Preliminary impact of the *weCare* social media intervention to support health for young men who have sex with men and transgender women with HIV

By: Amanda E. Tanner, Eunyoung Y. Song, Lilli Mann-Jackson, Jorge Alonzo, Katherine Schafer, Samuella Ware, J. Manuel Garcia, Elias Arellano Hall, Jonathan C. Bell, Cornelius N. Van Dam, and Scott D. Rhodes

Abstract:

Young racial/ethnic minority men who have sex with men (MSM) and transgender women with HIV often have poor health outcomes. They also utilize a wide array of social media. Accordingly, we developed and implemented *weCare*, a social media intervention utilizing Facebook, texting, and GPS-based mobile social and sexual networking applications to improve HIV-related care engagement and health outcomes. We compared viral load suppression and clinic appointment attendance among 91 participants during the 12-month period before and after *weCare* implementation. McNemar's chi-square test analyses were conducted comparing the pre- and postintervention difference using paired data. Since February 2016, intervention staff and 91 intervention participants (79.1% African American and 13.2% Latino, mean age = 25) exchanged 13,830 messages during 3,758 conversations (average: 41.3 conversations per participant) across a variety of topics, including appointment reminders, medication adherence, problem solving, and reducing barriers. There were significant reductions in missed HIV care appointments (68.0% vs. 53.3%, $p = 0.04$) and increases in viral load suppression (61.3% vs. 88.8%, $p < 0.0001$) 12 months postimplementation. Our results highlight the initial success of *weCare* in improving care engagement and viral suppression. Social media is an important tool, especially for young MSM and transgender women, to support individual- (e.g., viral suppression) and community- (e.g., reduced transmission efficiency) level health. It may also be a useful tool for improving engagement with biomedical HIV prevention tools (e.g., PrEP use).

Keywords: HIV care | young MSM | transgender | social media | intervention

Article:

Introduction

Men who have sex with men (MSM) and transgender women of all races/ethnicities and age groups continue to be disproportionately affected by HIV in the United States. Although the overall annual HIV diagnosis rate in the United States decreased by 19% from 2005 to 2014, the number of new HIV infections among MSM continued to increase.[1] The rate of new HIV diagnoses among MSM is 44 times that of other men and 40 times that of women.[2,3] In addition, it is estimated that ~25%–39% of transgender women are living with HIV.[4–8] Racial and ethnic minority MSM and transgender women, including African American/black and Latino individuals, are particularly affected by HIV.[6,9–12] Rates of HIV are also increasing among youth of ages 13–24 years in the United States who accounted for 21% of all new infections in 2016.[13]

These national trends hold true in the United States South, which is often referred to as the new HIV epicenter.[14] Fourteen of the 15 US cities with the highest rates of new HIV infections per capita are in the South, and the majority of all new AIDS diagnoses occur in this region.[15] In North Carolina (NC), MSM accounted for 64% of all the new HIV cases in adolescent and adult males.[16] African American/black and Latino MSM in NC had HIV infection rates nearly eight times and three times, respectively, the rate for white MSM, with young MSM in these groups disproportionally affected.[17] Less data are available related to transgender individuals in the United States South, but they suggest that HIV rates are higher among transgender persons in the region than among the general population.[18]

The disproportionate disease burden born by young MSM and transgender women is further exacerbated by low rates of HIV care linkage and retention. It is estimated that about half of people of ages 13–24 years are aware of their HIV status, and overall only about one-quarter are virally suppressed.[13,19] Thus, innovative care engagement strategies for young MSM and transgender women are crucial to improve health outcomes and realize the benefits of HIV-related biomedical and behavioral innovations (e.g., treatment as prevention).

Social media offers a novel and powerful approach to HIV prevention and care. Social media are widely available, used frequently by young people, can be accessed instantly, and are relatively inexpensive.[20–34] Young MSM and transgender women, in particular, have high rates of social media use, including Facebook, texting, and GPS-based mobile applications ("apps") designed for social and sexual networking (e.g., A4A/Radar, badoo, Grindr, Jack'd, and SCRUFF).[35] Young MSM and transgender women have also shown an interest in smartphone and online HIV prevention interventions.[36] Social media interventions may be particularly appropriate for social media users who may include "hard-to-reach" communities who may be less likely to be exposed to venue-based health promotion efforts (e.g., those who are in gay bars/clubs or community based) or identify with gay-focused health messages, including those delivered in-person or using specially developed HIV-engagement apps, and/or have more challenges engaging in HIV-related care.[37–41]

