



A Study on Perceptions of Undetectable = Untransmittable Among Gay Men with Human Immunodeficiency Virus in the HIV Community on Twitter in Japan: An Exploratory Qualitative Study Using a Modified Grounded Theory Approach

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Abstract

This study explores the perceptions of the Undetectable = Untransmittable (U = U) campaign among gay men with HIV in Japan who are part of the HIV community on Twitter. We conducted detailed semistructured interviews with 12 participants using a modified grounded theory approach. The analysis resulted in 31 concepts, 5 subcategories, 9 categories, and 2 core categories. The relationship between categories and core categories was examined in conjunction with the transcriptions, yielding a comprehensive category map depicting the process of understanding U = U. The three main processes emerged: participants expressed “expectations for improvement,” underwent stages of “understanding U = U,” and encountered “dilemmas” in forming their opinions. There are two routes to “understanding U = U”: Route 1 involved a frictionless understanding of U = U, and Route 2 involved difficulty in understanding the slogan. In both routes, participants experienced the dilemma of “but I still have HIV” and regarding its ease of use. These dilemmas and difficulties in understanding U = U affected their “expectations for improvement.” Efforts to promote U = U in Japan must address challenges in public understanding and related dilemmas. This entails reformulating the U = U message in simpler terms, leveraging professional explanations, disseminating it to a broader audience, and incorporating ideas from individuals living with HIV to enhance the message.

Keywords Gay · Undetectable = Untransmittable · Perception · HIV · Twitter · Online

Introduction

In Japan, male-to-male sexual contact is the primary transmission route of HIV [1]. Gay men are at a higher risk of contracting HIV and are a key population targeted by HIV public health efforts worldwide [2]. The Joint United Nations Program on HIV/AIDS (UNAIDS) has established various goals for 2025, including reducing the stigma faced by people living with HIV (PLHIV) and gay men as well as other goals related to treatment and prevention [3].

The slogan Undetectable = Untransmittable (U = U) implies that “when people living with HIV are on treatment and have an undetectable viral load, they cannot transmit HIV to their sexual partner” [4]. Additionally,

U = U is the central slogan of a campaign by the Prevention Access Campaign (PAC), an international organization seeking to decrease the stigma faced by PLHIV. The World Health Organization (WHO) and UNAIDS also support the U = U campaign [5, 6]. In Japan, information on U = U was included in the guidelines for antiretroviral therapy by the research group on overcoming the challenges of HIV infection and its complications for the first time in 2020 [7].

Previous studies have shown that awareness of the U = U campaign varies according to HIV status [8]; studies have also shown that successful communication of the U = U message has a positive impact on treatment adherence [9]. However, few studies have explored people’s perceptions of the U = U campaign. Okita et al. published a review summarizing the current situation of U = U in Japan [10]. Opinions of PLHIV on U = U were also analyzed as part of a web survey composed of several open-ended questions by HIV Futures Japan [11]. The survey found that although some people held positive opinions about the slogan, there

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was also confusion and doubt about U = U [11]. However, because of the nature of the survey, no additional questions were asked, and the study failed to provide detailed information on respondents' opinions of U = U. A symposium on U = U has been held every year since 2018 at the Japan Society for AIDS Research Conference. Although methods for communicating U = U to the patients [12] and public [13] have been discussed at this symposium, few studies have been conducted to develop suggestions for improving U = U communication in Japan.

Social media—which makes it more likely for PLHIV to engage with content by preserving anonymity—has been used to spread HIV infection messaging and reach gay men who may normally could not be reached by offline messaging [14]. On Twitter*, the second most used social media network in Japan after LINE [15], organizations such as PAC have uploaded many posts about U = U [16]. There is also an online community of gay men with HIV** on Twitter in Japan. In this community, gay men with HIV share their experiences related to HIV, informal information such as perceived medication side effects, and perspectives regarding regular medical check-ups. The community functions similar to peer support. However, there is insufficient research, nationally and internationally, exploring how U = U is perceived by people in such online communities. This study seeks to explore what gay men with HIV on Japanese Twitter think of U = U and the processes that led them to hold these thoughts. On this basis, this study derives insights into the social and interpatient communication of U = U.

*In July 2023, “Twitter” changed its name to “X.” However, as during the time of this study, the new name had not yet been implemented, we refer to this social media platform as “Twitter” in this study.

