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AIDS Research and Therapy

BRIEF COMMUNICATION Open Access

Missed opportunity: low awareness of undetectable equals untransmittable (U=U) among adolescents living with HIV

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Abstract

In 2022, South Africa (SA) had the second-highest HIV incidence rate among adolescents worldwide. This study's participants were boys living in SA aged 15–19 years old, in a current dating or sexual relationship, and diagnosed with HIV before the age of 10. Despite the launch of campaigns to spread awareness of Undetectable equals Untransmittable (U=U), our findings showed that a significant number of adolescents living with HIV do not demonstrate an understanding of the concept. This highlights the importance of integrating U=U messaging in ongoing conversations with healthcare workers given the potential positive impact on adolescent wellbeing, transmission risk perception, and safer sexual practices.

Keywords HIV, Adolescents, U=U, Healthcare workers, Disclosure, Transmission, Stigma

In 2022, South Africa (SA) had the second-highest HIV incidence rate among adolescents aged 15–19 years old worldwide [1]. The Joint United Nations Programme on HIV and AIDS [2] previously described the limited success in reducing new HIV infections as a "prevention crisis" [3]. In 2016, the Prevention Access Campaign launched a worldwide Undetectable equals Untransmittable (U=U) campaign to spread the knowledge that those who maintain an undetectable viral load cannot sexually transmit HIV to others [4]. Six years later, SA launched its first public information campaign about U=U [5].

While U=U has reached a significant number of adults, fewer adolescents are aware of this information [6]. Failure to ensure adequate understanding of U=U represents a missed educational opportunity for adolescents living with HIV (ALHIV) [6]. This lack of understanding may negatively impact adolescents' treatment adherence, risk perception, and sexual decision-making; the result of which may be worsening health outcomes and onward transmission. This study addresses a significant gap in the literature by measuring U=U knowledge and its potential association with HIV-associated beliefs and behaviors among adolescent boys living with perinatally-acquired HIV, a population underrepresented in HIV prevention research.

Methods

This study took place in Soweto, South Africa, a township in Johannesburg with high levels of poverty and unemployment. Although SA has a centralized viral

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load monitoring system and recommends routine testing, only 57% of adolescents are engaged in testing [7]. Participants were boys living in Soweto, aged 15–19 years old, in a current dating or sexual relationship, and diagnosed with HIV before the age of 10. They were recruited from local HIV clinics and completed screening and consent/assent procedures at a research clinic. For more information about study recruitment and sampling procedures, see Kidman et al. [8]. Participants completed a baseline survey and a one-year follow-up survey. Surveys were completed electronically on tablets at the clinic, in a private space, with study staff nearby to answer questions. Participants were debriefed by a counselor as required, and support was available through a 24-hour hotline. This study was approved by the research ethics committees at Stony Brook University in the United States (Approval ID: FWA#00000125, IRB2019-00567) and the University of the Witwatersrand in South Africa (Approval ID: 191001).

Data collection occurred between November 2020 and June 2023. For the present analyses, we use data from the follow-up survey, which had a higher number of participants reporting sexual activity. Participants answered questions about their HIV transmission risk behaviors: disclosure to sexual partners, unprotected sex, and antiretroviral therapy (ART) adherence, with acceptable adherence defined as 90% or higher, a cut-off commonly used in literature [9, 10]. They then answered questions about their HIV knowledge and beliefs: U=U knowledge (classifying the statement "You can still pass on HIV when your viral load is undetectable" as false vs. true), risk perception (perceived risk of transmitting HIV to a partner in their current state and a hypothetical undetectable state, on a scale of 0=no risk to 10=highest risk), HIV stigma, and disclosure self-efficacy (their belief that they can effectively disclose their status to a partner [11]). Finally, participants answered questions about previous discussions with healthcare workers (HCW) [12]. We conducted descriptive analyses and tested for differences in participant outcomes based on viral load at follow-up (defining undetectable as <200 copies/mL, in line with recent World Health Organization guidance [13]) and U=U knowledge. Analyses were conducted in R (version 4.2.3).

