

Demonstration Site Summary

weCare

Wake Forest University School of Medicine
University of North Carolina Greensboro
Winston-Salem, North Carolina

In the Ryan White HIV/AIDS Program (RWHAP), Part F: Special Projects of
National Significance (SPNS) Initiative

***Use of Social Media to Improve Engagement,
Retention, and Health Outcomes along the HIV Care
Continuum***

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EXECUTIVE SUMMARY

Estimates suggest that only about 30% of all individuals living with HIV in the US have achieved viral suppression. Gay, bisexual, and other men who have sex with men (collectively referred to as MSM) and transgender women, particularly racial/ethnic minority young MSM (YMSM) and young transgender (YTG) women, are at increased risk for HIV infection and may have even lower viral suppression rates. HIV testing rates among YMSM and YTG women are low and, when tested, racial/ethnic minority YMSM and YTG women have disproportionately lower rates of retention in care and viral suppression compared to other subgroups. weCare is a social media-based intervention designed to improve care linkage and retention and health outcomes among racially and ethnically diverse YMSM and YTG women, ages 16-34, living with HIV. The intervention harnesses established social media that YMSM and YTG women between these ages commonly use, including Facebook, texting, and GPS-based mobile applications. Community-based participatory research was used to develop and implement weCare, enhancing the quality and validity of the intervention by equitably involving community members, organization representatives, healthcare providers, clinic staff, and academic researchers.

INTRODUCTION

Rationale and Description of Need/ Scope of Problem

An estimated 29% of HIV infections occur among youth and young adults ages 13-29, and over 1,000 new infections per month occur in this age group (Centers for Disease Control and Prevention [CDC], 2011). It is estimated that less than half of youth ages 13-24 with HIV know their status, one quarter are in care, and only 6% achieve viral suppression (Tanner et al., 2014; Zandoni & Mayer, 2014). The greatest number of infections among youth and young adults occur among racial and ethnic minority young gay, bisexual, and other men who have sex with men (collectively referred to as MSM) and transgender (TG) women. MSM and TG women of all races/ethnicities and age groups continue to be disproportionately affected by HIV, accounting for nearly two-thirds of all new infections in the US (CDC, 2010; CDC, 2014). Although the overall annual HIV diagnosis rate decreased by 33.2% from 2002 to 2011, the number of new HIV infections among MSM has continued to increase. In addition, the rate of new HIV diagnoses among MSM is 44 times that of other men and 40 times that of women (Johnson et al., 2013; Johnson et al. 2014). Among all MSM, African American/Black and Latino MSM carry a disproportionate burden of HIV, resulting in profound HIV-related health disparities (North Carolina Department of Health and Human Services [NCDHHS], 2012). These national trends hold true in the US South, which is now referred to as the new HIV epicenter in the US. For example, in North Carolina, MSM accounted for 77% of all the new HIV cases in adult/adolescent males (NCDHHS, 2012). African American/Black and Latino MSM had rates nearly eight times and three times, respectively, the rate for white men, with racial and ethnic minority youth also disproportionately affected (NCDHHS, 2012).

Despite advances in HIV diagnostics, treatment, and behavioral interventions to increase medication adherence, youth and young adults continue to have low rates of care linkage and retention (Tanner et al. 2014; Zandoni & Mayer, 2014). A profound need exists for innovative interventions to improve health outcomes among young MSM (YMSM) and young transgender (YTG) women living with HIV and to achieve the objectives of the National HIV/AIDS Strategy.

Use of social media. YMSM and YTG women also 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) (Groves et al., 2013; Duggan et al., 2015; Smith A., 2013; Sun et al., 2015; Philips et al., 2014; Groves et al., 2014). These rates of social media use correspond to increased access to smartphones and other mobile devices.

The frequent and active use of Facebook, texting, and GPS-based mobile apps suggest that these are potentially powerful tools for HIV-related education, prevention, and care, especially given that they are widely available, inexpensive, and instant, thus holding promise as interactive platforms for health promotion and disease prevention interventions.

The weCare project is a direct result of the project team’s multiple experiences with developing and enhancing behavioral interventions and ongoing intervention research using the internet and mobile apps to promote HIV testing among MSM and TG women, including CyBER/M4M (Rhodes et al., 2016; Rhodes et al., 2011) and MAP’T (Jenkins Hall et al., 2017).