Social media interventions have several benefits for young MSM and transgender women. First, they can have a broad reach to those who are already active social media users. Second, they can increase knowledge, influence health behaviors, provide emotional and social support, and create a sense of community.[42] Several HIV-related interventions, including IknowUshould2 and MiCHAT, have utilized existing social media platforms such as Facebook, Twitter, Instagram,

and Youtube to increase HIV/STI knowledge and reduce risk behaviors.[43] Other interventions (e.g., HealthMpowerment, CyBER, and Get Connected!) have been shown to increase social support and HIV testing using a tailored approach on web and mobile platforms for young black MSM and transgender women.[27,36,44] Third, social media can improve health for persons with HIV through improved medication adherence and increased care engagement, especially for populations that may not be accessed through conventional intervention delivery channels and strategies.[41,42,45] Finally, social media interventions, if found to be efficacious, have the potential to be scaled up and readily disseminated.[46]

Given the profound need for innovative approaches to support HIV care (and prevention of secondary transmission), the purpose of this article was to describe the preliminary impact of *weCare*, an ongoing intervention to support HIV care linkage and retention for racially and ethnically diverse young MSM and transgender women[47] curently being implemented in central NC. *weCare* is implemented by a cyberhealth educator who sends theory-informed messages using social media platforms; these messages are designed to support engagement across the HIV care continuum.

Methods

Study setting

This ongoing study is being conducted in Guilford County, NC, at a regional infectious disease clinic that serves a six-county patient catchment area in NC by a community-based participatory research (CBPR) partnership. NC consistently ranks in the top 10 US states with the highest rates of new HIV diagnoses,[48] and the HIV incidence rate is 40% higher than the national rate.[6] Guilford County ranks 6th out of 100 NC counties for HIV.[49] The CBPR partnership includes MSM and transgender women living with HIV, representatives from public health departments, AIDS service organizations, and clinics that serve people living with HIV, and academic investigators. This partnership has an established history in intervention development, implementation, and evaluation to meet the needs of traditionally marginalized populations across the HIV care continuum.[50]

Intervention overview

A version of the *weCare* intervention is described more fully elsewhere.[47] In brief, we used CBPR to develop and implement an innovative tailored intervention that harnesses established social media platforms (i.e., Facebook, texting, and GPS-based mobile apps, such as A4A/Radar, badoo, Grindr, Jack'd, and SCRUFF). *weCare* is designed to improve care engagement and health outcomes among underserved, underinsured, and hard-to-reach racially and ethnically diverse young MSM and transgender women living with HIV.

Participant recruitment, enrollment, and retention

Individuals were eligible to participate in *weCare* who were between the ages of 16–34 years, identified as gay, bisexual, or transgender, and were living with HIV. Potential participants were referred to the study by clinic and health department staff. We also advertised the study on

Facebook through paid targeted advertisements and other social media platforms, in a local LGBTQ newspaper, through Craigslist, and posted flyers placed at bars, clubs, and coffee shops. We also recruited participants through word-of-mouth; enrolled participants would share information about the study with others in their social networks. If eligible, participants completed informed consent procedures with the cyberhealth educator and were enrolled. Enrolled participants chose their preferred social media platforms. Some participants worried that others may see their texts and thus wanted to avoid language that could raise questions about their health and well-being. Thus, some participants selected words (e.g., "clinic," "prescription" "provider," "nurse," "medication," and "pharmacy") that they did not want to be used during texting. To date, we invited 113 individuals to participate: 91 enrolled and 22 refused.

Because *weCare* focused on linkage and retention in HIV care, we collected extensive contact information from participants to locate participants. Contact information included friends and family who could be contacted to locate participants, aliases on various social media platforms, etc. If the cyberhealth educator had not heard from a participant despite (at least bimonthly) attempts to be in touch, the cyberhealth educator would attend the participant's next clinic appointment to reconnect with the participant, remind them of the intervention and how the cyberhealth education can help, and determine whether a different social media platform would be better for communication.

