

# ‘HIV made me fabulous’: a qualitative analysis of embodied storytelling in film to address stigma, further understandings of U=U and advance gender equity

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## ABSTRACT

**Background.** Even with the Undetectable equals Untransmittable campaign (U=U) campaign, women living with HIV continue to experience intersecting forms of stigma. We explored how the somatic experiences of viewing a film about U=U and women could help individuals gain deeper understandings of HIV and alter learned prejudices. **Methods.** *HIV Made Me Fabulous* is a film that utilises embodied storytelling to tell the story of a trans woman living through social and historical traumas of HIV. Four online film screenings and focus group discussions took place between June 2020 and June 2021, with participants attending from Canada, Australia, South Africa, Kenya, Zimbabwe and India. Two sessions were held with women living with HIV ( $n = 16$ ) and two with HIV-negative individuals ( $n = 12$ ). Transcripts were analysed via thematic analysis using Lafrenière and Cox’s framework to assess its impact. **Results.** Participants experienced strong, diverse emotional responses and sometimes physical effects from viewing the film. These somatic experiences furthered engagement with key messages in the film, including U=U, intersectional identities, and impacts of patriarchal systems. Women living with HIV commented on unique gendered risks experienced during disclosure, and the pressures of reaching an undetectable viral load. Women also commented how the film resulted in deeper reflection of their deservingness of pleasure. Regardless of HIV status, participants expressed motivation towards influencing change that included addressing biases and sharing U=U with others. **Conclusions.** Embodied storytelling in film is an effective method to counter both intra- and inter-personal HIV-related stigma by provoking responses that enhance compassion for oneself and others.

**Keywords:** embodied storytelling, film, HIV, knowledge translation, qualitative research, sexuality, stigma, U=U, women.

## Introduction

We women living with HIV lose our bodies as our bodies at diagnosis . . . and just take on this mindset to protect our lives and the people around us . . . and day-by-day we lose who we are, what our bodies are supposed to feel or be . . . (Fatima, a woman living with HIV)

The ground-breaking launch of the Undetectable equals Untransmittable or U=U movement led by the Prevention Access Campaign aimed to reframe the HIV narrative, target HIV stigma and promote equity in access to and uptake of antiretroviral therapy (ART).<sup>1</sup> Although this campaign has contributed to changing understandings about life with HIV today,<sup>2,3</sup> the benefits of this messaging have not been equally realised. Despite its transformative vision to increase access to treatment and support and encourage people who are virally suppressed to reimagine sexuality, the movement was introduced within, and thus subject to, the existing oppressive structures of sexism, racism, classism, anti-trans discrimination, and systemic misogyny that continued to put socially marginalised groups

at increased risks of violence, poverty, and HIV transmission.<sup>4,5</sup> Such structures can also compromise access to information about U=U and shape the opportunity to benefit from the ‘sexual liberation’ that U=U promises to offer.

Within these patriarchal systems and structures, women living with HIV experience gendered harms on the basis of sex, gender identity or expression, and associated stereotypes such as female promiscuity.<sup>6</sup> Women are also situated differently, with overlapping stigma for their involvement in sex work, use of substances, or experiences of racism, among other social factors or identity statuses.<sup>7</sup> HIV stigma has deep socio-historical roots tied to highly embedded emotions such as fear, anger, shame and despair.<sup>8–11</sup> It can manifest as labelling, prejudice and eventually discrimination, and this can be internalised by people living with HIV who may live in fear of stereotyping, threats and violence.<sup>9,12–14</sup> This manifestation of the intersectionality of HIV stigma can result in poorer outcomes, including those related to HIV treatment, care, and support.<sup>10–12,15–18</sup>

Moreover, although the discourse of ‘undetectable viral loads’ may be transformative for some, enabling people to enjoy sexual intimacy, safely conceive, or breastfeed their babies without anxiety or fear,<sup>19</sup> this HIV risk prevention and education strategy may also operate to exclude and marginalise others, by continuing to medicalise, control, and discipline bodies that never reach or eventually lose the ‘U status’.<sup>5,20,21</sup> The worry about one’s ‘U status’ can put incredible pressure on women for zero transmission to others and override their own health needs and priorities, including access to sexual pleasure and safety, particularly in social, cultural, and historical contexts in which revealing a U=U status may incite violence.<sup>21,22</sup>