**The Twitter users targeted in this study were gay men with HIV who referred to themselves as “+ people” (plus people) or simply “+” (plus). They connected with each other using the symbol “+” in their profiles as a distinctive marker. Although Twitter does not have a specific “community” function, this study defines groups connected through the symbol “+” as the “HIV community on Twitter.” Additionally, as the use of the “+” symbol by individuals other than PLHIV may carry a potentially derogatory connotation, this study refers to them as “gay men with HIV.”

Methods

Methodology

This study adopted a modified grounded theory approach (M-GTA) developed by a Japanese researcher Yasuhito Kinoshita. This approach is suitable for clarifying processes

of social interactions [17]. Qualitative research is essential for understanding complex, underexplored issues by prioritizing context, holistic explanations, and diversity [18]. In Japan, owing to the limited research on U = U, this study deemed it necessary to holistically understand the complex stories and emotions of participants related to U = U, which cannot be adequately treated using existing theories and research. Therefore, it was considered crucial to engage in dialog through qualitative methods like interviews and M-GTA. M-GTA, specifically in terms of its effectiveness in prompting deep reflection using worksheets, enhanced our awareness of the values influencing the study and improved our analytical approach. Moreover, M-GTA serves as a theoretical framework that provides methods for data collection (interviewing), analysis, and results reporting. The use of an “analysis worksheet” in M-GTA allows for a clearer analytical method compared to the original GTA [17]. Its theoretical framework is based on “social interactionism,” which assumes that society is constructed through subjective interpretations influenced by repeated interactions with others [19]. It can be assumed that gay men with HIV belonging to the HIV community on Twitter form perceptions of U = U in relation to various interactions, such as conversations with healthcare providers during treatment, and forms of information, such as Twitter posts.

Engagement in the Field

The first author had been personally involved in the HIV community on Twitter in Japan for over a year before planning this study. Despite not being PLHIV, the author has been engaging with the community, openly disclosing his identity as an HIV researcher. Therefore, the author shares personal posts related to his daily life and occasionally reacts to community members' posts about their everyday experiences and HIV. There have been instances of direct messaging with some members, and the author has met some of them in person. Even after the conclusion of this study, the author continues to actively participate in this community.

Recruitment and Sampling

Volunteer sampling was used to recruit participants. A post regarding the study was uploaded to the author's Twitter account. Gay men with HIV who responded to the post were contacted directly via direct message (DM) on Twitter and were asked to participate in the study. The number of participants in the study was determined using iterative sampling until theoretical saturation [18]. In this study, theoretical saturation was judged through discussions by two authors on whether the categories were sufficiently generated from the perspectives of polarity and similarity. Those who were unaware of U = U and were minors during the call were

excluded from the study. To protect the identity, confidentiality, and privacy of study participants, identification was also performed by issuing a four-digit random number in advance and asking participants to provide their number at the beginning of each interview.

Data Collection Periods and Methods

Between June 1 and August 31, 2022, detailed, semistructured interviews were conducted via Zoom for approximately 50 min per participant. Information regarding the participants' backgrounds was collected before and during the interviews. The interviews were conducted by one of the authors of the paper, a cisgender gay man who has joined the HIV community on Twitter. The questions from the interviews are presented in Table 1.

Ethical Considerations

This study was conducted in accordance with the Declaration of Helsinki and the Ethical Guidelines for Medical and Health Research Involving Human Subjects (revised March 10, 2022) and with the approval of the Kyoto University Medical Ethics Committee (R3481). Online informed consent was provided to the participants through Google Forms. After responding, a PDF copy of the answered form was sent to participants. They were also informed to consult with the researcher at any time via DM, email, or LINE if they had any questions. The researchers also confirmed that the participants gave permission to record when signing the informed consent form and at the beginning of each interview. After the interviews were concluded, the participants were provided with a 1000-yen Amazon gift card as compensation for their participation in the study and to cover communication expenses.

Data Analysis

The analysis was conducted in parallel with data collection from June 2022 to February 2023. The literal transcripts made from the recorded data were pseudonymized and later analyzed using the M-GTA "analysis worksheet"

(Fig. 1). In addition to the worksheet, a "notebook" was also created to describe the overall impressions of the participants. MAXQDA 2022 was used to manage the analysis data, and Microsoft One Note was used to create worksheets and notebooks. The coding units (Fig. 2), in order of increasing abstraction, were "concept," "subcategory (created if necessary)," "category," and "core category."