Target Audience

This intervention is designed for clinics or community-based organizations (CBOs) that provide services for YMSM and YTG women living with HIV. To effectively implement the intervention, a CBO needs to be connected to or have a close working relationship with a clinic that provides medical care for individuals living with HIV.

Social Media Intervention Overview

weCare is an innovative, tailored intervention that harnesses established social media platforms that YMSM and YTG women commonly use. It was supported by the Health Resources and Services Administration (HRSA) Special Projects of National Significance (SPNS) initiative and designed to improve care engagement and thus health outcomes (e.g., viral load suppression) among underserved, underinsured, and hard-to-reach racially and ethnically diverse YMSM and YTG women. To ensure the highest level of acceptability and meaningfulness of the intervention, the project used a community-based participatory research (CBPR) approach to develop, implement, and evaluate the intervention.

The weCare intervention is delivered over 12 months by a Cyber Health Educator who is trained on the intervention components, protocols, and the “nuts and bolts” of intervention delivery. The Cyber Health Educator uses a combination of Facebook messenger, texting, and app-based instant messages, based on the participants’ preferences, to communicate with each participant individually using theory-based messages specific to each participant’s place on the HIV Care Continuum. In addition to working with participants one-on-one via social media, the Cyber Health Educator also manages an optional Facebook secret group for participants. The Facebook secret group provides resources relevant to living with HIV and gives participants the chance to interact with one another to develop social support within an online community.

weCare has a direct impact on the health of YMSM and YTG women with HIV by addressing the US Department of Health and Human Services (HHS) Common HIV Indicators for use in HIV Care Continuum, which identifies care linkage and retention, ART prescription and adherence, and viral suppression among youth and young adults as public health priorities.

INTERVENTION DESCRIPTION

Intervention Approach/Theoretical Framework

Community-driven. To develop weCare, the project team used a CBPR approach. CBPR can yield deeper and more informed understanding of health-related phenomena and produce interventions and programs that are more relevant, more culturally congruent, more likely to be effective, and more likely to be adopted and sustained if effective and warranted. Similarly, study designs, including those to evaluate interventions and programs, like weCare, that are informed by the multiple perspectives of community members, organization representatives, healthcare providers, clinic staff, and academic researchers may be more authentic to the community and to ways that community members engage, convene, interact, and make change. Thus, interventions developed and evaluated using a CBPR approach may be more innovative and more relevant and realistic; recruitment benchmarks, including participation and retention rates may be higher; analysis and interpretation of findings may be more accurate; sustainability may be more likely; and dissemination may be broader (Rhodes et al., 2014).

During implementation of this intervention, a steering committee should be established and oversee implementation and evaluation to ensure the most culturally congruent approach to recruitment, retention, and intervention delivery; create targeted and meaningful intervention messages; and employ creative problem solving. The steering committee should be comprised of members from the local catchment area, including racially and ethnically diverse YMSM and YTG women living with HIV.

Theoretical underpinnings. Social media communications between the Cyber Health Educator and participants are based on social cognitive theory (Bandura, 1986), the theory of empowerment education (Freire, 1973; Wallerstein, 1994), and natural helping (Eng, Rhodes, & Parker, 2009). Social cognitive theory emphasizes information; mastery of skills and development of self-efficacy; enhancement of proficiency; and social support for behavior changes and positive action. Thus, the Cyber Health Educator identifies and fills knowledge gaps (e.g., what to expect when attending one’s first clinical appointment after an HIV diagnosis). A participant may express discomfort so the Cyber Health Educator will help increase self-efficacy by identifying and then reducing perceived barriers (e.g., perceptions that one will be judged by clinic staff). The Cyber Health Educator also may role-play (via social media) with a participant by having the participant practice asking questions they may have of their provider, support incremental steps (e.g., filling an ART prescription), and reinforce HIV care behaviors (e.g., taking ART as prescribed).

Further, as empowerment education posits that individuals move beyond learning and critically reflect to “get to” action, the Cyber Health Educator uses conversation “triggers” to promote critical consciousness. For example, using app-based instant messaging the Cyber Health Educator might applaud a participant who reports getting an ART prescription after diagnosis, and also ask him/her how he/she plans to get the prescription filled. As norms and expectations contribute to risk, raising consciousness is key and best facilitated by community insiders such as the Cyber Health Educator through social media platforms that the participants are already using.

