pleasure.<sup>6-8</sup> Additionally, knowledge of U=U might facilitate engagement in care for people with HIV and optimise medication adherence because of the added incentive of being able to have condomless sex without the fear of transmitting HIV to partners.

Despite the prospective benefits associated with U=U awareness, emerging research suggests that some health professionals anticipate and disapprove of people with HIV engaging in so-called sexual risk taking to an increased degree as a result of gaining awareness of U=U and have withheld or distorted information about HIV

transmission risk during patient interactions.<sup>9-11</sup> We argue that such responses from health professionals are not medically justifiable or morally acceptable because they perpetuate long-standing inequity in access to sexual pleasure, thus infringing on the sexual health and human rights of people with HIV. We call on health professionals and the broader public health community to help right this wrong by disseminating accurate information about U=U to people with HIV and society at large.

## Misalignment between current science and health guidance

Since the beginning of the HIV and AIDS epidemic, people with HIV have been informed by health professionals and the broader public health community that if they have sex without condoms, they risk transmitting the virus to their sexual partners. Although this information was correct when the first HIV medications were still in development and viral suppression was elusive for all except elite controllers, effective treatments facilitating viral suppression have been available to many people with HIV for decades. People with HIV have been led to believe that using condoms or altogether abstaining from sex with HIV-negative people were their only options for preventing sexual transmission, but scientists have now shown this to be untrue. Thus, many people with HIV have unnecessarily foregone condomless sex, avoided serodifferent partners, and otherwise sacrificed sexual pleasure in an effort to protect other people. When people with HIV are having sex, concern about onward transmission risk has led to cognitive preoccupation during sex and needlessly undercut sexual satisfaction.<sup>12</sup> Furthermore, inaccurate beliefs about HIV transmission held by society at large have hindered pleasure for people with HIV by propagating HIV stigma and criminalisation. With U=U now scientifically established as an effective biomedical HIV prevention strategy alongside PrEP,

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allowing such misunderstanding and injustice to persist—in essence, denying people with HIV the right to experience the same forms of sexual pleasure enjoyed by HIV-negative people, unencumbered by guilt, anxiety, and social penalisation—is unconscionable. Although missed opportunities for pleasure cannot be restored for people with HIV, future opportunities ought not be knowingly undermined by inaccurate or incomplete information. Health-care professionals have a medical and ethical obligation to inform patients about U=U and correct outdated health guidance, whether imparted by themselves or their predecessors. Beyond improving patients' health and quality of life, this individual-level intervention could support needed social and legal reforms by expanding social awareness.

At present, only a few studies have investigated patient-provider communication about U=U. However, extant research suggests that the overwhelming scientific evidence for U=U and associated revelation of flawed medical guidance have yet to compel commensurate adjustments in clinical practice among many health professionals. For example, in a study of over 2300 people with HIV from 25 countries who were surveyed in 2019–20, a third of participants reported that they had never discussed U=U with their health-care providers.<sup>13</sup> Similarly, among over 17000 US men who have sex with men (MSM) who were surveyed in 2018–19, a third reported that none of their providers had ever discussed HIV sexual transmission risk in the context of viral suppression with them or they were uncertain whether such a discussion had ever taken place. Three-quarters of the men surveyed did not report health-care providers to be a source through which they had been exposed to the U=U message.<sup>14</sup> Corroborating this evidence of inconsistency in health professionals' communication about U=U, a 2017–18 international survey study including over 500 physicians found that a third reported that they do not communicate the U=U message to their patients living with HIV who have sustained undetectable viral loads.<sup>11</sup> Such deficiencies in messaging around U=U are particularly troublesome in the face of persistent unawareness, disbelief, and misunderstanding of U=U reported by people with HIV and others.<sup>13–17</sup> Research has identified multiple reasons that health professionals are not routinely communicating about U=U with their patients, none of which are medically justifiable. These reasons include health professionals' own insufficient awareness about U=U, unfounded disbelief in U=U, and fear of patient blame for subsequent transmission events.<sup>9–11,18</sup> General discomfort with discussing sex with patients, which could be attributable in part to inadequate training,<sup>19</sup> is also likely to impede conversations with patients about U=U.