The analysis was conducted as follows:

1. An "analysis theme" that corresponds to the research objective and an "analysis focus" that is an abstraction of the attributes of the participants were determined. All coding was done bearing the following question in mind "What was a specific process (analysis theme) of the participants (analysis focus) like?" If the theme and focus did not match the data, adjustments were made to align them with the data.
2. Literal transcript was created for each participant's interview. While reading each transcript repeatedly, a worksheet was filled in the following order: "variations (examples)," "definition," and "concept name." Ideas were written in the "theoretical memos" column. After generating a concept from one variation that was considered important for the analysis theme, similar examples were considered and added to the variation column. When counterexamples were identified, a new concept was generated. One worksheet was created for each concept.
3. The same procedure was repeated to analyze the transcripts of the subsequent participants while referring to the completed worksheets. Concepts were modified, integrated, or eliminated as required.
4. Based on the relationships between concepts, categories (and subcategories if necessary) were generated. Furthermore, by examining the relationships between categories with richer data, core categories were generated.
5. Considering all the abovementioned steps, a category map was developed. The category map represents the relationship between categories and core categories, considering the transcriptions, and illustrates the processes corresponding to the analysis theme. Once the

Table 1 Questions in the interviews

How people perceive U = U

How did you feel when you first heard about U = U? Has your opinion changed at all since then?

How do you think that the people around you perceive U = U?

What do you think are the advantages and disadvantages of U = U?

Factors that affect people's perceptions of U = U

Have you ever had a doctor, another healthcare professional, or a social worker explain U = U to you? How did you feel about their explanation?

Do you have any feelings about posts regarding U = U that you have seen on Twitter?

Do you have any feelings about other information regarding U = U that you have seen so far?

Analysis theme	The process of developing expectations for improvement of U = U.
Analysis focus	Gay men with HIV who are gathering and disseminating information via the Twitter community in Japan.
Concept	Relief that HIV cannot be transmitted
Definition	To feel relieved to know that they cannot transmit their virus to others.
Variations	After I found out I was positive, I felt relieved (to know about U = U). I was like, "Oh, they say I won't infect others. (They say) the virus cannot be transmitted". (A, 28) I was seeing someone at the time (when I learned about U = U). Well, I was thinking that if I became U = U, I would be able to do that kind of thing (have sex with my partner) again. (B, 29) . . . Seven variations follow
Theoretical memos	The fact that the virus is 'uninfected' is significant for them. It seems to function as one of the central benefits of the U = U message. There seems to be the existence of a concept that conflicts with this. It seems contradictory that they feel relieved but also feel negative things in other categories. → Seemingly contradictory, but isn't this a 'conflict'? (6/6/2022) . . . More memos follow