Trained community insiders, who are natural helpers, can provide support as a peer who is socio-economically and experientially similar; possess an intimate understanding of social networks, strengths, and health needs (including worries) and priorities; understand what is meaningful and motivational to those like themselves; communicate in a similar style and language; and recognize and incorporate identities (including both racial/ethnic and sexual minority cultures and identities). We have seen in our research how insiders can be highly effective to promote health and health outcomes among those within their own communities (Rhodes et al., 2014).

In sum, the Cyber Health Educator uses social media-based communication to: “demystify” the HIV treatment process, help to link and engage newly diagnosed young MSM to care, offer social support and resources to deal with stigma and fears of rejection, provide guidance for navigating clinics, and support contingency plans for overcoming barriers.

Target Population

Our intervention is designed to improve care linkage and retention and health outcomes (e.g., viral load suppression) among underserved, underinsured, and hard-to-reach racially and ethnically diverse YMSM and YTG women

Eligibility criteria for the intervention are:

1. Being HIV positive;
2. Being ≥ 16 years of age and ≤ 34 years of age;
3. Self-identifying as male or as a transgender woman;
4. Having ever engaged in sexual activity with a man; and
5. Meeting at least one of the following criteria (based on self-report or medical records)
 - a. Being newly diagnosed (i.e., tested HIV positive for the first time within the last 12 months)
 - b. Not being linked to care (i.e., aware of their HIV infection status but have never attended an HIV medical visit*)
 - c. Being out of care or not fully retained in care (i.e., diagnosed with HIV more than 12 months ago, but has a gap in attending HIV medical visits of more than 6 months within the last 24 months);
 - d. Not being virally suppressed (i.e., had a viral load of less than 200 copies/mL at their last lab result).

*HIV medical visits are defined as seeing an HIV medical provider.

Intervention Typology

Program Summary	Social Media Intervention Overview	Evaluation Summary
<p><i>WeCare, Wake Forest School of Medicine</i> (Winston-Salem, NC)</p> <p><u>Target Population</u> Age: 16-34 Gender: Male Race/Ethnicity: All Sexual Orientation: MSM Sample Size: 192 (96 in each arm) Language: English and Spanish Setting: Clinic, university setting</p> <p><u>Inclusion Criteria</u> Unaware of HIV status: No Newly Diagnosed: Yes Not linked/engaged in care: Yes Not retained in care/Out of care: Yes</p>	<p><u>Intervention type</u> Adapted from other research methods Stand alone to existing services</p> <p><u>Technology Platforms Used</u> Facebook: Yes Social Networking Sites/Apps: Yes Text Messaging: Yes, live</p> <p><u>Functions</u> Communication: Yes Information: Yes Reminders General: Yes Medical appointments: Yes Social support/networking: Yes, private Facebook Group</p>	<p>Evaluation Comparison Group – Yes</p> <p><u>HIV Health Outcome Measures</u> Increase HIV testing/Positivity rate/: No HIV awareness: Yes Improve linkage/engagement in care: Yes Improve retention in care: Yes Improve medication adherence: Yes Improve viral suppression: Yes Improve utilization of support services: No Improve health literacy: Yes</p> <p><u>Other Ryan White Part Funding</u> Parts B, C, D</p>

Program Summary	Social Media Intervention Overview	Evaluation Summary
Not adherent to HIV medication: Yes Not virally suppressed: Yes		

weCare is based on ongoing research using Facebook, texting, and GPS-based mobile apps, and is tailored to the social media preferences of each participant, given that among YMSM and YTG women, there may be variations in use of different social media platforms. This allows the Cyber Health Educator to meet the participants where they are (as opposed to developing a new system [such as a new app] that requires extensive marketing to recruit).