Previous research has found that interventions aimed at increasing scientific knowledge about HIV to reduce stigma has had mixed effects, but that popular media interventions that incorporate a visual component can support a deeper immersion in the storyline and connection with the characters that can overcome pre-existing bias and resistances.<sup>23,24</sup> Film is an innovative knowledge translation tool that can help audiences gain a deeper, more holistic understanding of complex health issues such as HIV.<sup>25,26</sup> Indeed, other studies have found that interventions utilising film are effective in minimising HIV-related stigma.<sup>27,28</sup> However, the impacts achieved by using these arts-based methods are seldom evaluated in detail and even more rarely through engagement with specific theories of how change occurs.<sup>10,23,24</sup>

To further understandings of U=U, as experienced by women living with HIV, a team of researchers and women living with HIV partnered with director and producer, Edmond Kilpatrick, to create the 10-min film *HIV Made Me Fabulous* ([www.lifeandlovewithhiv.ca/film](http://www.lifeandlovewithhiv.ca/film)). The film invites audiences to empathise with the experiences of living and loving with HIV from a woman’s perspective. The film features voiceover narration by Juno Roche, who tells her story of finding self-love and pleasure despite living through

social and historical traumas associated with HIV. It also features three performers who represent Roche’s story visually using embodied storytelling; an arts-based technique leveraging movement and dance to provoke physical sensations and emotions in viewers’ bodies.<sup>29</sup> By inviting a sensory response that encourages introspection, contemplation, and empathy, this technique is thought to heighten awareness of individuals’ preconceptions that fuel stigma. Furthermore, by introducing a new emotional response at the moment those biases surface, embodied storytelling can hopefully create new feelings or understandings of HIV. The objective of this research study was to understand the impact of the film among people living with and without HIV, including influences on viewer knowledge, embodied prejudices and motivation to change.

## Methods

### Study design

We implemented a social justice informed arts-based knowledge translation strategy.<sup>30</sup> The project brought together researchers, women living with HIV, and a filmmaker to design the study, collect the data, and interpret findings. We used a variety of methods to understand the film’s impact, including film screenings and focus group discussions, website and YouTube analytics, and responses to an evaluation survey. This paper focuses on the results of the film’s focus group discussions. There were four focus group discussions in total, conducted between June 2020 and June 2021. Each session lasted 1 h, took place over Zoom, was audio-recorded, and had six to nine participants. In addition to understanding the film’s impact, learnings from the focus group discussions also supported the development of a film facilitation guide to support others to safely screen the film, before publicly launching the film and associated materials on World AIDS Day 2021.<sup>31</sup> At present, the film and facilitation guide<sup>32</sup> are currently available on the website, [www.lifeandlovewithhiv.ca/film](http://www.lifeandlovewithhiv.ca/film). Ethics approval for this study was obtained through a harmonised review from Simon Fraser University through the University of British Columbia (H20-00318).

### About the film

The script and story of this film was created in collaboration with Juno Roche and produced and directed by Edmond Kilpatrick. Over a series of long, intimate discussions on the phone, the two shaped the story by exploring Roche’s past and present and connecting those experiences to the body. The developing story was also shared with researchers and women living with HIV to ensure the messages were grounded in HIV science and reflected the broader experiences of women. The film begins with a brief sombre tune strummed on guitar strings contrasted against global statistics on HIV and women written against a dark background. The music stops and Roche begins to speak, ‘It’s a difficult enough thing to be a