Intervention messages

Based on each participant's social media platform preferences, the *weCare* cyberhealth educator uses a combination of Facebook messaging, texting, and app-based instant messaging to communicate using theory-informed messages specific to each participant's place on the HIV care continuum. We refined existing messages (e.g., UCARE4LIFE library[51]) and developed new messages informed by social cognitive[52] and empowerment theories.[53,54] Social cognitive theory emphasizes information, mastery of skills, and development of self-efficacy, enhancement of proficiency, and social support for behavior change/action. Empowerment theory emphasizes movement beyond learning to critical reflection and action. Messages were refined and developed in partnership with our *weCare* community steering committee comprising racially and ethnically diverse young MSM and transgender women (some of whom are living with HIV) and representatives from an AIDS-service organization, the health department, and HIV/infectious disease clinics.

Table 1 provides examples of cyberhealth educator-initiated messages across the HIV care continuum. These messages served as a guide for the cyberhealth educator; throughout each social media conversation, the cyberhealth educator may exchange multiple messages with a participant about a variety of topics. These messages are tailored to the specific context of the participant (e.g., age, time since diagnosis, and/or specific challenges with care) to assist in addressing each participant's unique needs (e.g., medical appointment attendance, provider communication, family challenges, navigating healthcare coverage, and other sexual health education such as PrEP information for participants' sexual partners). Messages that were initiated by the cyberhealth educator often ended in a question to ensure that the social media platform continued to reach the participant and there was participant engagement in the conversation, for example, that the conversation was two way. Further, the cyberhealth educator

used emojis when appropriate to convey feelings within messages. Participants also initiated conversations with the cyberhealth educator as needed or desired.

Data collection

Intervention data were collected and managed in two ways. First, social media conversations between the one *weCare* cyberhealth educator and each participant were captured and managed through REDCap (Research Electronic Data Capture), a secure web application for building and managing online surveys and databases. Data collected included date of the conversation, who initiated contact (the participant or cyberhealth educator), the social media platform used, and topic of the conversation. Topics of conversation included "check-in," "appointment reminder," "missed appointment," "appointment scheduling" (i.e., reminding participant to schedule or reschedule an appointment or helping participant schedule appointment), "prescription reminder," "problem solving/overcoming barriers to care" (e.g., transportation and insurance/benefit assistance), "enrollment questions," and "participant seeking other information/help." Multiple topics could be selected as appropriate. All messages exchanged between the cyberhealth educator and each participant in the same calendar day were coded as one conversation for the purpose of analysis; however, multiple topics could be discussed and thus coded for each conversation.

Second, medical chart data were abstracted at the clinic to obtain longitudinal (12 months preintervention implementation and for 12 months of intervention implementation) information related to missed HIV medical appointments and viral suppression for each participant. These data were captured and managed through REDCap. Missed appointments were coded as "yes" (1) if a participant missed any appointments and "no" (0) if a participant had not missed any appointments during the 12 months preceding his or her enrollment in the intervention and during the first 12 months of the intervention. Viral suppression was coded as "yes" (1) if a participant had an HIV viral load <200 copies/ml and "no" (0) if a participant had a viral load 200 copies/ml or higher (measured at time points closest to pre-enrollment and to end of the 12-month implementation period).

Wake Forest School of Medicine Institutional Review Board provided human subjects protection and oversight.

Data analysis

REDCap data were exported into SAS version 9.3 for analysis. Percentages are presented for all categorical variables and the means and standard deviations of all continuous variables were calculated. All statistics only include participants with complete data for the main outcome variables being analyzed; we choose this approach because some participants were new to care and some participants moved out of state with a care plan, so we did not want to assume that they had missed appointments. Pre- and post-intervention comparison analysis for categorical variable was done using McNemar's chi-square statistics.

Table 1. Theory, Engagement, and Cyberhealth Educator-Initiated Abbreviated Sample Messages