Fig. 1 A sample of the M-GTA worksheet

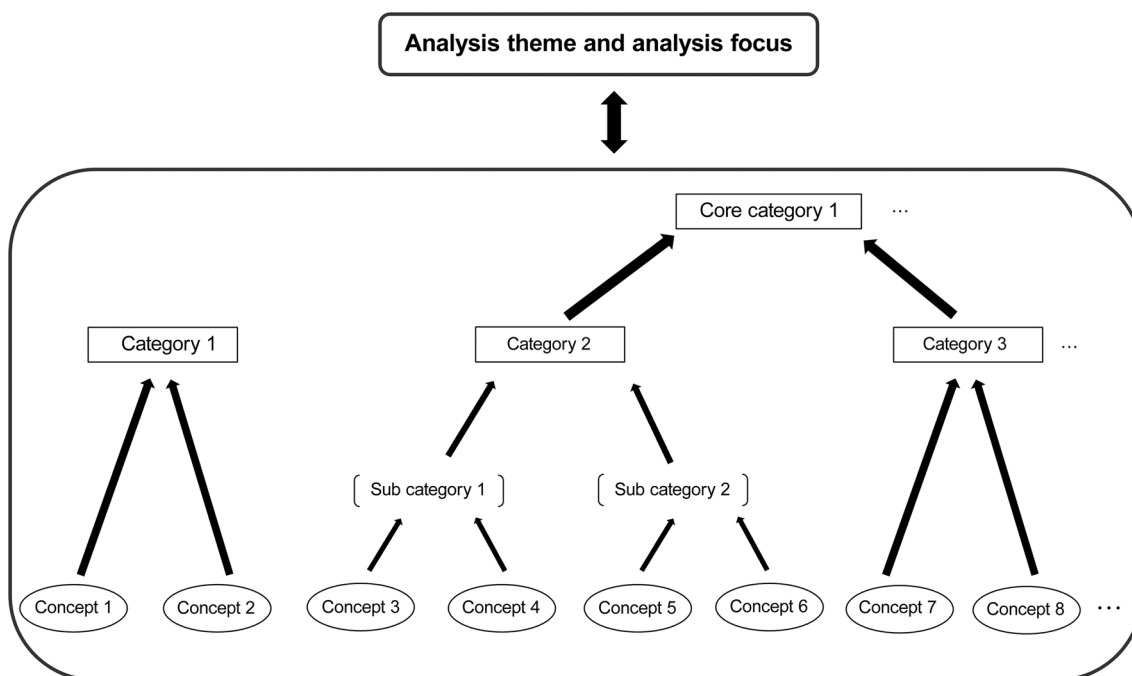


Fig. 2 The relationships between the codes in M-GTA

map was finalized, storylines were created, and the analysis was completed.

Rigor

To increase rigor, the author involved themselves in the community for over one year and actively interacted with the members to build rapport. Moreover, recordings of thinking processes (theoretical memos and notebooks) and researcher triangulation by the supervisor were used. The supervisor, an expert in qualitative research, collaborated with the researcher responsible for the analysis to discuss whether the coding aligned with the content of the manuscripts, whether sufficient categories were generated, and whether theoretical saturation had been reached. Member checking was also conducted to obtain feedback from the participants regarding research findings. The Standards for Reporting Qualitative Research (SRQR) [20] were followed in writing this paper.

Results

Summary of the Interviews

Twelve participants were interviewed, and their basic information is shown in Table 2. The average interview time per person was approximately 50 min, and the average length of the transcripts was approximately 15,250 Japanese words.

Summary of the Analysis

The initial analysis theme was “the process of understanding U=U.” However, as the study progressed, it became clear that participants had diverse experiences and emotions related to U=U, ultimately forming opinions about improvement to it. Considering these findings, the analysis theme was adjusted. The final analysis theme was “the process of developing expectations for the improvement of U=U.” Although the analysis focus did not undergo significant changes from the outset, it was subtly adjusted to highlight the fact that all participants in this study were Japanese residents. The final analysis focused on “gay men with HIV who are gathering and disseminating information via the HIV community on Twitter in Japan.” A total of 31 concepts, 5 subcategories, 9 categories, and 2 core categories were generated. The study participants had “expectations for improvement” toward U=U, and the process of reaching this opinion involved “understanding U=U” and “dilemmas.” The category map is presented in Fig. 3.

Structures of Each Stage

The nine categories and two core categories listed in Fig. 3 are described below. The letters preceding the statements refer to the pseudonyms used by each participant.

Table 2 Information on the participants' backgrounds

Pseudonym	Age	Place of residence	Experience of visiting community centers*	Experience of HIV-related activities**	Time since testing positive for HIV	In the state of U=U
A	40s	Osaka	1	Yes	Within 1 year	No
B	30s	Kanagawa	4	Never	1–5 years	Yes
C	40s	Tokyo	4	Never	1–5 years	Yes
D	30s	Tokyo	4	Never	1–5 years	Yes
E	40s	Hokkaido	4	Never	1–5 years	Yes
F	30s	Mie	4	Never	6–9 years	Yes
G	40s	Okinawa	2	Never	Over 10 years	Yes
H	50s	Fukuoka	1	Yes	Over 10 years	Yes
I	60s	Tokyo	4	Never	6–9 years	Yes
J	30s	Osaka	2	Never	1–5 years	Yes
K	40s	Tokyo	4	Never	6–9 years	Yes
L	30s	Tokyo	2	Never	1–5 years	No

*Participants were asked about their experiences of visiting facilities that provide information on sexuality and HIV, primarily in urban areas in Japan, on a 4-point scale: 1. I have been to such a place and still do so. 2. I have been to such a place but do not currently go. 3. I have never been but would like to go. 4. I have never been and do not particularly want to go

**Volunteering and participating in political and social movements related to HIV

Analysis theme	The process of developing expectations for improvement of U = U.
Analysis focus	Gay men with HIV who are gathering and disseminating information via the HIV community on Twitter in Japan.