woman in the world and exist proudly in your body...'. Roche's words over the course of the film are performed by three dancers whom, despite their diversity, are connected by their experience of HIV. The audience is introduced to a Black dancer (Jacky Essombe) sitting at her dressing table and adjusting her appearance, and two Indigenous Cree dancers, the first a transgender dancer (Quannah Style) who is seen applying makeup, and the second (Joleen Mitton) standing in front of her mirror smoothing out her dress, as Roche says 'Especially as a trans woman. There are so many layers of shame, and being born in the wrong body, this disassociation from the body, this rejection of the body...'. All three women wear a solemn, exasperated expression and move with anxiety and exhaustion. Additional scenes demonstrate each woman waiting apprehensively on a doorstep to meet a potential partner and disclose their HIV status, being thrown back on a park bench as a result of violence and stumbling as they walk uphill struggling to re-establish their equilibrium, all portrayed against Roche's verbal description of U=U and its complexities. About halfway through the film, the scene transitions to the women dancing freely in a garden, as Roche shares how she has created beauty around her and a safe space for her to come home to despite the challenges of HIV. Their internal struggles boil over, forcing the women to overcome them. They are then seen with defiant, confident expressions, doing the same activities they performed in the first half of the film, except with more confident, bolder and vigorous movements. The end of the film showcases a closeup of each woman as Roche asks, 'HIV made me fabulous. What has it done for you?'

### Participant recruitment

Participants were invited to the film screenings and focus group discussions through advertisements that were circulated on social media and email. The advertisements were promoted by Simon Fraser University, the BC Centre for Excellence in HIV/AIDS, Women's Health Research Institute, Oak Tree Clinic, Life and Love with HIV, and community-based organisations in Canada and globally via their social media platforms and online newsletters to their members. The research team also circulated the advertisement on email to their global networks of researchers, healthcare providers, colleagues living with HIV, and organisations related to HIV, art, film, 2S/LGBTQI+ (Two Spirit, Lesbian, Gay, Bisexual, Trans, Queer, Intersex and more) communities, and gender equity.

Film screenings and focus group discussions were free to attend, and open to individuals who were aged  $\geq 19$  years and were comfortable communicating in English. The sessions were divided into two main stakeholder groups – women living with HIV who experience HIV stigma (described as the 'stigmatised' by Mahajan *et al.*<sup>10</sup>), and the general public (the potential 'stigmatisers') who likely held less knowledge about HIV. Two sessions were held with a total of 16 women living with HIV, and the other two sessions were held with 12

individuals not living with HIV. Although detailed demographic data were not collected, participants were observed to be diverse in age, cultural background, and time living with HIV; individuals were from six countries including Canada, Australia, South Africa, Kenya, Zimbabwe and India, and 26 of the 28 participants were women.

### Focus group discussions

Film screenings and focus group discussions were facilitated by two research team members, including one researcher without HIV and one peer researcher living with HIV. Participants were given permission to keep their video cameras on or off and were encouraged to ask questions at any time during the session. The sessions began with a land acknowledgement and speaker introductions, including statements on positionality. After this, an oral consent process took place (where participants gave consent to participation and publication of the study), followed by a short icebreaker exercise to get participants comfortable speaking, and then a brief introduction to the film, U=U, and embodied storytelling was shared to prepare participants and frame the film appropriately. Once this was complete, a short breathing exercise took place to ground the participants, and then the 10-min film was played.

After the film was screened, a facilitated 30- to 45-min larger group discussion took place where participants were encouraged to share thoughts and feelings of the film. Questions were posed using the Lafrenière and Cox framework,<sup>33</sup> which was used to evaluate art-based work and included: *What key messages did you take away from the film?; How did the film make you feel?; How did the film affect your understanding of how women may experience U=U differently from men?; Did you learn anything about yourself while watching the film?; and How might the film affect you or inspire change?* At the end of the group discussion, participants were also given the link to an optional, online survey to give the research team further feedback. If individuals did not want to participate in the research, they were still welcome to watch the film and stay for the discussion and were not required to speak. Each session was recorded and transcribed with participant consent. Research team members also took general notes of their observations during the sessions and were also observant of participant reaction to the film and discussion, in case participants were assessed as being in need of mental health support and further debriefing.