Among health professionals who are aware of U=U, another reported reason for not informing patients about U=U is anticipated changes in patients' sexual behaviour<sup>9</sup> and implications for—in the words of one provider—

“personal responsibility”.<sup>11</sup> A 2017–19 qualitative interview study in Kenya found that some health professionals refrained from communicating the U=U message to their patients living with HIV because they believed it would encourage them to have multiple sexual partners.<sup>9</sup> As one provider explained, “Sometimes, we do not tell them that their chances of infecting others is minimal because some will get loose.”<sup>9</sup> In a 2019 survey of nearly 350 midwestern US providers, attitudes varied considerably by US state; however, in any given state, up to 50% of providers agreed that patients would be more likely to engage in so-called sexual risk-taking behaviours when relying on viral suppression for HIV prevention than when not relying on it, and up to 61% of providers did not report feeling comfortable counselling patients with durably suppressed viral loads that viral suppression alone, without condoms or PrEP, sufficiently prevented sexual transmission of HIV.<sup>10</sup> Health professionals have also expressed reservations about other new prevention methods on the basis of anticipated patient sexual behaviour change, including about PrEP and HIV biomedical technologies still in development (eg, vaccines and topical microbicides).<sup>20–22</sup>

Among those health professionals who report broaching the topic of U=U with patients consistently, some deliver information in an ambiguous or distorted way that suggests condoms are still necessary.<sup>10,23</sup> For example, in a 2018 survey of over 250 British HIV-care professionals, 99% of surveyed professionals reported having heard of U=U and 71% reported raising the topic routinely with patients, but only 37% accurately communicated that there was no risk of HIV transmission. Instead, many used language that (inaccurately) suggested low but nonetheless existent transmission risk (eg, extremely low or negligible).<sup>23</sup> These seemingly subtle differences in language have meaningful implications for the perceived infectiousness of people with HIV and need to implement alternative forms of protection, as well as for their consequent access to sexual pleasure.

### Anticipated sexual risk-taking and misinformation

There are multiple reasons that anticipated changes in patient sexual behaviour do not justify withholding or distorting information about U=U and thereby allowing misinformation about viral transmission to persist. First, any given patient might or might not change their sexual behaviour if newly informed about U=U. Some research has shown an association between treatment optimism or HIV infectiousness beliefs and condomless sex.<sup>24–28</sup> For example, in a 2013–14 prospective study of over 500 people with HIV, baseline infectiousness beliefs and perceived transmission risk associated with an undetectable (*vs* detectable) viral load were predictors of whether individuals had condomless sex with potentially uninfected partners during the subsequent month.<sup>26</sup> However, the association between HIV infectiousness

beliefs and sexual behaviour has not been universally upheld across studies or across individual study participants.<sup>24,29</sup> Additionally, qualitative research calls into question the direction of causality in the subset of studies relying upon cross-sectional data. For instance, some individuals have reported adjusting their treatment beliefs to rationalise past behaviour (*vs* their behaviour being driven by treatment beliefs).<sup>24</sup> Ultimately, patients will vary in their behavioural response to learning about U=U, and although some might have more condomless sex or increase their number of partners, others will not.

Second, more frequent condomless sex, a higher number of sexual partners, and other changes in sexual behaviour that are traditionally considered to be indicators of increased risk of HIV transmission and could occur after learning about U=U, do not actually confer an increased risk of HIV transmission among people with HIV with sustained viral suppression. No HIV sexual transmission risk exists for people with sustained viral suppression, with or without a condom. No HIV sexual transmission risk exists for people with sustained viral suppression, with one partner or multiple partners. Thus, labelling these behaviours as risk behaviours or conceptualising them as risk compensation would be erroneous when considered in the context of HIV alone.

When considering sexual health holistically, sexual behaviour change could lead to undesirable consequences, such as unwanted pregnancy or sexually transmitted infections (STIs) other than HIV, if corresponding precautionary measures (eg, condom use or other contraception, regular STI testing, and vaccination against preventable STIs such as human papillomavirus) are not simultaneously implemented. These other sexual health issues are pervasive and merit attention in their own right; global estimates suggest that nearly half of all pregnancies are unintended, and the burden of STIs is persistently high worldwide, with STI diagnoses on the rise in the USA and disproportionately high among key populations at risk of HIV.<sup>30–32</sup> Nonetheless, these epidemiological challenges are multifactorial,<sup>33,34</sup> and fear that informing patients about U=U will drive behaviour that could lead to such outcomes does not justify withholding information about U=U. Providers' role is to inform patients about the risks associated with sexual behaviours, to educate patients about available prevention options, and to treat any undesired health consequences should they occur.

Furthermore, communicating about U=U with patients has the potential to indirectly help to prevent and address unintended pregnancy and STIs to the extent that it strengthens patient use of sexual health services. Discussing U=U can help to cultivate an open dialogue about sex and sexual health that encourages ongoing engagement in care. For example, such open communication could facilitate contraception counselling and uptake, thereby preventing unwanted pregnancy. It could also prompt more frequent STI screening, resulting

in more immediate STI diagnosis and treatment than would otherwise occur. Providers who convey comfort and openness around discussing patients' sexual behaviours, needs, and desires might be more likely to elicit candid sexual histories, which could help providers to optimally tailor their care. In a sex-positive setting where U=U is part of the conversation about patients' sexual health practices and priorities, condoms can be discussed as an option to prevent unwanted pregnancy and STIs but also discussed as unnecessary for preventing the sexual transmission of HIV if people with HIV have a sustained undetectable viral load. Patients should be educated about the risks and benefits of all preventive options and empowered to make informed decisions.