Results

Our analytic sample consisted of 236 adolescent boys who completed the follow-up surveys. Participants were 17.4 years old (IQR=16–19) on average. Most identified as Black African (90%, $N=213$) and were enrolled in school (68%, $N=160$). Table 1 describes their behaviors, beliefs, and experiences at follow-up. Notably, less than half of the sample (44%, $N=103$) correctly identified that an undetectable viral load meant they could not transmit HIV. This low level of understanding was mirrored in risk perception for the full sample. Participants reported comparable levels of perceived risk for HIV transmission in their current state ($M=5.54$) versus a hypothetical undetectable state ($M=5.08$). However, there were differences in risk perception by U=U knowledge. Participants who understood U=U reported significantly lower risk perception in their current state ($M=4.89$) than those who did not understand U=U ($M=6.08$). Similarly, participants who understood U=U reported significantly lower risk perception in a hypothetical undetectable state ($M=4.07$), compared to those who did not understand U=U ($M=5.90$).

This was a sample at high risk of HIV transmission. Less than one-third (28%, $N=65$) of participants reported acceptable ART adherence and approximately one-third (29%, $N=69$) had a detectable viral load. Among those who were sexually active (53%, $N=125$), there were low levels of HIV disclosure to their most recent partner (22%, $N=28$), though over half of participants consistently used condoms with their most recent partner (61%, $N=76$). Many participants had discussed safer sexual practices (69%, $N=163$) and HIV disclosure to a sexual partner (50%, $N=117$) with an HCW. Participants' risk behaviors and experiences with HCW were unrelated to their U=U knowledge.

Discussion

In this sample of SA ALHIV, fewer than half of the participants demonstrated an understanding of U=U. Those who did understand U=U perceived their own risk of onward transmission to be lower. Participants also commonly engaged in risky behavior, including suboptimal adherence to ART, low disclosure to sexual partners, and low condom use. Among adults, U=U education interventions have led to increased treatment adherence and safer sex practices by decreasing stigma, improving HIV knowledge and care seeking, and motivating prevention of transmission to partners [14]. Increasing U=U awareness may similarly improve wellbeing and reduce risk of onward transmission among adolescents, but SA HIV programs have been slow to incorporate U=U into HIV education initiatives [15]. This represents a critical missed opportunity for ALHIV.

This study found that many ALHIV are already engaging in HIV support groups and talking to HCW about safer sex behaviors, but that these interactions are not associated with knowledge of U=U. HCW may not discuss U=U with their patients for several reasons, including insufficient awareness about U=U,

Table 1 Safe sex behaviors, beliefs, and experiences among adolescent males with perinatally-acquired HIV at follow-up

	Total	By viral load[1]		By U = U knowledge	
	(*N* = 236)	Undetectable (*N* = 164)	Detectable (*N* = 69)	Yes (*N* = 103)	No (*N* = 133)
Behavioral outcomes					
Past month ART adherence[2] N(%)	65 (27.54)	56* (34.15)	8* (11.59)	29 (28.16)	36 (27.06)
Sexually active N(%)	125 (52.97)	88 (53.66)	35 (50.72)	54 (52.43)	71 (53.38)
Disclosed HIV status to most recent partner[3] N(%)	28 (22.40)	20 (22.73)	7 (20.00)	9 (16.67)	19 (26.76)
Consistent condom use with last partner[3] N(%)	76 (60.80)	53 (60.23)	21 (60.00)	32 (59.26)	44 (61.97)
HIV knowledge, beliefs, perceptions					
U = U knowledge N(%)	103 (43.64)	73 (44.51)	28 (40.58)	-	-
Disclosure self-efficacy [1–4] *M*(*SD*)	2.20 (0.58)	2.15 (0.58)	2.30 (0.55)	2.18 (0.58)	2.21 (0.57)
HIV stigma [1–7] *M*(*SD*)	3.82 (1.94)	3.85 (1.97)	3.75 (1.90)	3.80 (1.91)	3.83 (1.97)
Risk perception[4] - currently [0–10] *M*(*SD*)	5.54 (3.52)	5.51 (3.52)	5.59 (3.64)	4.89* (3.42)	6.08* (3.55)
Risk perception[4] - if/when undetectable [0–10] *M*(*SD*)	5.08 (3.60)	4.83 (3.51)	5.73 (3.67)	4.07* (3.65)	5.90* (3.33)
Healthcare experiences					
Discussed HIV disclosure to a sexual partner with HCW N(%)	117 (49.58)	82 (50.00)	32 (46.38)	49 (47.57)	68 (51.13)
Discussed safer sex practices with HCW N(%)	163 (69.07)	117 (71.34)	43 (62.32)	67 (65.05)	96 (72.18)
Accessed support groups for HIV + youth last year N(%)	83 (35.17)	55 (33.54)	25 (36.23)	43 (41.74)	40 (30.08)