### Data analysis

Transcripts were deidentified and pseudonyms used to preserve participant anonymity; these pseudonyms are also used to identify the quotes in this paper. The analysis was conducted by the research trainee and principal investigators using reflexive thematic analysis,<sup>34,35</sup> a theoretically flexible, six-phase approach to analysing qualitative data that sees researcher subjectivity as an analytic resource. The six steps were as follows: (a) familiarisation by fully reading all four

transcripts multiple times; (b) coding by identifying and contextualising data against the Lafrenière and Cox framework<sup>33</sup> for assessing the impact of arts-based works, which emphasises four criteria (emotions, understanding, response, and change); (c) generating themes inductively based on recurring ideas within each criterion; (d) reviewing themes, defining and naming themes; and (e) summarising and writing up these themes and examples in an extensive matrix in a Microsoft Word (Microsoft Corporation, Redmond, WA, USA) document. When reviewing the data, key considerations were made to engage with embodiment theory and identify if the film elicited any physical sensations that may have influenced any emotions experienced, knowledge gained, deeper reflection or willingness to change.<sup>36</sup> To enhance rigour and validity, we debriefed with facilitators after each screening, discussed the data and our interpretations at regular team meetings (between AC, AB, and AK) throughout the analysis process, and involved co-authors in triangulating the findings and conclusions. Team members were encouraged to reflect on their position and positionality, which included academic and personal experience of living with HIV, and reflexively engage with theory, data, and interpretation.

## Results

Four main themes were identified through thematic analysis of the focus group transcripts. The first theme related to the complexity of emotions provoked by the film, the physical sensations associated with them, and the lived embodied experiences of those emotions. The second theme revealed how these emotions played a vital role in deepening understandings of the myriad of issues at stake with U=U, such as balancing disclosure with the need to ensure one's own safety and the right to control one's own body. The third theme focused on how the film furthered engagement and response by prompting internal dialogue and interpersonal discussion about the persistence of patriarchy in the HIV epidemic and how it continues to marginalise women living with HIV. The fourth theme identified the willingness of participants to take action to counter HIV stigma in themselves and others.

### Emotions: performance art as a precursor to bodily feelings

Both women living with HIV and the general public shared that the film elicited a number and range of emotions, which sometimes included a physical component mirroring the characters portrayed. Many participants commented that watching the film was an emotive journey; in the words of Georgia, a woman living with HIV, the film was an 'emotional rollercoaster' that included relief at having her struggles validated, and stress when thinking about how she and other women could overcome these challenges. These emotions were also accompanied with a visceral response; for example, Sachi, another woman living with HIV, exclaimed:

Yeah, I still got goosebumps! It moves me, it really moves me.

HIV-negative participants commented that they appreciated the cultural diversity of the dancers, and could even see themselves in the vulnerabilities experienced by characters to the point that they were moved to tears, as Veronica noted:

I kind of felt like I was her and kind of like what she was struggling through (voice breaking). It was more relatable.

Andrew, a man who is not living with HIV, also identified with the characters and experienced strong physical sensations when watching the scene of the women waiting at a door preparing to disclose their HIV status to a potential lover:

I definitely felt a bit of anxiety and a bit of, kind of like a gut-wrenching feeling.

Members of the general public noted how embodied storytelling was a more effective medium to understand the issues raised in the film, compared to reading facts about U=U. For example, Leela noted:

Cognitively understanding a message of U=U is okay, but when you connect emotionally with a message, it is processed differently. And I guess you feel more connected to the message and empathetic to the people whose lived experience they are sharing.

Some participants noted that the film evoked challenging emotions, including anger and frustration at the difficulties that women living with HIV still experience during dating and disclosure, as well as the burden placed on them to educate others around U=U. As Salome, a member of the general public shared:

This is where the frustration comes in... why do we not have an open discourse about this...

For women living with HIV, these negative emotions were felt more acutely; many felt activated by the film, as the film echoed difficult and familiar experiences of dating, difficult disclosures, violence and internalised stigma. As Maya, a woman living with HIV, noted:

I still struggle with seeing myself as fabulous cause, like I said, I've lost my butt, my face, my arms, my legs, everything. Um, so yeah that really (sobs) triggered that right now.

Importantly, participants also felt a range of positive emotions, including happiness, joy, and self-acceptance. A woman living with HIV shared:



There was a joyful moment where I felt that I need to embrace myself more, that it doesn't matter, the fact that I am HIV positive shouldn't make me feel sad, shouldn't make me question myself or even judge myself.

