



Barriers, Facilitators and Opportunities for HIV Status Disclosure Among Young Men Who Have Sex With Men: Qualitative Findings from the Tough Talks Intervention

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Abstract

Disclosing one's HIV status can involve complex individual and interpersonal processes interacting with discriminatory societal norms and institutionalized biases. To support disclosure decision-making among young men who have sex with men (YMSM) living with HIV, we developed *Tough Talks*TM, an mHealth intervention that uses artificially intelligent-facilitated role-playing disclosure scenarios and informational activities that build disclosure skills and self-efficacy. Qualitative interviews were conducted with 30 YMSM living with HIV (mean age 24 years, 50% Black) who were enrolled in a randomized controlled trial assessing *Tough Talks*TM to understand their experiences with HIV status disclosure. Interviews were recorded, transcribed, and thematically coded. Barriers to disclosure focused on fear, anxiety, stigma, and trauma. Facilitators to disclosure are described in the context of these barriers including how participants built comfort and confidence in disclosure decisions and ways the *Tough Talks*TM intervention helped them. Participants' narratives identified meaning-making within disclosure conversations including opportunities for educating others and advocacy. Findings revealed ongoing challenges to HIV status disclosure among YMSM and a need for clinical providers and others to support disclosure decision-making and affirm individuals' autonomy over their decisions to disclose. Considering disclosure as a process rather than discrete events could inform future intervention approaches.

Keywords Status disclosure · Stigma · Men who have sex with men · People living with HIV · Mental Health

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Introduction

In the United States (U.S.) men who have sex with men (MSM) are disproportionately impacted by the HIV epidemic, accounting for 67% of new cases in 2021 with higher rates among MSM under age 34 [1, 2]. The burden of HIV is more concentrated among MSM of color due in large part to social and historical conditions driving health disparities including discriminatory policies, systems, and social norms [2–7]. Younger individuals have lower rates of viral suppression, with these same conditions impacting delayed diagnoses and undermining adherence to antiretroviral therapy (ART) [2, 8–10]. In many areas of the U.S., the intersections of HIV stigma, racism, and heterosexism underlie the challenges of accessing and persisting with HIV treatment [11–16], particularly during the critical social, cognitive, and behavioral development periods of adolescence and young adulthood [17–19].

Within this context, young MSM (YMSM) diagnosed with HIV can experience personal traumas from learning their status and from disclosing it to others [20–22]. HIV status disclosure carries the anxiety of experiencing discrimination, anticipated and actual loss of social and familial support, intimate partner rejection and/or violence, and physical harm [20, 23–25]. Those who do not disclose their HIV status to avoid perceived or repeated negative outcomes may experience interruptions in HIV care and loneliness or depression associated with the lack of social support [25, 26]. Tailored interventions for YMSM are needed to support HIV management and status disclosure decisions while recognizing that disclosure interactions happen within the inequitable social conditions previously described [27].

HIV status disclosure has been associated with safer sex and better HIV health outcomes [28–31]. However, there has been a lack of nuanced behavioral and educational interventions tailored to YMSM to aid in the decision process of disclosing their status [32]. *Tough Talks*TM, a mobile Health (mHealth) intervention, was developed to fill this

gap. The *Tough Talks*TM application utilizes artificially intelligent (AI)-facilitated role-playing disclosure scenarios and interactive self-efficacy and knowledge-building activities to support disclosure decisions [33, 34]. The full *Tough Talks*TM intervention program is described in detail on ClinicalTrials.gov [35]. In brief, participants are asked to complete four modules (‘Understanding Disclosure’; ‘Should I Disclose?’; ‘How Do I Disclose?’; ‘Preparing for the Outcome’) that include 24 short activities and eight AI-facilitated scenarios (two per module) that provide the opportunity for participants to practice the disclosure skills and strategies they are building in the context of different types of partner responses. Table 1 displays all intervention modules, their included content, and sample images from the program. We analyzed feedback from YMSM with HIV who used the *Tough Talks*TM application in a randomized controlled trial (RCT) to better understand HIV disclosure among this critical age group and to identify key interventional areas that may assist with disclosure decision making.

Table 1 *Tough Talks*TM intervention program content, overview descriptions and sample images


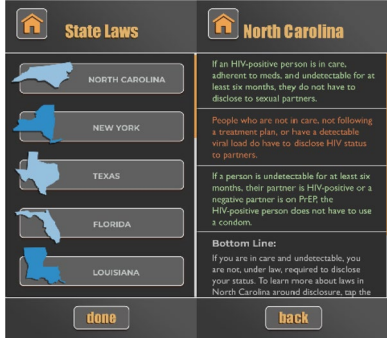



Module & activities	Description & sample image
Introduction 0.0 Meet your coach 0.1 Welcome to Tough Talks 0.2 Let’s set some goals	<p>Participants meet their virtual guide to the program, get an overview of the program, and set initial short and long-term goals around disclosure. Goals are editable and encouraged to be revisited throughout the program</p> 
Module 1 Understanding disclosure 1.0 What is disclosure? 1.1 Disclosure and state laws 1.2 Who needs to know? 1.3 I am [fill in the blank]... 1.4 What would you do? 1.5 Virtual disclosure practice	<p>Education and activities focused on disclosure foundations are presented through choose-your-own-adventure scenarios, animated videos, quizzes, interactive screens, and fill-in-the-blank reflections. Virtual disclosure practice skill-building scenarios begin with giving advice to a friend and disclosing to a supportive partner</p> 

Table 1 (continued)