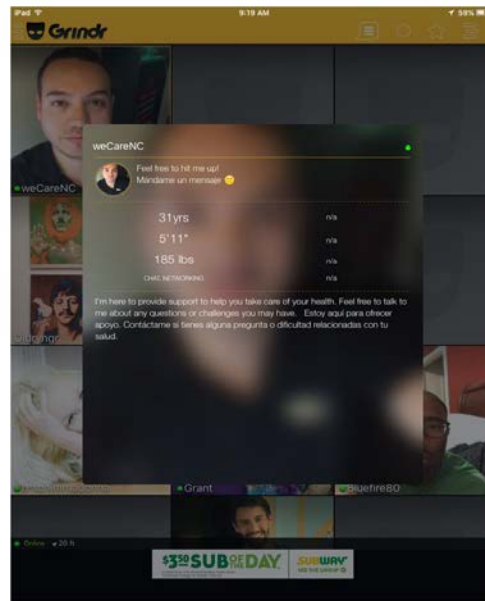
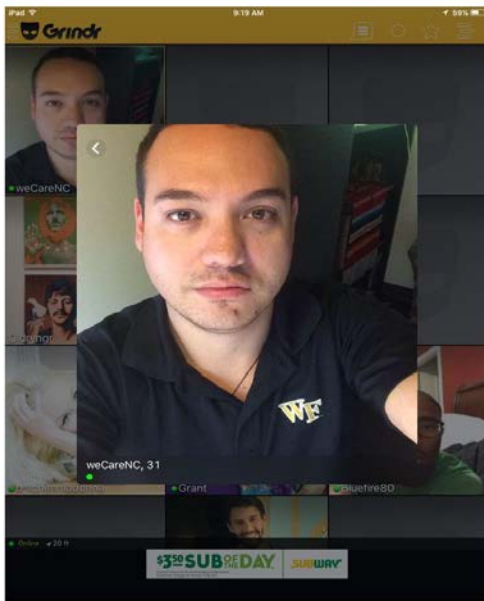
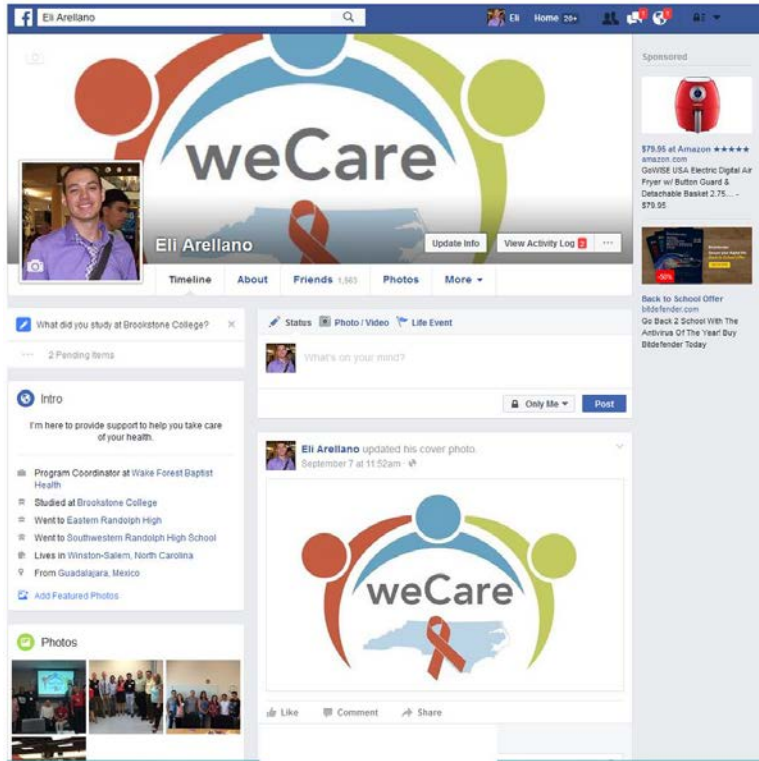
The intervention is also personalized to each participant. There are many places across the Care Continuum that may be missed opportunities for racially and ethnically diverse YMSM and YTG women to engage in HIV-related care, and these missed opportunities have implications for health outcomes. weCare is unique in this individualized approach for each participant based on their specific needs and context.

Intervention Functions

weCare is comprised of the following intervention functions that support engagement in medical care, medication adherence, and achieving viral suppression for YMSM and YTG women living with HIV.