These positive emotions were linked to the energetic performance of the dancers; for example, Sachi commented,

That feeling when they move their bodies back, and you just see them go, oh, fuck it . . . fuck this patriarchal idea of what a woman should be. And they just shed it and you just see them glowing, and that's that sense of relief that comes.

### **Understanding: U=U can be both empowering and disempowering for women**

The emotions participants felt brought to light new understandings of U=U, which differed between stakeholder groups. Most members of the general public were not aware of U=U prior to watching the film, and asked facilitators to explain it further after the film was screened. They also expressed confusion and frustration about whose responsibility it was to create awareness around U=U and about how disclosure should take place. For example, Salome asked:

And engaging in casual sex, does that mean the person has to, like do you bring slides? A slide show and a presentation? And here's a pamphlet of information to destigmatize my reality?

Furthermore, it was noted that there was a need for greater understanding of U=U and the social issues women face among health providers to help women and HIV-negative partners better navigate intimate experiences, as Piper, an Indian healthcare worker, commented:

A lot of healthcare workers do not know how to handle this – because what you said, the U equals U part is absolutely true, we study it, but we can't explain it.

Participants who were living with HIV all appeared to have knowledge of U=U prior to the screening, and the film generated new questions and inspiration for dialogue and alternative perspectives. For some participants, the film and message of U=U was an opportunity to reinforce their deservingness and entitlement to pleasure, love and acceptance, as Amelia said about her takeaway from the film:

And we are also entitled to love, and also we have the right to allow ourselves to be loved.

Participants living with HIV also voiced the unintended consequences of U=U raised in the film that they experienced, including the social pressures to remain undetectable, and how the medical language used provokes embodied memories of contagion and the corresponding physical and emotional responses associated with proving that you are 'clean' (as Roche described in the film). The women living with HIV shared that they usually held the responsibility and risk of explaining U=U to their partners, and how more often than not, that their HIV status would be weaponised against them, resulting in rejection and violence. As Fatima shared:

When you do your disclosures then there are so many things that happen and [in the video] the dancers, they sit on the couch and are thrown back. And with every time that happens, I just think of all those moments that my disclosures have put me in the face of violence. And it's like feeling the slap again . . .

The women expressed that the lack of awareness and understanding about U=U in the general public contributes towards prevalent societal stigma and discrimination experienced with not only with romantic partners or friends, but especially in online public spaces. As Danny shared:

The other day, I wrote something on Twitter, and somebody said 'people living with HIV need to be stamped or tattooed so that we know who they are, and we know that they are river full of crocodiles.'

The participants living with HIV also noted that as women, they felt that U=U was being used as a mechanism to control them and their bodies for the sake of minimising risk to others, and not for their own wellbeing, as explained by Sabrina:

I initially jumped on the U=U bandwagon, like the biggest cheerleader ever, and I have backed off it quite a bit. Because I have seen it being used against woman . . . that you have this moral, ethical, legal responsibility. In Canada, it [HIV non-disclosure] is still criminalized here, so you have a legal responsibility to be undetectable.<sup>A</sup> And that's not quite as empowering as the message seems.

<sup>A</sup>In Canada, people living with HIV do not have a legal responsibility to be undetectable. However, in 2012, the Supreme Court of Canada ruled that people living with HIV must disclose their HIV status to sexual partners prior to sexual activity that poses a "realistic possibility" of HIV transmission.<sup>37</sup> The duty to disclose can be averted if the person living with HIV both uses a condom *and* has a low plasma HIV-1 RNA viral load during vaginal sex. This is one of the strictest legal standards criminalising HIV non-disclosure worldwide and has resulted in a high rate of prosecutions of people living with HIV in Canada.<sup>38</sup> People living with HIV who do not disclose their status prior to sexual activity that poses a "realistic possibility of HIV transmission" can be charged with different offences under the *Criminal Code*, including aggravated sexual assault.<sup>37</sup> Public health advocates, HIV clinicians, legal experts, and community leaders argue that the overly broad use of the criminal law against people living with HIV undermines efforts to engage individuals in health and social care, exacerbates known gendered barriers to care experienced by women living with HIV, and undermines the messaging of U=U.<sup>38</sup> In January 2023, the Canadian government launched a public consultation to review the criminal law regarding HIV non-disclosure.<sup>39</sup>

On the surface, that is, 'Oh great, I'm undetectable. I can't transmit the virus.' But that comes packed with layers of responsibility, of expectations, and of potential shaming if you fail.