Module & activities	Description & sample image
<p>Module 2 Should I disclose? 2.0 The dating game...with a twist 2.1 Your past experiences 2.2 To disclosure or not to disclose? 2.3 Is now the time to do it? 2.4 Right time, right place 2.5 Virtual disclosure practice 2.6 Reflection</p>	<p>Education, activities and skill-building focused on disclosure decisions are presented through games, videos, and reflective exercises on past disclosure experiences and future plans. Virtual practice scenarios include “in-the-moment” decisions prior to a hook-up. Participants revisit their goals set at the beginning of the program and can change or edit according to their progress</p> 
<p>Module 3 How do I disclose? 3.0 He likes me...he likes me not 3.1 Breaking the ice subtly 3.2 Tell it over text 3.3 Conversation starters 3.4 The cat's out of the bag 3.5 Virtual disclosure practice</p>	<p>Education, activities and skill-building focused on disclosure logistics and conversation approaches are presented through games, videos, and reflective exercises on a range of hypothetical scenarios and sample conversations. Virtual practice scenarios include focus on disclosure in the context of a new relationship</p> 
<p>Module 4 Preparing for the outcome 4.0 How did you find out? 4.1 Q&A: HIV edition 4.2 What are you willing to answer? 4.3 How would you answer? 4.4 What am I most afraid of? 4.5 Get out while you can 4.6 Virtual disclosure practice 4.7 Reflection</p>	<p>Education and activities focused on preparing for the outcomes of disclosure decisions are presented through videos and reflective exercises. Participants prepare to answer common questions about HIV, reflect on what they do and don't want to share (e.g. how to respond to “How did you get HIV?”), plan conversation exit strategies, and identify disclosure fears. Virtual practice includes challenging disclosure scenarios. A final reflection exercise revisits disclosure goals and plans</p> 

Methods

Study Design & Participants

YMSM participants ($n = 156$) were recruited and enrolled into an RCT conducted May 2019 through April 2022 to assess whether exposure to the *Tough Talks*TM HIV status disclosure support intervention could increase sustained viral suppression. Eligibility criteria included being assigned male sex at birth, identifying as male at the time of screening, being age 16 to 29 years old, living with HIV, having a smartphone or tablet, being conversationally fluent in English, and reporting anal intercourse with a male partner in the last 6 months OR reporting an STI diagnosis (urethral/rectal gonorrhea, chlamydia or syphilis) in the past six months (self-report verified by medical chart review including review for record of lifetime past sex with a male partner). Participants also needed to have a viral load measure within the past 12 months of their study screening date which could be assessed by retrospective chart review, a new blood draw, or a medical record result shared by participant via video teleconferencing or secure upload via Qualtrics.

Those who screened eligible were consented by study team members from study sites in four states (North Carolina—NC, Texas—TX, New York—NY, and Florida—FL). At enrollment, participants completed a baseline computer-assisted survey and were randomized into a standard of care control arm ($n = 52$) or one of two intervention arms that used the *Tough Talks*TM program either with the support of clinic staff or on their own at home ($n = 104$). All participants completed three self-administered computer assisted follow-up surveys (at 1-, 3-, and 6-months post enrollment) to assess changes in demographics, HIV outcomes, social and behavioral factors associated with HIV care and disclosure outcomes, and changes in disclosure decisions and perceptions. In May 2020, a study amendment was approved to include remote procedures (e.g., conducting study visits via secure videoconferencing platform) to accommodate the continued conduct of the study during the COVID-19 pandemic and to open the study to national enrollment. Participants within each original study state were enrolled by that state's respective study team. Participants outside of the original four states were enrolled by region (NC—midwest, TX—west, NY—northeast, FL—south) or if unavailable, by the University of North Carolina (UNC) lead study team.

All participants who used the *Tough Talks*TM program were invited to complete an optional qualitative interview after their one-month follow-up visit. To ensure a diverse sub-sample was achieved, interviewee characteristics were tracked including age, race/ethnicity, enrollment site, HIV diagnosis within the past year, past disclosure experience, and intervention use. Interviews were offered until a sample

size of 30 interviews was reached which allowed for variation across these characteristics and could provide sufficient data for finding saturation in key themes [36–39]. This analysis uses data from the 30 participants who completed qualitative interviews including their baseline and one-month survey responses and their interview transcripts. All participants received financial remuneration for their time.

Survey Assessments

A baseline survey collected demographics (age, race, ethnicity, education, employment), clinical background (depressive symptoms as measured by the Patient Health Questionnaire-8 (PHQ-8) [40] and anxiety symptoms as measured by the Generalized Anxiety Disorder-7 (GAD-7) [41], HIV status disclosure behaviors [42], perceptions of HIV stigma [43], perceived disclosure consequences [44], and HIV transmission risk beliefs [45]. Clinical viral load was abstracted from medical records or provided by participants. The one-month follow-up survey collected participants' feedback on the *Tough Talks*TM app [46] and its impact on disclosure decisions [47]. All surveys were conducted through Qualtrics. For the qualitative subsample responses, Microsoft Excel was used to calculate descriptive statistics. Selected survey response data from the 30 interviewees is included in this analysis to describe the qualitative sub-sample and add context to the psychosocial barriers to disclosure that participants described. Analyses of the full RCT sample and study outcomes will be presented in subsequent manuscripts.

Qualitative Interview Procedures

Semi-structured interviews, lasting approximately 40 to 60 min, were conducted from July of 2019 through January of 2021 by two UNC study staff in-person ($n = 4$) or over a HIPAA-compliant licensed videoconferencing platform ($n = 26$). Remote interviews were offered to allow for consistency—using the same interviewers across geographically dispersed study sites—and to support ongoing research activities during the COVID-19 pandemic. Interviewers used a question guide that focused on participants' previous experiences with HIV disclosure, barriers and facilitators to disclosure, and reflections on the *Tough Talks*TM intervention's utility for supporting their future disclosure decisions. In participants' interview dialogues, narratives about disclosure decisions and experiences were not limited to discussing the intervention. With this openness, participants could describe their experiences with the intervention—and its strengths and limitations—while keeping intact their narratives about actual disclosure events and reflections from before and during their time enrolled in the study. Participants received \$50 USD as remuneration for completing an in-depth interview.

Qualitative Data Analysis

Audio recordings were transcribed verbatim by a professional transcription service (Verbalink) and reviewed by the study team for accuracy against the original recording. Participant identifiable information was redacted from transcripts prior to importing them into Dedoose Version 8.0.35. The analytic team used an inductive thematic analysis approach [48, 49]. They first read all transcripts and collaboratively identified high-level themes related to barriers and facilitators to HIV disclosure, impact of the behavioral intervention on disclosure decisions, and outcomes of disclosure. These themes were developed into a structured codebook with definitions and examples, discussed and refined among the full study team, and used to systematically code all transcripts. Each transcript was coded by two team members separately and then reviewed together to identify differences in the application of codes. Coding discrepancies were discussed among the full coding team at weekly meetings and updates made to the final coded transcript and codebook, as needed, to reflect the outcomes of these discussions. The coded sub-themes pertinent to disclosure decisions and the emotional context of disclosure are explored here. Illustrative quotes were excerpted and excess filler words removed (e.g. “like”, “um”, “uh”), but are otherwise presented verbatim. Specific quotes were chosen from among a pool of representative quotes for each theme/sub-theme with attention to including the voices of as many participants as possible and aiming to show diversity within themes.