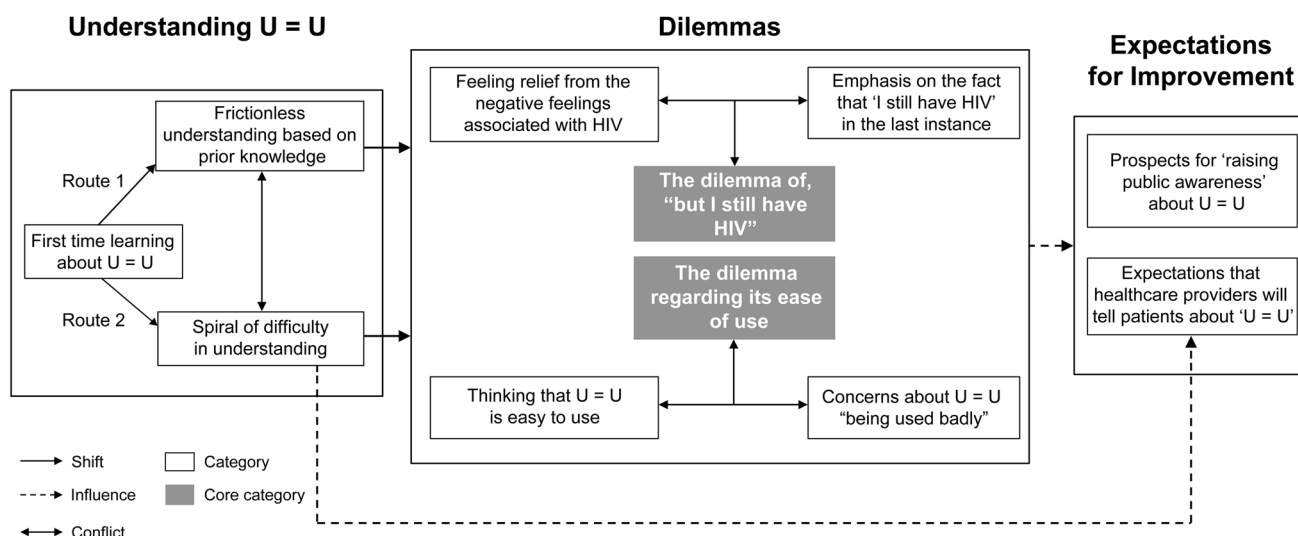


Fig. 3 Category map

Understanding U = U

At the beginning of the interviews, participants were asked how they first became aware of U = U:

(L) *The first time I determined about it [U=U] was when I went to the hospital and they [healthcare workers] told me.*

(F) *I mean, [I learned about U=U] on the internet. I was not told about it [by anyone].*

(I) *I think the first time I saw U=U was at a [pride] parade in Yoyogi, where people were holding U=U placards. Later, I searched about it on the internet, and I realized that is what it meant.*

As these excerpts demonstrate, participants learned about U = U by listening to an explanation at a medical institution or by seeing information on the internet or elsewhere. Concepts encompassing these data were aggregated into a category labeled "first time learning about U = U." This category was considered to mark the initial stage of the process where the participant first encountered U = U. The participants' impressions when they learned about U = U were divided into two categories. Some participants had no difficulty understanding U = U because they possessed prior knowledge of HIV from their previous experiences like interacting with other PLHIV:

(G) *There were a few HIV carriers around me. [...] So I accepted it [U = U] easily.*

Concepts including such data indicating a smooth understanding of U = U based on prior knowledge were categorized as "frictionless understanding based on prior knowledge" and labeled Route 1. Conversely, many participants who followed Route 2 had trouble understanding U = U because of difficulties understanding the term "undetectable" or the English words and their Japanese translation:

(A) *Below the detection limit was something like... When I used to volunteer, "50 copies" was the detection limit. Is it 20 now or is it 25?*

(F) *The characters [for spelling U=U] are bad; no one understands the meaning if I say it [U=U] in katakana [one of the Japanese alphabets], and if I say it in kanji [Chinese characters], it is too long. It is not functional as a symbol in Japan.*

As they encountered different types of information, repeatedly experiencing the challenges of understanding U = U, concepts for these data were grouped into the category "spiral of difficulty in understanding." This was positioned as a contrasting route for smooth understanding. Furthermore, the abovementioned three categories related to learning and understanding U = U were consolidated into a stage called "understanding U = U." Regardless of the route, participants who experienced "understanding U = U" went through the next "dilemmas" stage.