This loss of bodily autonomy as women after being diagnosed with HIV, and the impact this has on women's lives, was also further expanded by Fatima:

We, women living with HIV, lose our bodies as our bodies, at diagnosis at some point and just take on this mindset to protect our lives and the people around us and that becomes like the centrefold of everything that we do and day-by-day we lose who we are, what our bodies are supposed to feel or be . . .

In addition, both women living with HIV and the general public noted that women living with HIV often carry the burden of having to educate others and explain U=U. As Leela, a member of the general public, noted:

So, U=U would be great if the rest of the world understood it and had the knowledge, but they don't. The burden is on the person living with HIV to educate people. That's really complicated, and I could imagine, I don't know, but it could get exhausting as well.

### **Response: existence of widespread HIV stigma and its patriarchal influences**

Through emotions and understanding came further engagement and response with the issues raised in the film at a systems level in both stakeholder groups. Regardless of HIV status, both groups of participants noted how intersections of gender, race and sexuality influenced experiences of living with HIV, and that even in present day, white, *cis*-male, gay voices dominated the HIV field. For example, Sachi, a woman living with HIV said:

The Australian HIV response has been MSM [men who have sex with men] . . . Gay men have been the priority population. They have been the majority of the population. And I walk into rooms often where I am the only woman in the room. I have been shushed by men. I have been held out at meetings. I have been called a bitch. I have been called a fag hag.

The women living with HIV also shared that U=U on a broader level had not reduced their experiences of systemic discrimination, as Sachi added:

You know it [U=U] doesn't change where we are today with that politicization and criminalization of our bodies.

Women living with HIV also shared that even in well-resourced settings, systemic misogyny inhibited their ability

to obtain funding for women's research and resources, as well as leadership opportunities in the HIV sector. Many women living with HIV further noted that when they have tried to advocate for themselves, they have experienced violence; for example, Sabrina from Canada disclosed:

I have also been trolled, I have been abused verbally, I have been put down for my opinions as a HIV-positive woman speaking out and being out with my status, by predominantly men . . .

Participants from both groups also noted that social systems tend to further blame women living with HIV. Members of the general public lamented on how their education never exposed them to the social impacts of HIV, and how their current knowledge was informed by social media and television that mostly presented men living with HIV. In the rare cases where women living with HIV were included, they would be framed as undeserving to have romantic relationships, as Samantha, a member of the general public, shared:

There was one series . . . where it was like one woman that like, basically had to apologize because she was HIV positive and wanted to be in a relationship.

Attendees noted the danger of these stereotypes, as one healthcare worker, Camila, commented:

I had a client that was HIV positive, that has had an undetectable viral load for years and years and years, and in Canada, that is considered high risk still. Even though they wanted to have a home birth with midwives, the midwives said no, and then in the hospital they were treated as if they were shedding virus everywhere. They had a really awful experience.

Women living with HIV shared how this systemic discrimination can be internalised and result in feelings of unworthiness, significantly impairing quality of life. As Amelia observed:

Recently I was just thinking about all this, the U=U, and then I was just having such emotional thoughts around it to say, in trying to explain this to your sexual partner, and the stigma you have to go through . . . Every day you are questioning yourself . . .

Both stakeholder groups appreciated that the film addressed social issues and positively framed sexuality, as opposed to traditional biomedical narratives on HIV related to transmission and risk. For example, Stevie, a member of the general public noted:

So much of the media that shows people living with HIV is so negative and not, like, shown them in a positive light,

and this movie – really I think the take away for me is that it was showing these women who were saying ‘no, I’m going to own this’.

Participants commented that they valued that while the film highlighted the complexities of U=U, it empowered women, reminding them that one can still thrive with HIV. As Samantha stated,

It’s turning what the world wants to be weakness and navigating that, and turning that into the source of power.