Protocol Registration and Approvals

This study was approved by the UNC Institutional Review Board. Participants enrolled May 2019–April 2020 gave written informed consent, those enrolled May 2020–October 2021 gave electronic signed consent due to COVID-19. The main RCT was registered through clinicaltrials.gov (NCT03414372).

Results

Survey Responses: Participant Demographics, Clinical Characteristics, HIV Stigma and Disclosure Perceptions

Selected demographic characteristics of the 30 YMSM who completed a qualitative interview are presented in Table 2. Unless otherwise noted, all prevalence measures are reported as out of 30; there were no missing responses for these measures. The qualitative sub-sample included 13 participants

who were assigned to the in-clinic intervention arm and 17 participants who were assigned to the at-home intervention arm. The mean age was 24 years old, 9 (30%) identified as Hispanic/Latinx, and 14 (47%) identified as Black or African American. Most participants (27, 90%) were from the southern U.S. due to the distribution of the research sites. At baseline, all interviewed participants had reported condomless anal sex with a male partner in the past six months and self-identified as gay (23, 77%) or bisexual (7, 23%).

At baseline, 23 (77%) participants were virally suppressed, 13 (43%) reported sub-optimal ART adherence in the last month, and one was not taking ART. Nine (30%) participants had received their HIV diagnosis within the past year. Half (50%) self-reported having been diagnosed with a sexually transmitted infection (STI) other than HIV in the past six months. In terms of mental health, seven (23%) participants reported symptoms consistent with moderate to severe depression on the PHQ-8 (total score ≥ 10) and eight (27%) scored within a range consistent with moderate to severe generalized anxiety disorder on the GAD-7 (total score ≥ 10).

Sixteen participants (53%) reported worrying that people who knew their status would tell others. Over half of the participants (17, 56%) agreed with the belief that most people think that a person with HIV is disgusting and 11 (37%) reported feeling as though they are not as good a person as others because of their HIV status. Half (15, 50%) reported believing that most people with HIV are rejected when others find out and 13 (43%) reported being hurt by how people reacted to learning their HIV status in the past. When asked to think about disclosure to a potential sex partner, most participants agreed that disclosure was important for improving relationships (27, 90%), getting emotional support (25, 83%), and allowing for blowing off steam (22, 73%).

At baseline, 23 (77%) participants had ever disclosed their HIV status to a sex partner, 21 (70%) to a family member, and 20 (67%) to a peer (e.g. friend, co-worker, schoolmate). Twelve (40%) participants reported half or fewer of their sex partners (past or present) were aware of their HIV status, 21 (70%) reported half or fewer of their family members were aware (with nine reporting no family members aware), and 24 (80%) reported half or fewer of their peers were aware (friends, co-workers, schoolmates). At one-month follow-up, a number of participants reported that the *Tough Talks*TM intervention had impacted their decisions to disclose to sex partner(s) (15, 50%), peer(s) (14, 47%), and family member(s) (11, 37%). The qualitative sample included seven individuals who had never disclosed to a sex partner prior to joining the study; of these, two disclosed for the first time to a sex partner during their first month in the study.

Table 2 Selected baseline survey characteristics of 30 interviewed Young Men Who Have Sex With Men living with HIV enrolled in the *Tough Talks*TM HIV status disclosure support intervention

	N = 30	(%)
Clinic enrollment site		
Florida	12	40
New York	3	10
North Carolina	12	40
Texas	3	10
Demographics		
Age in years (mean, range)	24 (19–29)	
Race/ethnicity		
Black or African American	14	47
White	9	30
Asian	1	3
Other	2	7
More than one category selected ^a	3	10
Decline to answer	1	3
Hispanic/Latinx ethnicity		
Yes	9	30
No	21	70
Sexual orientation		
Gay, homosexual, same gender loving	23	77
Bisexual	7	23
Enrolled in school	8	27
Employed	18	60
Clinical information		
Symptoms consistent with moderate to severe depression (PHQ-8 total score ≥ 10)	7	23
Symptoms consistent with moderate to severe anxiety (GAD-7 total score ≥ 10)	8	27
Virally suppressed at baseline	23	77
$\leq 90\%$ adherent to ART	13	43
Diagnosed with HIV within the last year	9	30
Diagnosed with STI in last six months	15	50
HIV status disclosure		
Ever disclosed HIV status to a sex partner	23	77
Disclosed to \leq half of past or present sex partners	12	40
Ever disclosed to a family member	21	70
Disclosed to \leq half of family members	21	70
Ever disclosed to a peer (friend, co-worker, schoolmate)	20	67
Disclosed to \leq half of peers	24	80
Perception HIV stigma ^b (Number of those who Agree or Strongly Agree)		
I have been hurt by how people reacted to learning I have HIV	13	43
I have stopped socializing with some people because of their reactions of my having HIV	10	33
I have lost friends by telling them I have HIV	7	23
I am very careful who I tell that I have HIV	18	60
I worry that people who know that I have HIV will tell others	16	53
I feel that I am not as good a person as others because I have HIV	11	37
Having HIV makes me feel unclean	10	33
Having HIV makes me feel that I'm a bad person	8	27
Most people think that a person with HIV is disgusting	17	57
Most people with HIV are rejected when others find out	15	50

Table 2 (continued)

	N = 30	(%)
Perceived consequences of disclosure to a potential sex partner ^c (Number of those who Agree or Strongly Agree that the statement is important)		
I could blow off steam	22	73
Get emotional support	25	83
Understanding	29	97
Improve the relationship	27	90
Partner had a right to know	27	90
Transmission risk beliefs ^d (Number of those who believe the statement is Somewhat True or Absolutely True)		
HIV can be prevented if you start taking medication right after unsafe sex	15	50
If your viral load is undetectable, there is very little chance of transmission	27	90
Someone on HIV treatment can infect an HIV-negative person with a drug resistant strain	16	53
It is unlikely that someone on HIV treatment would transmit HIV during sex	18	60
Because of PrEP, HIV-negative men do not need to be as worried about getting HIV	11	37

^aMultiple racial categories selected with write-in responses: Black/African American and Dominican; Biracial; White and Asian