Communication

The Cyber Health Educator creates Facebook and app profiles (within apps that are commonly used in the implementation catchment area, these may include apps such as A4A/Radar, badoo, Grindr, Jack’d, and SCRUFF), which he uses for two-way interactive communication with intervention participants about HIV care linkage and retention once enrolled in the intervention. These profiles should be created in collaboration with, and approved by, the project steering committee. These profiles are designed to spark interest among intervention participants, provide information about the intervention, and accurately represent the Cyber Health Educator’s roles, including his affiliation with the intervention and purpose within each social media site. All profiles are bilingual (English and Spanish) to ensure that the intervention reaches Spanish-speaking Latino YMSM and YTG women. The Cyber Health Educator should change their profile photo at least once a month; the photos should be real “G-rated” pictures of themselves, as we have learned that being straightforward about who the Cyber Health Educator is and his role increases trust among participants. The following are examples of Cyber Health Educator Facebook and app (Grindr) profiles used in the original weCare project:



The Cyber Health Educator personalizes theory-based messages to the specific questions, challenges, and successes that each participant communicates to the Cyber Health Educator to meet each participant's needs and care-related goals (see Appendix 1). These messages are tailored to the specific context of the individual participant (e.g., age, time since diagnosis, and/or specific challenges with care) to assist in addressing their unique needs (e.g.,

communicating with providers, challenges with family, navigating healthcare coverage, and other sexual health education such as PrEP information for participants' sexual partners).

In addition to the social media interactions, the Cyber Health Educator may have limited face-to-face interactions (e.g., at delivery of HIV diagnosis and at enrollment in the intervention). These face-to-face interactions help with relationship development and trust building and lay the foundation for communication via social media. The project staff found interpersonal connections are valuable for participant recruitment and retention and assist with improving health indicators. The participant knows who is on the other side of the social media communications and feels “connected”.

Information

The Cyber Health Educator provides information to participants about living with HIV and resources they can access; they fill information gaps. weCare also includes an interactive bilingual Facebook group that is optional to intervention participants, using the secret Facebook group feature (see screenshot below). All aspects of this secret group are invisible to those who are not members, and only participants who are enrolled in the weCare intervention are invited to join and admitted in to the group if they choose. The posts displayed in this group contain information related to sexual health, including HIV care linkage, and brief facts about HIV, including short videos, low literacy articles and guides about living with HIV. Graphics that illustrate the rates of MSM who are linked to care, retained in care, and have suppressed viral loads are also used to raise consciousness among YMSM and YTG women of the importance of staying in care. Posts are in English and Spanish, and designed to be engaging, informative, and accessible (see Appendix 2)



Education

Intervention participants sometimes have little knowledge of medical jargon related to HIV, and they may turn to the Cyber Health Educator for information and clarification. Examples include questions regarding the meaning of “CD4 count”, how the billing/insurance system works, and what to expect when attending one’s first clinical appointment after an HIV diagnosis. The Cyber Health Educator identifies and fills knowledge gaps. Also, the posts displayed in the secret Facebook group contain engaging and accessible information designed to educate and create awareness about the importance of staying in care.

Reminders

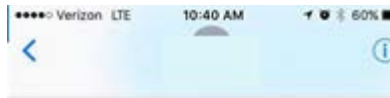
The Cyber Health Educator is trained in and has access to the electronic medical record (EMR) system used by the clinic, in order to identify participants’ upcoming HIV care appointments and confirm whether participants attend these appointments. The Cyber Health Educator reminds intervention participants of upcoming appointments and follows up immediately with those who do not attend a scheduled clinical appointment. Examples include:

- “Good morning Mark, how are U? R U enjoying the summer? Don’t forget ur appointment tomorrow.”
- “Hi Jim, I heard u missed ur appointment today. Are u ok? Please call the clinic to reschedule at ###-###-####, let me know ☺”

If participants successfully attend their appointment, the Cyber Health Educator also follows up and acknowledges them for making it to their appointment. Participants are also reminded to ask their providers questions or clarify medical concerns and are encouraged to bring their questions ready to their appointment.

The Cyber Health Educator also reminds participants, using “live” reminders, not automated, to fill their prescriptions for ART and to take their medications correctly and consistently. Examples of reminder messages include:

“Good morning Mark, how are U? Don’t forget 2 pick-up ur prescription at the pharmacy, its ready today”.