For women living with HIV, the film prompted deeper contemplation of the role of HIV in their lives, and their journey combatting internalised stigma and getting to a place of self-love and acceptance of their present selves. As one woman living with HIV commented,

[We need to] believe it in ourselves that we are beautiful and worthy and fabulous, and we having this HIV has built resilience and a lot of other beautiful things that we need to be proud of.

### **Change: opportunities for intra- and inter-personal action**

Most participants were moved to change in two ways; at an intrapersonal level, and at an interpersonal level through the desire to influence others. Women living with HIV strongly emphasised the need to reclaim their own narrative, regardless of viral load. For example, one woman noted:

I was actually thinking the next time I want to disclose to someone, if I find myself shying away or feeling fearful or it’s not worth it, that I can think of this movie and channel that energy of encouragement and hope and use that to propel me.

Participants not living with HIV said the film made them more aware of a subconscious bias that they carried, and that the film moved them towards more mindful behavioural change to treat people living with HIV with increased curiosity for their stories, compassion, respect and inclusion. For example, Taylor shared:

I think an inherent bias we all might have unfortunately, which is just something you have to work on everyday, whenever you meet someone to, sort of not, not discriminate, but also not to behave differently if someone with HIV is around you. I think that’s something I also felt a little guilty about when I was watching the film. And I was just thinking to make sure I work on it from now on.

Both women living with HIV and the general public also suggested that they may participate in and/or conduct

research in order to amplify the voices of women living with HIV. Two members of the general public also shared there was a strong desire to conduct personal research on HIV and U=U, as Jasmine shared:

I am left with a spark. In that the film is a spark to ignite the conversation and the conversation has kind of left me with a spark to Google after this and do a bit of research.

Both women living with HIV and the general public agreed that sharing the film could make participants more compassionate towards the experiences of women living with HIV; for example, as one woman living with HIV noted:

I feel that it gives you a glimpse into our lives. So, I am hoping it will help people to be more empathetic by seeing, you know, how we have been affected.

Members of the general public noted that this film would be beneficial to people in the HIV field, including healthcare workers; for example, Jasmine noted that this film may add ‘an additional layer of humanity’ to the medical care and support they provide.

Women living with HIV, in particular, were motivated to nurture sisterhood and to continue to empower other women living with HIV, noting that not all women living with HIV have access to the science of U=U. As Danny commented:

So, let us start by giving them the information that they need to believe in themselves so much, because we have that information, but some people don’t have that information, they don’t have the privilege of the information. So, let us start by that, enabling them to own their own narrative, and once you own your own narrative, you are able to actually change your own narrative.

## **Discussion**

This study found that the embodied storytelling in the short film, *HIV Made Me Fabulous*, was an effective method to counter HIV-related stigma among people living with and without HIV, by driving emotional connections, developing understanding and reflection, and sparking a willingness to influence positive change. As Almeida and Sousa<sup>40</sup> have noted, stigma can transpire as emotions, cognitions and behaviour, and our findings reveal that the film was able to impact each of these facets.

Regardless of HIV status, participants described a range of positive and negative emotions, including relief, empathy, joy, anger, frustration and anxiety, which were accompanied by somatic responses, such as feeling goosebumps, teary, experiencing a slap, and a ‘gut-wrenching’ sensation. Kilpatrick<sup>36</sup> describes these as ‘transformative psychosomatic moments’,

where imagery and movement such as dance can activate sensations in the physical body (the soma) and trigger thoughts and feelings (the psyche). These reactions and emotions are interpreted differently depending on distinct emotional schemas, developed from personal beliefs, societal influences, and earlier life experiences.<sup>41,42</sup> This means that each individual watching the film may have a different reaction based on their unique embodied memories. This may explain why some women living with HIV had stronger, more triggered reactions to the film as they have experienced enacted and internalised HIV stigma, which framed their perception.<sup>43,44</sup>