Theory	Construct	Enrollment	Linkage and retention		Retention			Linkage and retention		Retention
			Check-in	Following up on previous conversation	Missed appointment	Prescription reminder	Medication adherence	Overcoming barriers	Appointment reminder	Reinforcing
SCT	Information	Hi, we will use this (*social media platform*) to stay in touch. Is that still ok with u?	Remember, U can rely on me 4 help! That's what I m here 4! Do U need any info?	Do u have any more questions 4 me? I m here 4 u!	I think u missed ur appointment 2 day. Do u need the scheduler's phone #?	ur prescriptions r ready 2 pick up 2 day. Let me know when u have picked them up, ok?	It's important 2 take meds as directed to make sure they are the most effective.	U know that ur case manager can help you with housing and food, right?	Hi, did u have a good weekend? Don't 4get ur appointment 2morrow at 3PM. U gonna be there?	Is great that u r helping ur friends. Our friends often need the same info that we once needed.
SCT	Outcome expectancies	What is important to u? Reduced VL? U = U? we can get U closer to what u want.	How is it going today? What is important to U? UR health? Reduced VL? U = U?	Hi, how are u? Last time we talked u wanted to make ur appt & u did. Congrats! What does that mean to u?	I m sad that u missed ur appt. How can I get u back here?	Get your meds 2gether for this week, so u can slay! U hear?	It u want to get to U = U, u need to take meds as directed, without fail. How can I help u meet ur goal?	When a case manager starts working with you, it will be easier to connect you with services u want & need	ur doctor can help u meet ur goals, if u make it 2 ur appointment	How do u feel about today? Do you feel like u met ur objective? I am proud of ur progress.
SCT	Self-efficacy	I feel confident that u & I can work well together, don't u?	u have had a lot of success (*add example here*). u should feel good about ur next step. Do you think u'll be able 2 (*next step here*)?	Anything u want 2 talk more about? (Triggers about health, successes, challenges)	Hey, we missed u 2 day. We need to get you back n soon. I no u can do it. What do u need to feel u can?	U were able 2 get 2 your appt successfully, now u can get 2 the pharmacy. Do u think u'll b successful?	U have been so successful managing. U can do this too, don't u think so too?	U have been so successful managing, & while it won't be easy, u can overcome this barrier too, don't u think so too?	U made it 2 ur appt last time. Do u feel confident about making 2morrow's app?	One more success that should help u feel more confident about managing ur health, right?
SCT	Direct experience	I am glad we were able to talk today. U took the first step for ur health & that is awesome. Let's build on this success!	Anything u want 2 work on? (*Triggers about health, successes, challenges*)	Sometimes It take ongoing communication for guys like u 2 feel comfortable asking 4 help. How do u feel about it?	Last time u missed an appt, u called & got a new appt. Will u do that again?	Think of what u have overcome (*example*) how can u use those experiences to overcome this challenge?	Think of what u have overcome (*example*) how can u use those experiences to overcome take the meds as directed.	It was great that u made it 2 the clinic again. I am glad they were able to connect you with services that u needed	How was it 2day? Why do u think the visit went so well?	U did it! How do u feel?
SCT	Vicarious learning	I know it is scary 2 think	Some guys like me to check n with	Sometimes it takes ongoing	Let's get ur missed appt	Some people put their meds	Try this app: Care4today, is	For some it is helpful 2 go 2 a	Sometimes people miss	All the other people I talk to

Theory	Construct	Enrollment	Linkage and retention			Retention		Linkage and retention		Retention
			Check-in	Following up on previous conversation	Missed appointment	Prescription reminder	Medication adherence	Overcoming barriers	Appointment reminder	Reinforcing
		about, but lots of guys just like u were scared but used this program so pat urself on the back 4 being like them and taking care of yourself	them 2 help out. Anything I can do 4 u?	communication for people 2 feel comfortable asking 4 help. Do u need any help around (e.g., *making appt, getting meds*)?	rescheduled. Most people feel better when they get back in2 a routine	in different bottles so that no one knows that it is these meds. Does that sound like something u could do?	free and helpful, and some people find it useful. Others find pillboxes make it easier to remember their meds. Let me know what u'll try, ok?	support group; there is one every other Friday. Would you be interested? I know a couple people who go & they say they get a lot out of it. What do u think?	their appointments and then are less healthy. I don't want u to be one of them!	say that staying n care helps them stay healthy. & talking 2 me helps them 2!
	Persuasion/social support	Hi great to meet u 2 day at the clinic. I will b n contact & don't forget 2 let me know if u need me, ok?	Hi, how have u been? u have told me how important ur health is. I am here to support you. How is it going today?	Hi, did u have a chance 2 call the clinic yesterday? Did u pick up ur prescription?	Hi, did u have a chance 2 call the clinic yesterday? U know that this is so important, right? How can I help u?	It's normal to forget ur meds once n a while. Don't beat yourself up about it. But u'll be better off if u take regularly! Text me if u want some ideas to help u	U have overcome so many challenges. U can handle this too. How can I support u take them as directed?	If ur having trouble with ur meds, I can connect u to someone who can help	Hi, it was great to see u a few weeks ago! When r u coming back?	How can I help u care 4 urself?
SCT	Incentives	l m glad that u enrolled. u'll get a lot of good support that will help u feel better and healthy	It sounds like you are taking good care of yourself! Congratulations! (*include happy/congrats emoji*)	How did things go with…? Wow! Sounds like u had success!	U will feel better when u get this appt rescheduled. U wont worry about it any more and u'll b prioritizing ur wellbeing	If u did what it took to get your meds this week, treat yourself! I no u have wanted (*example here*)	If u made it through the week without missing a dose, treat yourself! I no u have wanted (*example here*)	U r doing wonderful showing 2 all of ur appointments, even when I know u have 2 work and go 2 school, treat urself this weekend	After ur appt do, treat urself to (*something that the cyberhealth educator knows that the participant values/wants and is*	If u make this appointment, pat urself on your back. U are doing it right. U r making me proud.