Third, regardless of anticipated behaviour change and whether such behaviour change confers other health risks, patients have a right to know about U=U. Distorting or withholding information about U=U constitutes a violation of medical ethics. Globally, medical organisations have established codes of ethics dictating clinical practice standards, which often include the expectation that information will be shared with patients. For example, according to the American Medical Association's Code of Medical Ethics, "A physician shall continue to study, apply, and advance scientific knowledge, maintain a commitment to medical education, [and] make relevant information available to patients".<sup>35</sup> Consistent with a patient-centred or client-centred model of care, a model commonly embraced across health professions, the American Nurses Association Code of Ethics states that "Patients have the moral and legal right to...be given accurate, complete, and understandable information in a manner that facilitates an informed decision."<sup>36</sup> Furthermore, for people with HIV who are currently on treatment, withholding information about U=U not only represents a failure to provide up-to-date medical information, but also a failure to fully disclose the risks and benefits of their treatment.

Fourth, allowing concerns about behaviour change to be grounds for distorting or withholding information from patients allows health professionals' biases and personal values to impact patients' U=U knowledge and consequent access to pleasure. This is particularly problematic because withholding information to prevent sexual behaviour change could actually cause harm. For example, the toll taken on sexual health by restricting access to sexual pleasure might outweigh the gain of averting other STIs, particularly when the risk–benefit analysis is calibrated according to a patient's values and priorities rather than their provider's.

If health professionals' biases result in some groups of patients being educated about U=U less often than others, these biases could perpetuate health inequities. For example, as has been suggested in the context of PrEP, societal stereotypes casting Black MSM as sexually irresponsible could lead providers to assume that Black

MSM would be more likely to engage in increased condomless sex if informed about U=U than if they were not, which could, in turn, reduce their willingness to inform Black MSM patients about U=U compared with other patients.<sup>6,37</sup> However, these implications for racial disparities in U=U communication are speculative, and a survey of over 17 000 MSM with HIV indicated that Black MSM were more likely than White MSM to report a provider having discussed the risk of HIV sexual transmission occurring when viral load is undetectable (although not necessarily that there was no risk of transmission).<sup>14</sup> Variability in U=U education among patients could also result from health professionals' perception of the different motivations for patients' prospective behaviour change and the value that health professionals attach to those motivations. For example, health professionals might be more willing to accept patients discontinuing condom use to facilitate conception than to facilitate pleasure, rendering health professionals more inclined to inform serodifferent heterosexual couples with reproductive goals about U=U than they would be to inform same-sex male couples.<sup>38</sup>

Finally, limiting access to U=U knowledge and pleasure is a violation of sexual rights. WHO describes sexual rights as the application of existing human rights to sexuality, and asserts that "Sexual rights protect all people's rights to fulfil and express their sexuality and enjoy sexual health, with due regard to the rights of others and within a framework of protection against discrimination."<sup>1</sup> Sexual rights encompass the right to autonomy, equality, non-discrimination, information, education, freedom of expression, and the highest attainable standard of sexual health, among others.<sup>1</sup> Misinformation about HIV transmission risk and associated restrictions imposed upon the sexual wellbeing of people with HIV infringe upon these rights.

### Recommendations for moving forward

Awareness of U=U can be transformative for people with HIV and their partners by supporting multiple aspects of sexual health, including pleasure. Substantial strides have been made in promoting U=U awareness, thanks primarily to grassroots efforts, including a worldwide campaign called the Prevention Access Campaign aimed at disseminating this crucial information. However, ignorance persists, and health professionals and the broader public health community need to be proactive in addressing misinformation about HIV transmission risk that has unduly compromised sexual pleasure for many people with HIV.

Increasing mobilisation around U=U messaging by health professionals, health centres, and public health organisations necessitates them being aware of U=U, being motivated to disseminate the U=U message, and having the capacity for such dissemination. Leading health authorities, including both individuals and institutions, can have a crucial role in establishing these

conditions. Health leaders unequivocally endorsing U=U, clarifying standards and expectations surrounding U=U message dissemination, and communicating these standards to health professionals are crucial first steps. The updated 2019 US Department of Health and Human Services Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents with HIV explicitly recommends that "All persons with HIV should be informed that maintaining a plasma HIV RNA (viral load) of <200 copies/mL...prevents sexual transmission of HIV to their partners."<sup>39</sup> Other medical authorities should similarly affirm that, in clinical settings, informing patients about U=U is the expected standard of care (vs an optional or discretionary component of care), and this standard should be extended beyond patients with HIV such that HIV-negative or status-unknown patients are also informed about U=U when counselled about sexual health.