^bAdapted from the Brief HIV Stigma Scale for youth [43]. Five-point Likert scale from Strongly Disagree to Strongly Agree

^cAdapted from a scale on perception of the importance of possible consequences of disclosure to sex partners [44]. Four-point Likert scale from Strongly Disagree to Strongly Agree

^dAdapted from transmission risk belief scale [45]. Five-point Likert scale (absolutely false, somewhat false, neither true nor false, somewhat true, absolutely true)

Qualitative Interview Themes

We organize the results of our thematic analysis in three main sections. First, we present the major psychosocial barriers to disclosure that participants described, focusing on fear, anxiety, stigma, and trauma. Next, we present facilitators to disclosure in the context of these barriers including how participants shared their building comfort and confidence in disclosure decisions. In this section we include ways that participants noted the *Tough Talks*TM intervention was helpful to them, while also describing disclosure facilitators beyond the intervention. Our third theme highlights additional meaning-making and actions that participants identified within disclosure conversations including opportunities for educating others and advocacy. This theme identifies possible targets that future interventions could draw from in support of positive disclosure experiences. Table 3 lists the three major themes and all subthemes.

Theme 1: Psychosocial Barriers Inhibiting Disclosure

Participants' experiences reflected persistent societal-level HIV stigma that influenced how and when they disclosed their status. Multiple participants shared concerns about the continued misunderstandings around HIV, including that "a lot of people hear the word HIV [and] in their minds automatically go to AIDS." (Participant AC, White, Age 21). Because HIV is still perceived by some as a death sentence, as one participant explained, "I don't want them

Table 3 Analytic themes and subthemes from the *Tough Talks*TM intervention exit interviews with young men who have sex with men

<i>Theme 1: Psychosocial barriers inhibiting disclosure</i>
Experiencing societal ignorance, fear and discrimination around HIV
Internalizing shame and fear
Acknowledging overlapping stigmas of HIV and homophobia
Having a traumatic HIV diagnosis experience
Worrying that information about one's HIV status will not be protected
Anticipating future rejection based on past rejection experiences
<i>Theme 2: Building comfort and confidence in disclosure decisions</i>
Receiving insufficient prior guidance and education hindered disclosure
Receiving information and education about HIV helped build disclosure comfort and confidence
Practicing disclosure scenarios helps prepare to initiate conversations
Practicing disclosure scenarios helps prepare to respond to partners' reactions and questions
Drawing strength and social support from examples of others' disclosure stories
<i>Theme 3: Outcomes and meaning-making in disclosure</i>
Experiencing post-disclosure relief
Accepting oneself and one's HIV status
Using disclosure to educate others about HIV
Acknowledging the burden of educating others
Appreciating new narratives about HIV in mainstream media

[people I disclose to] thinking that I'm dying." (Participant V, White, Age 21). Further, experiences of discriminatory treatment were common, including some related to lack of knowledge about HIV transmission. In addition

to discouraging future disclosure behaviors, these experiences were stigmatizing and socially isolating:

You feel like you don't have anyone to talk to because there's certain friends that do, after you tell them, they will look at you like you're dirty. They don't want to share food with you, they don't want to share drinks...when I found out [my status] my dad had me wear gloves when I cook. (Participant X, Black/African American, Age 25)

These associations and experiences made it difficult for people to consider initiating a conversation about their HIV status as they anticipated the post-disclosure stigma.

For some participants, the negative stereotypes they described about HIV were internalized into shame and other negative self-perceptions. Getting to the point of being able to disclose then required working through these internal feelings. One participant shared how they struggled through these feelings amidst negative feedback from disclosure attempts:

When I first was diagnosed, I went with the whole, I might as well put it on my profile or whatever, but it would come with negative feedback ... It's made me sit in bed at night—I'm just sort of there feeling bad about myself, all sad. But then there's other nights where I'm like...I'm just me. I don't think about it. (Participant D, Not Reported, Age 19)

A number of participants' narratives also reflected overlapping stigmas around HIV and sexual orientation. As one participant shared, "*Along the way, there have been a lot of self-doubt and do I love myself?...I used to go to church too, so it was like, 'God, are you punishing me for being gay?'*" (Participant Q, Latinx, Age 24). Homophobia and internalized stigma about sexual orientation added another barrier to the disclosure decision. Participants commonly described these layered stigmas in regard to disclosure to family:

My family was very judgmental of my sexuality when I first came out. For me to sit there and have to tell them, 'I'm gay. And I have HIV.' was very, very hard to do. You know, like, they knew I was gay already. But it's just putting a stigma on top of a stigma. (Participant AC, White, Age 21)

Those who were not ready to share their sexual identity, or who did not want to relive the negative experience of coming out, were hesitant to disclose their HIV status to family and friends.

This layered stigma intensified the trauma of being diagnosed with HIV, with participants reporting fear of rejection, isolation, and despair upon learning their status. The period directly following diagnosis was identified by

many as a time when they had the most negative cognitions surrounding their future and health:

When I was first diagnosed...I was going through this thing that this is the end of life as I know it. Once I tell my family, its gonna disown me after this...I was 18 when I found out. So it's like I wasn't in a steady relationship...or even close to it and I was young and dumb...You live with the fear of you just being by yourself for the rest of your life. (Participant M, Black/African American, Age 26)

Overall, participants described heightened impacts of minority stress and rejection sensitivity following their diagnosis. For some participants, HIV-related rejection anxiety continued to deter disclosure for years following diagnosis. One participant explained how despite wanting to disclose, the fear of rejection was an insurmountable barrier:

The fear mostly is reject[ion] of the people who [are] the most you care, the most you love, and you go to them, trying to disclose, and take that thing out of your heart and mind, and you just see their faces, and you imagine, 'I can't.' (Participant R, Black/African American, Age 22)

As illustrated in the quote above, even the thought of sharing one's HIV status could trigger anxieties of past or anticipated future rejection.