Dilemmas

After being asked about how they came to know about $U=U$, each participant talked about the contrasting emotions they had toward $U=U$. First, they discussed how $U=U$ alleviated the negative emotions associated with being PLHIV:

(I) *It was as if the weight that had been pressing on my heart suddenly disappeared.*

Concepts showing that they realized that the burden of HIV that they carried within themselves was lightened by $U=U$ were categorized as “feeling relief from the negative feelings associated with HIV.” However, they were also conscious of others’ harsh perceptions of HIV:

(B) *If I tell my friends that I’m $U=U$, they will say, “But you still have HIV.” I guess they have a strong image of it [as something scary].*

Thus, even with $U=U$, they thought it was not sufficient to dispel the negative image of HIV in society. Therefore, they continued to carry a burden. Concepts containing these data were abstracted into the category “emphasis on the fact that ‘I still have HIV’ in the last instance.” Many of them were unaware of expressing conflicting emotions until this was highlighted by the interviewer, but some participants were conscious of such conflicts and talked about them directly:

(G) *It [$U=U$] just made my life easier. That is what made me feel better. [...] But it is like... when you become $U=U$, it does not change the fact that you have HIV.*

Such contrasting emotions related to the burden of HIV mentioned by participants led to the generation of a core category named “the dilemma of, ‘but I still have HIV’” from the two contrasting categories. Similar conflicts regarding the “convenience” of $U=U$ were also mentioned during the interviews. The participants actively used $U=U$ as the following convenient symbol:

(D) *I can see [from $U=U$ content on Twitter] that their treatment is going well. I’m not sure if it is like a sense of camaraderie, but it makes me happy. I do not know if it is accurate to say that we are friends, but we are working together every day on this kind of medication.*

(B) *This illness is the first barrier to starting a relationship; therefore, I think that explaining $U=U$ to a potential partner will help break down that barrier. Well, I think that it will be one advantage of $U=U$.*

As mentioned above, the participants observed that $U=U$ served as a symbol to enhance solidarity among members of

the HIV community on Twitter. In addition, some participants believed that $U=U$ could function as a clear symbol for communicating about HIV to people other than PLHIV. Concepts including such data were abstracted into the category “thinking that $U=U$ is easy to use.” However, they also mentioned the negative aspects of its ease of use:

(E) *So, is everyone who is not $U=U$ wrong? [...] I do not think it is always justified to introduce it [$U=U$] like that.*

(C) *Some people on Twitter use it [$U=U$] for a specific purpose [looking for sexual partners], and they use it in a way like, “It’s okay; I’m $U=U$ now.” This makes the value of $U=U$ decrease significantly.*

Respondents were aware that the ease of use of $U=U$ could lead to a potential division of PLHIV and promotion of condomless sex. Concepts containing such data were categorized as “concerns about $U=U$ being used badly.” Furthermore, from these two conflicting categories regarding “ease of use,” the core category of the “dilemma regarding its ease of use” was generated:

(H) *I am very grateful for $U=U$, but there are a lot of people who use it as a pretext for... It is probably not a bad thing, but I have a feeling that more people are doing that [risky sexual behavior].*

In contrast to the first conflict, many participants were aware of the second conflict and strongly recognized that $U=U$ had both advantages and disadvantages. The two core categories were grouped into the “dilemmas” stage, thus significantly influencing participants’ opinions about $U=U$ and positioned at the center of the process.

Expectations for Improvement

Participants expressed their opinions and suggestions for improvement related to the two conflicts and the difficulty of understanding $U=U$ at the end of the interviews. Many of them proposed increasing awareness about $U=U$ in society as a way of alleviating the burden related to HIV:

(J) *I think we need to get more people without HIV to know that there is a treatment and that people with HIV can have sex safely as long as they regularly take their medication.*

As illustrated in the above example, respondents expressed the feeling that $U=U$ was targeted at PLHIV, but to improve the stigma associated with HIV, it needed to be directed at non-PLHIV as well. Concepts including such data were categorized as “prospects for raising public awareness about $U=U$.” Some participants had expectations of healthcare providers:

(G) *I think that [doctors] telling patients about U=U would not only help relieve their anxiety but also help them understand U=U correctly.*

As illustrated by this example, some participants believed that healthcare providers, by appropriately explaining U=U to PLHIV, could contribute to overcoming the difficulty in understanding and informing sexual partners regarding the pros and cons of engaging in condomless sex. Concepts including expectations toward professionals were categorized as “expectations that healthcare providers will tell patients about U=U.” Expectations toward U=U, as indicated by these two categories, align with their experiences in the first two stages. Therefore, it has been placed at the end of the process under the name “expectations for improvement.”