Mon, Oct 31, 10:08 AM

Hi Happy Halloween 🎃 how are you? I noticed that you don't have an appointment scheduled do you need help scheduling one? Eli

Mon, Oct 31, 1:34 PM

Yes

Mon, Oct 31, 2:49 PM

It's very simple you just have to call this number 336 716-2700



Hi how are you? Are you having a nice Sunday? Please don't forget your appointment tomorrow at 2:15PM. See you then! 🍻

Kik

Thanks for reminding me! I thought it was Tuesday.

Sun @ 9:00 PM

Sure! Yes, it is tomorrow 🍻

Today @ 10:25 AM

It was great to see you yesterday! Will be in contact! 🍻

Always a pleasure to see





Skills Building

Lacking experience with clinics and healthcare providers may further complicate the ability of YMSM and YTG women to navigate the healthcare system. Access to and retention in HIV care can be challenging as clinics are conceptualized as places that require advanced skills. Youth and young adults may lack the skills necessary to negotiate clinical policies and procedures

(e.g., appointment scheduling, payment, insurance, and residency/immigration documentation), especially within clinics without bilingual and bicultural services.

If a participant expresses discomfort attending his/her appointment, the Cyber Health Educator can help increase self-efficacy by identifying and then reducing perceived barriers (e.g., perceptions that one will be judged by clinic staff). The Cyber Health Educator may also role-play (via social media) asking questions of a provider, support incremental steps (e.g., filling a prescription for ART), and reinforce HIV care behaviors (e.g., taking ART as prescribed). The Cyber Health Educator may also show participants ways to access resources related to their HIV and navigate care services. Examples include:

- Participant: “Hey Eli, can u give me the number of the ADAP lady?” (ADAP=AIDS Drug Assistance Program).
Cyber Health Educator: “Hi Mark, sure this is the ###-###-####. Please let me know if you can’t reach her.”
- Participant: “Hi Eli, can u give me clinic’s phone number? I need to reschedule my appointment”
Cyber Health Educator: “Hi Mark, sure this is the number ###-###-####.”



Social Support/Networking

Through their participation in the secret Facebook group, participants are provided a tool to connect, interact, and provide each other with social support. They can ask questions related to their health and the Cyber Health Educator provides appropriate answers. Also, peers (e.g., other racially and ethnically diverse YMSM and YTG women living with HIV) make “guest” posts sharing about their lived experiences with HIV care and offering social support. The Cyber Health Educator also posts and updates informal and welcoming pictures and videos of clinic staff to increase the self-efficacy of participants to attend appointments. Studies have

shown that clinic staff attitudes often communicate larger messages of homophobia, race- and ethnicity-based discrimination, and HIV-related stigma (Lichenstein 2003, Lichenstein & Bachmann 2005, Kempf et al. 2010). The Cyber Health Educator offers participants support and resources to deal with stigma and fears of rejection, emphasizing to them that clinics are places where they can feel secure and not judged, which can improve care linkage and retention.

In the case that a participant were to have a negative experience with a staff member at the clinic where they receive care (e.g., due to perceived stigma and/or discrimination), the Cyber Health Educator may connect the participant with a patient navigator or other trusted clinic staff member, to whom they may report this experience. The Cyber Health Educator will follow-up, ensuring that the issue was addressed by the clinic staff, and communicate outcomes to the participant. However, the Cyber Health Educator also may choose to let the clinic director know, while maintaining the confidentiality of the participant.

Participants interactions with posts and with other members of the group may be limited, possibly due to the fact that some may not feel comfortable acknowledging their HIV status (associated with being a member of the group) with others they do or don't know, even if they are also HIV positive. However, participants may still benefit from the information provided in the group and from knowing that there are others who are part of the group who have similar experiences to theirs, even if they do not actively post or like or comment on others' posts. To increase interaction, the Cyber Health Educator can discuss with participants the option of using a Facebook profile under an alias (rather than their real name) to make them more comfortable actively participating.

“Check-ins”

The Cyber Health Educator often sends messages to participants to “check in” and offer support and resources. These messages are adapted from scripted theory-based messages to meet participants' specific context and communication style. To further build rapport, the Cyber Health Educator sends text greetings for participants' birthdays and on holidays such as New Year's Eve and Thanksgiving; the Cyber Health educator also offers support through crises, such as breakups with partners or loss of housing. The Cyber Health Educator should be sensitive to the fact that not all messages are appropriate for all participants. For example a “Happy Friday” message might be meaningful to some participants, but might not be appreciated by participants who do not get weekends off or those who are unemployed.