To ensure health professionals' understanding of U=U and accurate message dissemination, relevant content should be integrated into health education and training programmes. For example, schools of public health, medicine, and nursing, as well as other health professions' training programmes, should review and amend their curricula as needed to ensure that the next generation of health professionals is aware of the latest science on HIV transmission risk and capable of fluently communicating it to others. Professional societies and HIV training organisations should also offer didactic opportunities related to U=U, such as webinars attached to educational and recertifying credits.

Optimising the educational content and messaging directed at health professionals to motivate their dissemination of information about U=U to individuals and communities will also be essential. Early research with health professionals has already elucidated content that might be helpful to incorporate in education and messaging for health professionals. For example, the disbelief and low basic awareness about U=U that has been reported among health professionals suggests that the underlying evidence supporting U=U should be clearly presented.<sup>9,11</sup> The concerns about sexual behaviour change that some health professionals have expressed suggest a need to directly discuss and discredit such concerns as a basis for withholding information about U=U.<sup>9,11</sup> Highlighting the key benefits of informing patients and communities about U=U could motivate the dissemination of information about U=U. In the aforementioned 2019 survey of Midwestern US providers, when providers were presented with multiple motivational messages, they were particularly convinced by messages focused on patients' right to know about U=U, the prospective public health benefit of such knowledge, and the positive implications of such knowledge for patients' adherence and retention.<sup>10</sup>

Appealing to health professionals' sense of responsibility could also motivate dissemination of U=U



information. Previous research with PrEP, another scientific advancement that has been slow to gain traction with health professionals, suggests that health-care providers' perception of PrEP as being outside of their purview operates as a barrier to implementation, whereas providers who perceive PrEP as being within their purview express interest in adopting PrEP into their clinical practice and a responsibility to actively promote it.<sup>40,41</sup> Positioning dissemination of the U=U message squarely within the purviews of a wide range of health professions (eg, physicians and other prescribers, nurses, pharmacists, and public health workers) might accelerate the dissemination process. Additionally, enhancing health professionals' recognition of sexual pleasure as fundamental to sexual health, and sexual health as fundamental to human health and human rights, could lead to increased perceived value and consequent investment in communicating about U=U and other dimensions of sexual health.

Beyond U=U awareness and motivation to disseminate the message, capacity for such dissemination will also be crucial. Funding and other resources should be designated for the development and evaluation of educational content and social marketing campaigns related to U=U. Additionally, health organisations, foundations, and other grant-making bodies can allocate funding for research that will support such interventions. Research and scholarship that will enhance clinical and public health practice around U=U messaging can be incentivised by prioritisation of such work for publication in academic journals and presentation at scientific conferences, priorities that can be stipulated in journal and conference submission guidelines. For practising clinicians, capacity also includes the individual-level skills and comfort required to effectively engage patients in a dialogue about U=U and sexual health, both of which can be developed through formal training.

In addition to engaging in deliberate efforts to disseminate the U=U message to patients and the general public, health professionals should update definitions and measures of sexual health behaviours to reflect current science and destigmatise sexual health choices. For example, conceptualising condomless sex as a marker of HIV transmission risk during serodifferent sexual encounters is inaccurate unless viral suppression and PrEP status are also considered. In the current era of biomedical HIV prevention, labelling condomless sex as risky or unprotected is not only imprecise but also stigmatising and counterproductive.<sup>42</sup> Prioritisation of sexual pleasure for people with HIV and their partners necessitates a broader shift in the way that sexual behaviour is conceptualised and discussed in health research and practice settings.

## Conclusion

Less than a year into the COVID-19 pandemic, misinformation about COVID-19 transmission and its

implications for health behaviour have been key concerns expressed by many health professionals, who have rushed to set the record straight to enable people to make accurately informed behavioural choices. Similarly, health professionals need to express concern and urgency with respect to correcting long-standing misinformation related to HIV. Crucial insights into HIV transmission that have direct implications for health behaviour have emerged, but health professionals and the broader public health community have not consistently disseminated this new information to people with HIV or society at large. Thus, there continues to be widespread unawareness and disbelief surrounding U=U. Ownership and action are needed not only to inform people with HIV about U=U, but to educate all people about U=U to set the record straight and dismantle social and structural harms rooted in past misbeliefs.

### Contributors

SKC led the conceptualisation and writing of the Viewpoint with input from JLM and KHM. All authors have read and approved the final manuscript.

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