Discussion

The data from this study indicate that gay men with HIV in the HIV community on Twitter have expectations for improvement regarding U=U. Moreover, difficulty in understanding U=U and the emotional conflicts associated with it seem to affect these expectations. An essential finding of this study is not whether PLHIV endorse U=U or not, but rather that they accept it with complex emotions. In one web survey conducted in Japan, participants were able to fill out a free-answer section [11], with some PLHIV answering that U=U could help relieve their anxiety. However, others stated that “HIV is still considered scary.” Our study suggests that these conflicting opinions coexist in many participants, as represented by the “dilemmas of, ‘but I still have HIV.’” Additionally, Ohkita et al. identified “dividing PLHIV,” “mandatory treatment,” and “the possibility of an increase in other sexually transmitted infections” as three concerns related to U=U [10]. Of these, concerns about polarization among PLHIV at the individual and community levels and increases in other sexually transmitted infections were also identified in our study under the category “concerns about U=U ‘being used badly.’” This was related to the category “thinking that U=U is easy to use,” which they understand as a benefit of U=U, leading to the “dilemma regarding its ease of use.”

It is also useful to consider pre-exposure prophylaxis (PrEP) studies for this discussion. The promotion of PrEP, a drug that can prevent HIV infection among HIV-negative people, began around the same time as the U=U campaign. PrEP research has pointed to the existence of a “PrEP stigma.” That is, those taking the drug are “being perceived as having a risky sex life because of PrEP use.” Moreover, this stigma has been identified as a cause of reduced interest in PrEP [21]. The “concerns about U=U ‘being used

badly’” in our study are similar to the PrEP stigma. If in the future, members of the Twitter or gay communities are fearful of being seen as pursuing a risky sex life by admitting that they are U=U, this may lead to “U=U stigma.” In turn, this can lead to a decline in interest in U=U. Therefore, it will be necessary to address these “concerns about U=U ‘being used badly.’”

In the context of online communities, it has been suggested that Twitter is an important virtual space for gay men to forge their identities through sexual satisfaction [22]. However, our study shows that gay men with HIV have an aversion to tweets that encourage risky sexual behavior among people who are U=U. This suggests that gay men do not necessarily embrace all types of sexual tweets on Twitter. In addition, treatment decision-making factors in medical settings have been identified as factors influencing HIV medication adherence in Japan [23]. However, in our study, gay men with HIV said that they were encouraged to continue taking their medication while feeling camaraderie with others in the HIV community on Twitter seeking to achieve U=U status. This suggests that social support in online communities can also promote adherence among PLHIV.

Our findings also indicated that difficulty in understanding the U=U slogan is a major problem in Japan. The website of the U=U Japan Project, the leading source of online information on U=U in Japan, introduces U=U by stating, “U=U (Undetectable=Untransmittable) is a message that states ‘undetectable=no HIV infection’” [24]. The issue of translating “U=U” was also raised at the 2018 conference of the Japan Society for AIDS Research [13]; however, the discussion has since shifted to the three concerns mentioned above by Ohkita et al. (divisions among PLHIV, mandatory treatment, and the possibility of an increase in other sexually transmitted infections). Moreover, a “spiral of difficulty in understanding” regarding the term “undetectable” and difficulties with the English language and translation were identified in our study. They indicate that it may not be easy for the Japanese to understand what “U=U” means.

The WHO introduced three categories for “viral load levels” in 2023 [25]. The first is “undetectable,” where the virus is not detected through testing. The second is “suppressed,” for a viral load of 1000 copies/mL or below, and the third is “unsuppressed,” where the viral load exceeds 1000 copies/mL. As per the U=U message, having an undetectable viral load implies zero risk of HIV transmission through sexual activities. Similarly, the state of being “suppressed” is associated with an almost zero risk of transmission through sexual activities. This study reveals the challenges in translating the term “undetectable” into Japanese. As there is still no widely adopted Japanese translation for “suppressed” or “unsuppressed,” there is a need for clearer expressions and presentation of specific viral load definitions