			Linkage and retention		Retention			Linkage and retention		Retention
Theory	Construct	Enrollment	Check-in	Following up on previous conversation	Missed appointment	Prescription reminder	Medication adherence	Overcoming barriers	Appointment reminder	Reinforcing
ET	Critical consciousness	This program can help those who enroll 2 get 2 U = U. Do u know about that?	Attending all of ur appts is the first step 2 feeling better. How has this been 4 u?	People who check in with me regularly and let me help them tend 2 b healthier than those who don't. What do u think about that?	A missed appt can = increased VL & being less healthy	Not picking up meds can lead to increased VL & being less healthy	Not taking meds can lead to increased VL & being less healthy	There are a lot of things that stop us from getting the care we need	*reasonable and within reach*) Missing ur appt can hurt ur health. R u gonna to make it tomorrow?	Gotta get to appointments and take meds as prescribed to get to U = U
ET	Action	Thanks for taking the step 2 allow me 2 work with u!	U took action today. Congrats!	What do u think u'll do about what we talked about yesterday? What steps will u take?	U should ask for the day and time that ur mostly going to be able to make it. What day is best for u?	Did u pick up ur meds?	Any missed doses in the last 7 days?	It is important to overcome barriers we face in life. What can u do to get the care u need and deserve?	U continue to do all the right things to protect ur health	Ur staying in care is making a difference for your health. Don't u think so?

ET, empowerment theory; SCT, social cognitive theory; U = U, Undetectable = Untransmittable; VL, viral load.

Results

The mean age of the 91 *weCare* participants was 25: 79.1% self-identified as African American/black, 13.2% as Hispanic/Latino, and 7.7% as white or other. See Table 2.

Table 2. Participant Characteristics (Baseline, $N = 76$–91)

	N *or Mean*	*% or SD*
Race/ethnicity ($n = 91$)		
African American/black	72	79.1
Latino	12	13.2
Multi-racial	6	6.6
White	1	1.1
Age ($n = 91$)	25.0	5.1
Language used ($n = 91$)		
English	78	85.7
Spanish	7	7.7
English and Spanish	6	6.6
Preferred mode of communication ($n = 88$)		
Cell phone text message	76	86.4
Facebook	7	8.0
GPS-based mobile apps	3	3.4
Telephone call	2	2.3
Viral suppression ($n = 86$)		
Viral load <200 copies/mL	54	62.8
Missed medical appointment ($n = 76$)		
0	24	31.6
1 or more	52	68.4

A total of 13,830 messages across 3,758 conversations were exchanged between the cyberhealth educator and the participants during the 12-month implementation period; again, each conversation denotes 1 day of messaging between the cyberhealth educator and a participant. The majority of conversations ($n = 3,343$, 90.8%) were initiated by the cyberhealth educator, and each participant had a mean of 41.3 conversations (range $= 1$–100).