Our findings also highlight how heightened emotional responses stimulated by the film led to greater understanding and response to key themes and issues pertaining to U=U for women living with HIV. A key difference between audience groups, however, was the depth of knowledge about HIV that they had before watching the film and thus the level of complexity with which they could engage with the film's themes. For most of the general public, the film was their first introduction to U=U, and we found that they needed supplementary information on this. Our team hence modified our screening protocols accordingly to provide this background information prior to screening the film and documented this in the film facilitation guide.<sup>32</sup> In contrast, for women living with HIV, their reflection went much deeper as they explored the benefits and challenges of the U=U message and how it has affected their past, present and futures, including impacts on self-love, bodily autonomy and control, and the continued role of patriarchy in the HIV space. Participants agreed that although in theory U=U has the potential to dispel stigma, the movement was introduced in existing oppressive structures of sexism and systemic misogyny that influences health and health outcomes, in particular placing women at risk of violence when disclosing to new partners.<sup>21</sup> This suggests the need for gender transformative approaches to U=U that simultaneously tackle HIV, gender, and rights together.

Importantly, the film also resulted in shared impacts among participants living with and without HIV in regard to increased empathy and motivation to address HIV stigma. This suggests that the film supported a blurring of identities between the *stigmatised* and *stigmatisers* where HIV-negative participants identified with themes and identities presented in the film. Members in both audience groups acknowledged that the film made them recognise existing bias and compel them to behave more compassionately; and for women living with HIV, they felt more empowered to reclaim their narrative, and embrace acceptance for their bodies beyond the constraints of maintaining an undetectable viral load. Both stakeholder groups also noted that there was a great need to increase awareness of U=U and that to achieve this, the film could be a useful tool to easily share with others. The power of artistic media has been reflected in previous research suggesting that the benefits of such approaches lie in their ability to elicit affective and somatic responses that are hard to provoke through information or statistics

alone.<sup>45,46</sup> There is a growing body of scholarship highlighting that the processes involved in learning and change include affective, embodied, and pre-conceptual consciousness.<sup>45,46</sup> This study adds to the literature demonstrating the benefits of the arts for social change and has important implications for future educational campaigns that aim to raise awareness about U=U and reduce HIV stigma in the community.

## Strengths and limitations

The strength of our approach is that it centred on women living with HIV in the research and translation process; considered the impacts of the film on both people living with and not living with HIV; and had global reach with participants from Canada, Australia and countries in Africa and Asia. Key limitations of the study include that there was a limited representation of men and gender-diverse participants. Although we did attempt to reach out to these stakeholder groups, few self-selected to join the focus groups sessions. We considered that the film may have been perceived as 'women centric' and future work will aim to clarify that the film is for all audiences. Our findings could have been influenced by this self-selection, as the predominantly women participants may have had a stronger identification with Roche compared to men.<sup>27</sup> We encourage future studies to proactively incorporate additional genders including men, who as sexual partners and community members, are essential to engage to promote gender equity.<sup>47</sup> Second, we did not collect demographic information of the participants beyond what they shared during the focus group discussions. This information may have been beneficial to understand how responses may have deviated between different sub-groups, and hence how to best adapt the screening for a particular sub-group. For example, it was inferred in the focus group discussions that the film could have useful impacts for healthcare providers. This is consistent with previous global research, which indicates a need to bolster sexual health education and stigma reduction among healthcare providers.<sup>23,27,48,49</sup> Third, although virtual platforms can increase accessibility and representation for focus group discussions, we recognise that attendance may have been limited by access to technology, a stable internet connection and digital literacy.<sup>50</sup> Furthermore, some participants chose to keep their video off, which obstructed our ability to decipher their body language and facial expressions in response to the film. Finally, although co-facilitation with a peer had benefits of increasing the comfort for women living with HIV to engage in the sessions and of humanising the experiences of women living with HIV, the general public may have experienced social desirability bias where they felt compelled to share positive, affirming feedback. Furthermore, the general public may be more likely to generate empathy after interaction with the peer



researcher,<sup>23</sup> which may be conflated with the perceived impacts of the film.

## Conclusion

Overall, these findings endorse that the film's embodied storytelling was an effective knowledge translation tool to impart education, stimulate reflection and elicit willingness to address stigma at intrapersonal and interpersonal levels. Furthermore, the film could support empowerment for women living with HIV, minimise their burden to disseminate information on U=U, and serve as an important reminder for women to celebrate themselves regardless of viral load.

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