when explaining these categories to Japanese patients. Furthermore, explanations given by health professionals will help patients understand the correct meaning of $U=U$ or viral load levels. Health professionals are hesitant to explain $U=U$ to patients because of concerns about the increase in other sexually transmitted infections [26]. The evidence suggests a correlation between antiretroviral therapy (ART) and increased risk behavior among PLHIV [27]. However, there is also evidence that does not support this correlation, emphasizing that conveying appropriate prevention messages alongside ART is crucial [28]. Furthermore, informing PLHIV patients about the preventive benefits of ART has a positive impact on adherence [9], which is crucial in the overall strategy for HIV treatment. As indicated by the explanations of $U=U$ provided by healthcare providers, participants wanted professionals to supplement their knowledge of $U=U$. Explanation of $U=U$ by healthcare providers can enhance understanding and prevent risky behaviors, maximizing the benefits of $U=U$. PrEP research also has important implications for the two dilemmas discussed in this study: Although PrEP is distributed mainly in gay communities, targeting a wider audience may help gain additional public and policy/financial support [21] and alleviate the stigma surrounding PrEP [29]. The $U=U$ message, which is not well-known outside gay communities [30], should be disseminated to a wider audience as a solution to these two dilemmas. Furthermore, it has been highlighted that research on the impact of $U=U$ in more diverse settings and with more diverse subjects is required [30]. There has been little research and few practical activities focusing on the HIV community on Twitter in Japan, leaving community members without any opportunities to express their opinions on $U=U$. Greater Involvement of People with AIDS (GIPA) [31], intended to involve PLHIV in the development of HIV services and policies, may be entirely lacking in relevance to the online community and the $U=U$ message in Japan. To address this gap, initiatives such as those involving members of the online community in the $U=U$ Japan Project [24] and conducting larger surveys targeting the community to enable them to express their perspectives on $U=U$ are needed.

Although previous studies on HIV have utilized social media as an intervention tool [32, 33], our study is novel in that it considered social media as a community and qualitatively examined the perceptions of $U=U$ by members of this community and their interactions with the community, healthcare providers, and surrounding people. Moreover, as shown in Table 2, our study included people who are difficult to interact with in offline environments, such as those who had no experience or willingness to visit “community centers,” which play an important role in HIV/AIDS-related research in Japan. A further strength of this study is that the author, who is also a gay man, was able to build a rapport with the study participants by engaging with the community

over a long period. This allowed the researcher to elicit a wealth of responses during interviews, which enabled theoretical saturation to be reached despite the relatively small number of participants. Another achievement of the study is that it inextricably linked various advantages and disadvantages of $U=U$, all of which had been discussed in previous studies, with various “dilemmas.”

One limitation of this study is that the participants were exclusively cisgender gay men. Therefore, it may be inappropriate to apply the results of this study to other genders and sexualities, such as heterosexual or bisexual men or transgender individuals. Furthermore, there is a possibility of selection bias. Because the study focused on Twitter users, the participants were likely to possess relatively high internet literacy. Another limitation of the study is that there were no participants in their 20 s. Although previous studies have not shown age to have a significant influence on perceptions of $U=U$, the possibility remains that there may be ideas specific to younger people. Furthermore, in this study, the first author, an HIV researcher and not a PLHIV, openly disclosed his identity while participating in the community. Given that some members of this community may reject followers who are not PLHIV, it is possible that individuals with such preferences were excluded from the study, and those who were relatively tolerant of researchers participated. Moreover, this study assumed that the $U=U$ message has a certain value for public health, which might have influenced the qualitative analysis. Despite these limitations, the results of this study can be considered applicable to the analysis of “gay men with HIV who are gathering and disseminating information via the HIV community on Twitter in Japan.” More research should be conducted outside the Twitter community to include other genders, sexualities, and nationalities.

Conclusions

Gay men with HIV who participate in the HIV community on Twitter in Japan have an understanding of $U=U$ and experience dilemmas regarding $U=U$. They also harbor expectations regarding future improvements. In conclusion, $U=U$ efforts in Japan need to incorporate these community members’ ideas about the $U=U$ message, and there is a need to rephrase the $U=U$ campaign slogan using appropriate words for Japanese audiences. It is also recommended to promote explanations by health professionals and dissemination of the $U=U$ message to a wider audience.

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Author Contributions Takashi Nakadomari planned the research project, conducted the interviews, analyzed the data, and wrote and translated this article. Miho Iwakuma supervised the research processes and contributed to researcher triangulation during the analysis phase.

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Data Availability The audio files recording the interviews are not shared because the participants did not agree for the raw data to be shared with other researchers due to the sensitive nature of this study. The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Declarations

Competing Interests There are no conflicts of interest to disclose.

Ethical Approval This study was approved by the Kyoto University Medical Ethics Committee (R3481). Also, this study was conducted in accordance with the Declaration of Helsinki and the Ethical Guidelines for Medical and Health Research Involving Human Subjects (revised March 10, 2022).

Consent to Participate All participants completed informed consent forms online.

Consent to Publish All participants completed publication consent forms online.

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