Table 3. Topics of Conversations

Topics	N
Regular check-in	1562
Appointment reminder	811
Rx reminder/medication adherence	525
Problem-solving/overcoming barriers to care	305
Participant seeking information	285
Missed appointment	189
Following up on previous conversation	166
Enrollment in project	91
Other	49

The content of conversations varied (Table 3), including check-in ($n = 1562$) ("happy bday!"), appointment reminder ($n = 811$) ["Hi (name), how are you? Don't forget your appointment

tomorrow at 10:00AM"], missed appointment ($n = 189$) ("Saw missed appt. Are you ok? Please call to reschedule!"), prescription reminder/adherence ($n = 525$) ["I am just reminding you to make an appointment to renew ADAP (AIDS Drug Assistance Program)/HMAP (HIV Medication Assistance Program)"], problem solving/overcoming barriers to care ($n = 305$) ["So sorry to hear that (you didn't have enough gas). We have bus tickets here in the clinic, so u know for next time. Any one of your family or friends can help u get to the clinic?"], and participant seeking other information/help ($n = 285$) ("Hey do you know why my ADAP/HMAP is still pending? I got my last refill and they said I needed to reapply or get it approved?").

Among the 91 participants who enrolled in the *weCare*, 14 participants were new patients at the clinic and 1 participant transferred from another state so they did not have any HIV-related clinic appointment data before the enrollment. One participant passed away and so did not have appointment (or viral load) data during the 12-month intervention period and was excluded from the outcome analyses. Therefore, a total of 75 participants were included for the missed appointments data analysis. The percentage of participants with missed appointments decreased from 68.0% to 53.3% from the 12-month period before enrollment to the 12-month period after enrollment among the 75 participants with complete data ($p = 0.04$). For the viral suppression analysis, five participants did not have viral load data 12 months before enrollment (e.g., enrolled in *weCare* the same day they initiated HIV medical care) and an additional five participants did not have the 12-month intervention period viral load data (e.g., moved to a different state). Similar improvements were reported for viral suppression among the 80 participants with complete data; viral suppression rates increased from 61.3% at pre-enrollment to 88.8% at the end of the 12-month implementation period ($p < 0.0001$).

Discussion

Innovative intervention methods are needed to meet the National HIV/AIDS Strategy goals of reducing HIV incidence and prevalence, particularly in key populations such as racially and ethnically diverse young MSM and transgender women who carry a disproportionate HIV burden.[1,11] Our results highlight the initial success of the *weCare* intervention in improving viral suppression and reducing missed medical appointments, two important factors linked to individual- and community-level health (e.g., undetectable equals untransmittable[55]). This success highlights the utility of providing theoretically informed messages that are targeted to diverse young MSM and transgender women, tailored by each participant's preferred social media platform, and personalized to each participant's needs along the HIV care continuum. Although the intervention dose, including the number and content of messages, varied across participants, the messages addressed each participant's unique needs. Our preliminary results provide further support for using existing social media platforms to provide "live" (not automated[56]) and bidirectional support for HIV care linkage and engagement and health outcomes for young people.[43,45] Critical to this approach is the relationship between the cyberhealth educator and the participant. The use of social media platforms facilitates efficiencies in communication[57]; yet, the intervention also relies on the cyberhealth educator getting to know the participant, learning what the participant values and using this knowledge to design meaningful messages.[47] It also relies on the participant knowing who is sending the messages, that a real person is there who knows and cares whether the participant is engaged in his or her own HIV care.

Social media interventions can have a broad reach to individuals who are already active social media users and provide them with support for HIV-related prevention and care.[42,43] Although our focus was on care engagement for individuals living with HIV, *weCare* (and social media interventions more broadly) could be an important tool for HIV prevention (e.g., PrEP use).[58] Recent data suggest that young PrEP users have high care disengagement within the first 6 months of use,[59] thus the tailored and personalized approach of *weCare* for supporting young people could be valuable for increasing rates of PrEP use for high need populations.

Through our CBPR approach, we translated theory into culturally congruent social media messages to help move participants across the HIV care continuum. Harnessing established social media platforms is a promising approach to support care and medication adherence of young MSM and transgender women living with HIV. The sample in this analysis was relatively small, thus future analyses need to further examine these important health indicators with a larger sample and a longer follow-up period. These findings do provide preliminary evidence for adding this type of social media intervention to our HIV care toolbox. *weCare* can improve health and well-being by meeting individuals' specific needs in familiar social media environments through the use of targeted, tailored, and personalized messaging.[47]

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Author Disclosure Statement

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