Fear of rejection, internalized stigma, and cautionary warnings from friends contributed to participants' hesitancy to trust others with protecting information about their HIV status. As one participant worried:

I fear smear campaigning...and my prior history of being harassed, on Grindr. And like people making fake profiles of you and whatnot, and blasting your status everywhere. I've had friends who have crazy exes who called their parents and told them or sent them letters in the mail and told their family that they're positive. So I'd more so fear, like if I tell someone, that they wouldn't keep it confidential in the way that I would want them to. (Participant AB, White, Age 21)

This quote illustrates the perceived loss of control that may accompany disclosure. Some participants shared stigmatizing experiences that informed their hesitancy to trust others with knowing their HIV status. Descriptions of these experiences included emotional attacks and threats to participants' self-worth. In the case of one participant, the pain and trauma from a bad disclosure experience left a deep and lingering pain:

It hurts to repeat it. Even now, the words—the exact words he used was, 'Who in their right mind would

risk their life to be with you?’ And that was heart-breaking. Because it’s like you’ve already been with me for two years...From then, that’s when I became to where I didn’t even want to talk about it. It literally broke me to even be in the same vicinity of the conversation. (Participant I, Black/African American, Age 23)

Participants connected anticipated and experienced harassment with avoiding talking about their HIV status.

Alongside the concerns of what might happen if one discloses, participants also feared exposing sexual partners to HIV. The stress of these uncertainties was reflected in how participants talked about disclosure to sexual partners. As one participant described:

One of the things that I fear is that although I’m undetectable, like what if that person gets HIV from me? Or what if I’m sleeping with someone and there’s a blip in my virus. There’s all those what ifs because my biggest fear is always transferring HIV to someone else. So that’s always my fear too, like I tell them, and the sex isn’t the same. (Participant A, White, Age 27)

The perceived need to both conceal *and* disclose left some participants caught in a cycle of fear and anxiety about the impacts of disclosure and non-disclosure on their relationships. A participant with numerous negative disclosure experiences confided, “I’m pretty much [keeping to] myself, so much trauma that I have become asexual. I don’t have to worry about putting anyone at risk.” (Participant AD, Not Reported, Age 28). A few participants described this approach of avoiding sexual relationships altogether, rather than having to feel anxious about exposing a partner to HIV or managing the risks of disclosure.

Summarizing *Theme 1*, key barriers to disclosure among participants included the fear and anxiety of rejection and judgement related to sexuality and serostatus, and fear of onward transmission. These feelings were reinforced by previous negative experiences disclosing sexuality and/or serostatus, alongside internalized and anticipated HIV-related stigma, trauma, and homophobia.

Theme 2: Building Comfort and Confidence in Disclosure Decisions

When considering prior HIV education, the clinic was one of the few spaces where participants discussed their HIV status right after diagnosis. However, participants in this sample described receiving limited support or resources in the context of the clinic to equip them to navigate status disclosure following their diagnosis. One participant specifically identified a gap in support for the emotional components of disclosure:

They [providers] don’t walk you through on how to do it or how to deal with someone else’s emotion outside of yours because you’re already kind of walking into the situation a little broken; a little skeptical, anxious and scared. So, there’s no written thing out there. No video to help someone process that. (Participant X, Black/African American, Age 25)

Before using *Tough Talks*TM, a number of participants described the disclosure education they experienced as primarily focused on the punitive implications of nondisclosure based on state laws. One participant explained how information from the clinic is “*not really information that helps you, it just tells you that you need to disclose—it’s not really explaining to you how you need to do it and tips to help you with it.*” (Participant M, Black/African American, Age 26) Another participant was frustrated that their doctors were generally “*more focused on the clinical aspect of it [HIV]—not more of the behavior like, hey, now that you are undetectable, are you having sex and like, would you like to disclose your HIV status?*” (Participant A, White, Age 27) Overall, most participants reported that in the past they had not received sufficient guidance about disclosure or education about HIV to have disclosure conversations outside the clinic.

Some participants noted that information included in the *Tough Talks*TM intervention (e.g., about living healthy with HIV and the importance of HIV medications) helped with their own and others’ anxieties around HIV. As one person described, “*this study has given me a lot more information, has given me a lot more confidence, I would say to talk to other people about it [HIV].*” (Participant G, White, Age 25). Knowledge helped counter negative perceptions around HIV and provided reassurance in the face of fears and anxieties. Participants also described how education and understanding supported their own greater acceptance of their diagnosis and feelings of confidence about disclosure:

You come to an understanding to where okay, I shouldn’t have to beat myself up or how can I say, be combative with myself, with my inner thoughts rather than trying to have this conversation (Participant L, Biracial, Age 24).

The part [in *Tough Talks*TM] where it tells you, “See, nothing has changed in your life even after you were diagnosed.” That part is pretty emotional. It tells you, “See, everything’s okay. Nothing has changed.” Perhaps it gives you a better understanding about your own health compared to other people. (Participant J, Asian, Age 23)

These conversations illustrated the important role of information about both HIV and status disclosure in

countering the fears and anxieties YMSM experienced following diagnosis and in preparing for disclosure decisions.

Each of the intervention's four modules (Table 1) concluded with role-playing practice scenarios of different types of disclosure conversations. Participants highlighted a variety of ways these practice scenarios could support disclosure decision-making. One person felt that the practice scenarios helped normalize talking about one's HIV status because otherwise *"it's awkward talking about it [HIV], and I guess the app really helped with like why it shouldn't be awkward—like why it should be a normal thing."* (Participant B, Black/African American, Age 24) Participants also appreciated experiencing different types of partner reactions in the program. In some cases, having these experiences offered reassurance that a disclosure conversation could have a more positive outcome:

I thought it [Tough Talks™] was really awesome... the responses that I was getting were great, especially when it did the two different scenario ones where he would have one reaction to what I said about disclosing HIV versus a different reaction. And that was definitely helpful, because it's like, oh, if I go about it this way, he's going to respond like this. If I go about it this way, they're going to respond like this. So it does help me and other people to know how to talk about it. (Participant AC, White, Age 21)

In addition, several participants shared that they could relate to the types of questions that the virtual character partner raised in the disclosure scenarios. One person explained how you have to be prepared for how people will react:

They will ask you a lot of questions. So, "oh my god, you have HIV, what does it mean? Does that mean you have AIDS?" Or, "What are viral loads?" and how your recent test result came out to be... You have to be prepared. In the app, there's one scenario where the person reacted with many questions [just like that]. (Participant J, Asian, Age 23)

A number of participants noted that they often had to explain concepts like PrEP or ART during a disclosure conversation. One participant endorsed how the disclosure scenarios could help them prepare for these conversations stating that by using the app, *"now you actually have to think of, 'How am I going to say this?' And once you figure out a good one, you can use it a thousand times."* (Participant Z, Black/African American, Age 28) As suggested in the quotes above, the practice scenarios were generally well-received and helped shift some of the emotional aspects that had previously dominated disclosure experiences to more cognitive aspects that could be worked through like solving a problem.