Note Significant differences between groups are marked using *. Tests for between-group differences control for participant age

[1] Undetectable is defined as < 200 copies/mL. Viral load data are missing for 3 participants

[2] Aceeptable adherence is defined as >= 90%

[3] Denominator for sexual behavior outcomes is the number of sexually active participants

[4] Risk perception is measured on a scale from 0 (no risk) to 10 (highest risk)

disbelief in U = U, fear of patient blame for subsequent transmission to partners, or fear that this knowledge would encourage a patient to have multiple sexual partners [16]. However, conversations regarding U = U between HCW and patients have the potential to strengthen patients' use of sexual health services, foster an open dialogue about sex and sexual health, and elicit candid sexual histories, which could help HCW tailor their care [17]. Moreover, some adolescents still have doubts about the availability and effectiveness of HIV medication – a potential barrier to the effectiveness of the U = U campaign [15]. To address this, HCW should consider specifically discussing common myths about HIV medication and identify ways to increase patient trust in HIV treatments.

To better support these essential exchanges and bridge the U = U literacy gap, we need to tailor the U = U message to meet adolescents' and HCW concerns. HCW can appeal to adolescents' interests by using modern communication tools for U = U messaging. Recent effective interventions have incorporated U = U storylines in graphic novels and smartphone apps designed for ALHIV [18, 19]. Increasing the availability and awareness of these tools may encourage HCW to discuss U = U by providing a streamlined system for referring ALHIV to existing interventions rather than initiating new conversations at each encounter. Researchers can further improve interventions by engaging both adolescents and HCW in qualitative studies to identify misinformation, knowledge gaps, and communication preferences about U = U.

In this sample, U = U knowledge was not significantly associated with sexual risk behavior or ART adherence. However, U = U knowledge was associated with risk perception, which may inform behavioral decisions. These findings might suggest that U = U knowledge alone is not enough to influence adolescents' safer sexual practices or ART adherence. It may be necessary to reinforce U = U knowledge with consistent messages from HCW and other HIV education initiatives to spark behavior change. Moreover, adolescence is a period during which ALHIV are just beginning to manage their own medications and engage in sexual activity (only 50% of participants in this sample were sexually active). ALHIV may need more support than adults from HCW to develop behavioral strategies for medication adherence and negotiating sexual relationships. Associations between knowledge and behavior may change over time as ALHIV mature and gain more autonomy. Future longitudinal studies should track how HIV-associated behaviors change among adolescents with age and consistent U = U messaging.

The study's limitations include potential recall and social desirability bias in self-reported data on participants' medication adherence, sexual practices, and disclosure. Strengths of this study include the recruitment of adolescents living with HIV since birth, who are underrepresented in U=U literature and may particularly struggle with medication adherence and sexual risk-taking. This study found a critical knowledge gap among ALHIV, suggesting the need for HCW to develop tailored, consistent, and comprehensible U=U messages.

Abbreviations

SA	South Africa
U=U	Undetectable=Untransmittable
ALHIV	Adolescents Living with HIV
HCW	Healthcare Workers
ART	Antiretroviral Therapy

Acknowledgements
The authors thank the respondents for their time and willingness to share their experiences. We also thank the research staff (field supervisors, interviewers, counselors, and many others) for their time, effort, and support of this project. In particular, we acknowledge the contributions of Candice Ramsammy, Phumla Madi, Janan Dietrich, Busisiwe Nkala-Dlamini, and Stefanie Vermaak.

Author contributions
S.S.: Conceptualization, Methodology, Writing -Original draft preparation. E.I.: Methodology, Formal analysis, Writing – Original Draft, Review & Editing, Visualization. D.J.: Investigation, Writing – Review & Editing. A.V.: Investigation, Writing – Review & Editing, Supervision, Funding acquisition. R.K.: Conceptualization, Methodology, Investigation, Writing – Review & Editing, Supervision, Project administration, Funding acquisition. All authors have read and approved the text as submitted to AIDS Research & Therapy.

Funding
Research reported in this publication was supported by the National Institute of Mental Health of the National Institutes of Health under Award Number R01MH119878.

Data availability
The datasets generated during and/or analyzed during the current study are not publicly available but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
Approval was granted by both the University of the Witwatersrand Human Research Ethics Committee (approval 191001) and the Stony Brook University Committees on Research Involving Human Subjects (IRB2019-00567).

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Received: 28 June 2024 / Accepted: 26 September 2024
Published online: 08 October 2024

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