In addition to practicing disclosure conversations, the *Tough Talks™* intervention content also included example

stories of other YMSM's disclosure experiences. This aspect of the intervention was rated highly and some participants connected these examples to encouraging their own disclosure decision-making:

I still enjoy hearing how other people, like what their experiences have been with disclosure. And I guess the app just helped me think deeper into it. And like, helped me solidify how I feel about things and how I want to go about things... sort of put forward the options that I have. (Participant AB, White, Age 21)
It [the Tough Talks content] just gave me that boost, the wanting to talk about it and disclose it. And then when you see other people's stories, that just gives you a little bit more confidence as well. (Participant P, Black/African American, Age 25)

Building on the example stories within the app, a few participants expressed ideas for social support for disclosure outside of the context of the intervention including sharing experiences with HIV positive peers or sharing disclosure experiences in an accepting group setting to help people not feel alone in this process.

As described in *Theme 2*, these interviews illustrated how building comfort and confidence for disclosure decisions could be grounded in having access to more educational resources and support post-disclosure. Informational support played critical roles in reassuring YMSM, supporting self-acceptance and normalizing disclosure conversations. Feeling prepared—through information and practice—to answer difficult questions about HIV helped participants plan for disclosure with more confidence and equipped them to resist HIV-related stigma encountered in disclosure conversations. Disclosure confidence was bolstered through shared stories from peers living with HIV which provided encouragement and prompted additional self-reflection.

Theme 3: Outcomes and Meaning-Making in Disclosure

Participants were asked to reflect on ideas for improving the *Tough Talks™* intervention and other ways to support status disclosure. These conversations included examples of finding value in disclosure beyond the individual act of disclosing. One of the most positive outcomes of disclosure decisions that participants emphasized was experiencing relief or reducing a burden. These discussions were often framed as a contrast of "then" and "now" and could reflect a gradual growing support network. As one participant shared, *"one good thing is my boyfriend knows about it now, and my family knows about it. So, I feel a lot less burdened"* (Participant J, Asian, Age 23). For another participant, this was described as a more dramatic change after reaching a breaking point:

I was just done with having to hide that part of my life. As far as having to deny it and having to act like I'm straight, I was just living the truth and just, I'll bring a whole weight off your shoulders and how denying it can only bring more [pain]. (Participant AD, Not Reported, Age 28)

In both examples above, HIV status disclosure experiences that participants perceived as having good outcomes created positive reinforcement for thinking about future disclosure. Interventions could integrate this through components that help YMSM visualize positive disclosure outcomes as well as reflect on desirable results of past disclosure experiences.

Another approach participants identified for promoting disclosure involved shifting perspective to center the individual, rather than focusing on the judgements or reactions of others. These narratives from participants demonstrated a re-appraisal process of their HIV serostatus where internalized stigma was deconstructed.

I look at people now and I'm just like, 'Oh. I find you to be worthy enough to know a bit more about me.' And like, it kinda makes [things] easier. (Participant Q, Latinx, Age 24)

I will say I don't really feel it's about who you tell. I will say it's about being comfortable with looking at yourself in the mirror and telling yourself that, because it is very—it is very hard. It's very hard to look at yourself in the mirror and say all the things, and it's true. And then be happy with it at the end of the day. (Participant W, Black/African American, Age 21)

In contrast to the earlier theme of fear and anxiety around both concealing and disclosing, these quotes illustrate a stronger sense of control over information about one's serostatus that is centered in self-worth and self-acceptance. These elements can be incorporated into disclosure interventions using empowerment frameworks or techniques from cognitive therapy.

A number of participants described using disclosure conversations intentionally as spaces for educating others and connected these efforts to resisting stigma and ignorance. These opportunities could be used to create change as exemplified in how one participant shared his status with friends:

I took it [disclosing] as an educational opportunity... a lot of my straight friends, when I told them they were like pretty much, "You're not going to die, are you?" That was one of the reasons that I told them—was as an educational opportunity, like, "Look, you don't know this. Let me tell you so that you are pretty much not part of the ignorant stigma that's surrounding it." (Participant H, White, Age 25)

For some, efforts toward educating others were also connected to larger social meaning. As one participant described, "*When it [HIV] becomes cured, I can be like, 'I was a part of this movement, and I was the person who helped people around me understand'.*" (Participant D, Not Reported, Age 19). Another participant used these educational moments as a way to increase other people's comfort with HIV, explaining how:

I was always very open about it [my status] and I wasn't comfortable being open about it but my personality—I'm very true to who I am. And I really used it as a way to educate people about the disease and trying to make people feel more comfortable with it. So I mean I was very open about it as a way to help people. (Participant F, White, Age 22)

As expressed in the quote above, however, the work of educating others may still place the individual in a space of discomfort.

Other participants also acknowledged the burden of always having to play the role of educator or advocate. As one participant reflected, "*I feel like it's tough because sometimes as a person who lives with HIV, it's like my—some-what I feel like I'm obligated to always be the person that teaches the person about HIV. And then sometimes I don't always want to do that.*" This individual went on to describe their desire for their partner to take on some responsibility as well, saying: "*Sometimes it's more like hey, we're hanging out. I have HIV, but go online and read more about it, okay? I don't want to always be **that** person.*" (Participant A, White, Age 27). Recognition of this duality of disclosure was integrated into some of the activities within the *Tough Talks*[™] intervention, providing opportunities for an individual to reflect on their own goals and emotional capacity for disclosure in any given relationship. Sensitivity toward the benefits *and* burdens of being an educator for others can be incorporated into future intervention designs, for example in creating different types of materials and messages for different audiences.

Finally, some participants pointed toward trends in mainstream media as offering new narratives about HIV prevention and living with HIV that could be used to support disclosure. Some participants noted how more celebrities are sharing their status and television shows include characters who identify as gay or are living with HIV. One participant described how a television show prompted a disclosure conversation between him and his partner, saying:

Pose, that show passes on a lot of good LGBTQ issues that are still currently happening today...there was one scene where it was two positive gay men having sex and I'm like, "They know what they're doing, though, 'cause they know how to shake the table but also be

educational on it,” you know what I mean? So that’s kind of how that conversation started with me and him. (Participant U, Black/African American, Age 23)

Another participant reflected on how he felt the visibility of PrEP marked a notable social change. He explained that:

There’s been such a shift since, I guess, the PrEP commercials for Truvada. Before then, there was a lot of people making AIDS jokes or kind of like gay jokes. Now, it’s sort of like the current person I’m talking to, when I told them, I was, like, well, I have HIV. And they just sort of go, okay, it’s 2019. It’s not like you’re gonna die. So there’s a definite change that I’ve been seeing around the community and telling people (Participant D, Not Reported, Age 19).

As the above quote reflects, changing perceptions about HIV status disclosure were connected to both the public promotion of PrEP and recognized advances in HIV prevention and treatment. Moreover, participants appreciated that the burden on those living with HIV to educate others was increasingly shared by the media raising awareness and providing destigmatizing narratives. Disclosure interventions can build on this momentum drawing on entertainment, informational, and social media sources.

As presented in *Theme 3*, participants shared a wide range of ideas and suggestions for future support of HIV status disclosure decision-making. These included both cognitive processes like focusing on positive outcomes from disclosure and social processes like using disclosure interactions as opportunities for education and contributing to change. While caution is warranted for relying on those living with HIV to educate others, fostering the growing public visibility of HIV and status disclosure across media channels could help continue to dismantle stigma and opening more spaces for dialogue.

Discussion

There may be benefits in mental and HIV health that accompany greater comfort and confidence with making disclosure decisions, as well as implications for HIV prevention with improved communication skills and engagement in HIV care. However, the mixed nature of prior findings and those of the current study highlight the importance of a nuanced, contextualized understanding of disclosure. Behavioral health interventions, such as *Tough Talks*TM, could provide one means for supporting YMSM in processing an HIV

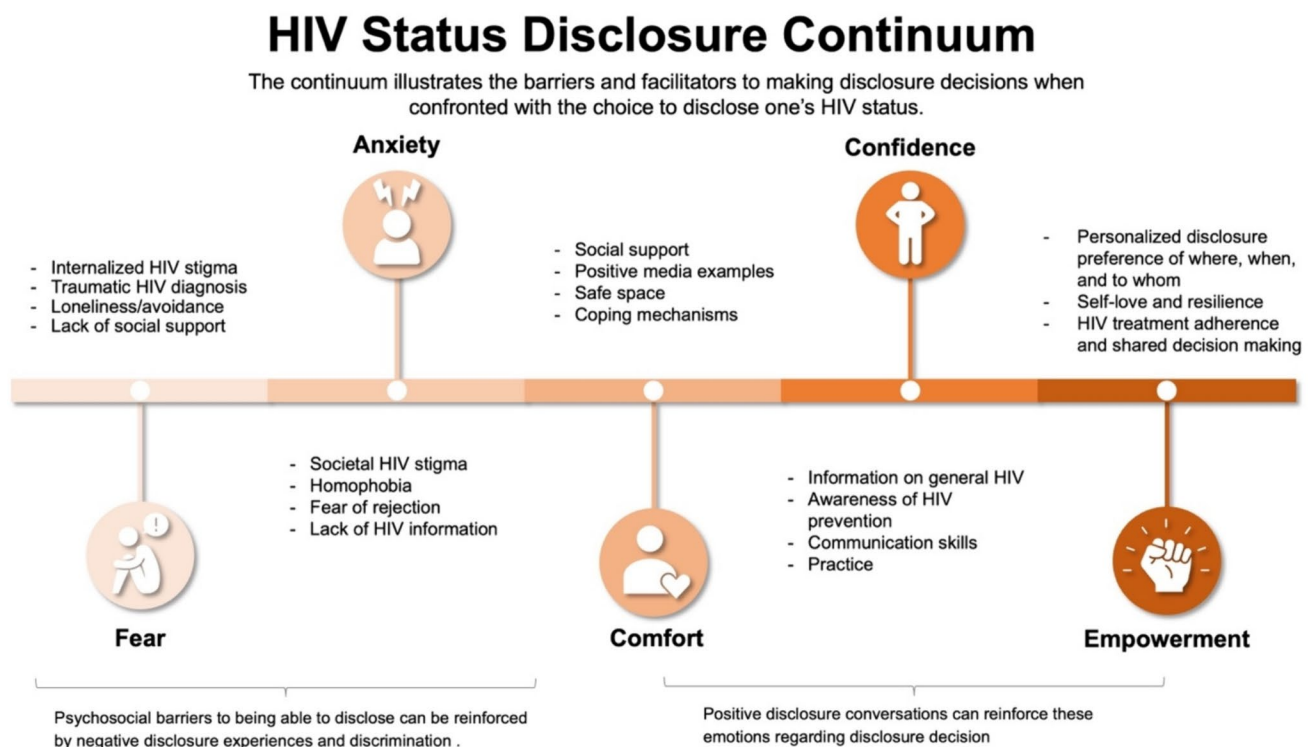


Fig. 1 Disclosure Continuum. It depicts the barriers and facilitators to making disclosure decisions when confronted with the choice to disclose one’s HIV status, including fear, anxiety, comfort, confidence, and empowerment

diagnosis and developing communication skills that aid in building a personalized HIV status disclosure decision strategy. To be most useful, this strategy—like disclosure itself—would be dynamic over time and experience.

We have synthesized our analytic findings in a framework that considers a fuller decision-making process, including the factors that inhibit disclosure and the facilitators that YMSM described as empowering them to decide when, where and how to disclose. Figure 1 illustrates this disclosure continuum framework informed by our study findings. The first two sections of the figure show the states of fear and anxiety that participants described accompanying disclosure decisions in relation to recent HIV diagnoses and ongoing experiences of stigma and discrimination. Participants in this study described how stigma and fear inhibited HIV status disclosure and isolated them from their support networks, with negative mental and physical health consequences. They also described a lack of educational resources for supporting disclosure decision-making. The third section of the figure reflects themes from our interviews of the core elements that supported individuals in building comfort around disclosure as they worked through fears and anxieties, including social support, examples, safe spaces, and coping mechanisms.

As shown in the fourth section of the continuum framework, themes from these conversations showed clear connections between the importance of HIV information in building confidence and readiness for disclosure, and in having disclosure conversations that could address stigma and alleviate fear and anxiety. Psychosocial interventions that address these unique stressors and cognitions for YMSM living with HIV must be available within post-diagnosis counseling and status disclosure assistance. More broadly, participants' dialogues throughout the interviews highlighted the need for general mental health support in the context of HIV status disclosure. Expanding resources and support in this area should be prioritized for future interventions. The fifth section in the continuum framework describes a state of empowerment where individuals may feel ownership over their personal approach to decide when—and to whom—to share their HIV status. Positive disclosure conversations can reinforce the emotions of confidence and empowerment regarding disclosure decisions, which also holds promise for increasing comfort with one's HIV diagnosis; fostering relationships with community, providers, and intimate partners; and supporting overall wellness [44]. Some participants found a sense of advocacy within their disclosure conversations when they felt prepared to educate others on HIV. This could be a powerful motivator and aligns with the rich history of social justice and human rights-oriented work by and with communities most affected by HIV [50–52].

The framework presented in Fig. 1 advances thinking of disclosure as a continuum or ongoing process refined by an individual's perception of their HIV diagnosis, disclosure experiences, and evaluation of disclosure outcomes which then shapes future decisions. Using a disclosure continuum framework could assist in identifying disclosure barriers and facilitators to support within intervention components including social support, health education, behavioral skills, and media destigmatization. Interventions seeking to mitigate post-diagnosis trauma and support overall wellbeing of YMSM with HIV, should consider including comprehensive, tailored disclosure support across the continuum.

Addressing persistent HIV stigma is critical for fostering disclosure conversations to reduce potential harm and trauma and increase positive outcomes [24, 34, 53]. HIV stigma is compounded by the stigmas surrounding sexual behavior, with many YMSM—including those in this sample—shouldering additional trauma related to sharing their sexual identity [14, 54]. Multiple marginalized identities or attributes can further compound the negative responses people experience when sharing their status [27, 28, 55] and should be considered in the development and evaluation of future interventions to support disclosure. Education on the advancements in HIV treatment, prognosis, and secondary prevention options can combat elements of HIV stigma, while continuing to dismantle the intersectional social stigmas that YMSM face in the context of HIV disclosure decisions.

The psychosocial distress of internalized stigma and concealing aspects of one's identity brings chronic stress for YMSM, who are a demographic group with rates of depression and anxiety substantially higher than the national (and global) average [56, 57]. Consistent with earlier studies [58, 59], participants in this study expressed emotions associated with fear, loneliness, avoidance, and anxiety while talking about their HIV diagnosis and approach to HIV status disclosure. For some participants, this led to indirect health consequences of delaying care while coping with their diagnosis. Prior research, including MSM living with HIV, found associations between stigma, disclosure concerns, depressive symptoms and ART adherence [26]. Other participants in this study expressed the mental health toll more directly by sharing symptoms of depression and thoughts of suicide. The mental health burden in YMSM with HIV has been shown in other studies [56, 57] but few have measured the association with HIV status disclosure [25], particularly in young adults. Further research should look at the direct intersections of disclosure decisions and depression/anxiety to better understand how interventions with substantive mental health focus might address an unmet need post-diagnosis. It should be noted that mental health may need to be a central focus, as at least one prior trial among similar

populations found no treatment effect of improving mental health via status disclosure decisional support [44].

Social support and media acceptance were other facilitators for disclosure conversations identified by participants. The media examples mentioned during the interviews were often noted to be from characters on television shows or celebrities that the participants could relate to. This is aligned with research that has indicated that culturally relevant media can be effective in reducing stigma [60, 61], but must be current, reliable, and not contribute to perpetuating stereotyping [62]. Online spaces can serve for both information and social support and should be considered for future disclosure interventions [63–65]. At the same time, our findings align with results that have been identified in other studies showing null or inconsistent relationships between disclosure and social support. For example, a robust qualitative study among 84 black and Latinx MSM living with HIV (Baltimore, Washington DC, Chicago), found mixed results in the relationships between disclosure and HIV care engagement and concluded that the complexities of the particular contexts and situations of disclosure must be considered [28].

This study has a few limitations to note. As a qualitative convenience sample within a larger RCT, these findings may not be generalizable to broader populations of YMSM. Further, it is not clear how self-selection bias may have influenced the make-up of both the RCT parent sample and the qualitative sub-sample—for example, disproportionately representing individuals with greater comfort speaking about their HIV status and disclosure experiences, or, alternatively, attracting those to participate who had more extreme disclosure experiences. To reduce the impact of these biases, the study team interviewed participants from all parent RCT recruitment institutions. In looking at key sample characteristics, the qualitative subsample are comparable to the full sample in terms of age, race/ethnicity, length of time since HIV diagnosis, viral suppression, and past status disclosure experiences [35]. Individuals in the younger age range (16 to 18 years old) were not represented in our sample as only 12 participants in the RCT fell in this age category in the intervention arm and we were unsuccessful at recruiting any of these individuals for a qualitative interview. Lastly, qualitative data analysis is subjective by nature; while we followed rigorous, theoretically grounded methodology in data collection and analysis [48, 49], the study team's interpretation of the data and presentation of the findings is influenced by their training, experiences, and worldviews. The study team included multiple members with experience in HIV behavioral health research, clinical care, and intervention delivery as well as individuals with diverse identities across gender, sexual orientation, race/ethnicity, age, geography, and education, among other attributes.

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Declarations

Conflict of Interests Authors Muessig, Hightow-Weidman, Knudtson, Soberano, and Claude completed this work as part of their full-time employment at the University of North Carolina at Chapel Hill. While their salaries were funded in part by the grant that supported this research, their employment was not contingent on the outcomes of the research study or results reported. Authors Vecchio and Hanshaw completed this work as part of their academic training at the University of North Carolina at Chapel Hill. While part of their training stipends and/or educational fees were funded in part by the grant that supported this research, this support was in no way contingent on the outcomes of the research study or results reported. Authors Vecchio and Hanshaw completed this work as part of their academic training at the University of North Carolina at Chapel Hill. While part of their training stipends and/or educational fees were funded in part by the grant that supported this research, this support was in no way contingent on the outcomes of the research study or results reported. Author Adams Larsen completed this work as part of her role as Director of Research and Training at Virtually Better. While her salary was funded in part by the grant that supported this research, her employment was not contingent on the outcomes of the research study, the results reported, or any commercial revenue the project may generate. There has been no commercial development or sales related to the Tough Talks™ intervention to date. All authors affirm that they have no other relevant conflicts of interest to declare.

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