Technology Platforms/Channels

The intervention should include a variety of social media platforms for the participant to choose how they want to be contacted. Participants decide how they want to be contacted by the Cyber Health Educators for one-on-one interactions; they can choose one or multiple social media platforms and they can change how they want to be contacted over time. The Cyber Health Educator, using these social media platforms, responds to participant needs in a normal, non-judgmental fashion. The Cyber Health Educator’s purpose is not to judge anyone or anything a participant says or does, but to listen and offer information and advice.

Social Media

The Cyber Health Educator uses Facebook messenger as one platform for communicating with participants about HIV care engagement. The Cyber Health Educator posts standardized theory-based conversation triggers on the intervention Facebook profile and changes these triggers 2-3 times a week. Mentioned previously, in addition to using Facebook messenger to communicate with participants, the Cyber Health Educator also establishes and maintains a bilingual Facebook secret group that is optional to intervention participants.

Text Messaging (“Texting”)

In addition to using Facebook and app-based instant messages to communicate with participants, the Cyber Health Educator also uses texting, including mobile phone-based messaging as well as texting apps such as Kik and Whatsapp. Texting, unlike Facebook and app platforms, does not allow for profiles, but it is a popular platform chosen by participants, probably because of its accessibility and quickness.

Social Networking Sites/Apps

weCare harnesses established GPS-based mobile apps that YMSM and YTG women commonly use for social and sexual networking. The Cyber Health Educator uses a variety of apps (e.g., A4A/Radar, badoo, Grindr, Jack’d, and SCRUFF) to communicate with participants. Apps should be selected from those commonly used in the catchment area. This is critical because different apps are preferred by users of different socio-demographic backgrounds and the popularity of these social media platforms changes over time.

In the original implementation of the weCare project in Winston Salem, North Carolina, we found that the social media platforms preferred by participants included text messages and Facebook messenger. Very few participants wanted to be contacted through social and sexual networking apps; this may have been because they did not feel comfortable disclosing that they used these apps or because they did not log in to these apps as frequently as they used Facebook or texting.

Intervention Core Elements

The following components that should not be changed when implementing the weCare intervention:

1. Targets MSM and transgender women with HIV
2. Is implemented by a Cyber Health Educator who reflects the target population on at least one of these characteristics: age, sexual orientation/gender identity, and/or race ethnicity.
3. Allows participants to choose the social media platform they prefer (“tailoring”).
4. Is implemented in partnership with a clinic or community-based organization that provides services for people with HIV.
5. Uses personalized -not automated- approach.
6. Harnesses established apps that are commonly used by MSM and transgender women (rather than creating a new one).

Intervention Key Characteristics

The following components can be changed or modified to suit a different target population or geographic location:

1. Targets MSM and transgender women ages 16-34.
2. Delivered in English and Spanish.
3. Uses a secret Facebook group to provide information about living with HIV.
4. Combines Facebook messenger, texting, and app-based instant messaging.
5. Uses face-to-face interactions between Cyber Health Educator and participants to establish rapport.

Implementation

Steering committee. As mentioned previously, implementation of this intervention should be guided by a steering committee. The steering committee should include representatives from different agencies that provide HIV testing and other HIV services to ethnically/racially diverse MSM and TG women ages 16-34 (some of whom should be living with HIV), and the project team.

Steering committee members can be identified through word-of-mouth and agencies that provide HIV services. The steering committee should meet with the project team monthly for about two hours for the first 6 months and quarterly after that.

Facebook and app profiles. Profiles for the Cyber Health Educators should be created on Facebook and other app platforms that MSM and TG women commonly use, as previously described. Steering committee members can provide insight into what apps are popular in a local catchment area. The profiles are used to communicate with participants about HIV care linkage and retention once enrolled in the intervention. These profiles are also used to create and update the bilingual secret Facebook group.

Logo. An intervention logo should be developed by the steering committee. We have learned that having a recognizable logo to brand the intervention is key to participant recruitment and retention.



Recruitment and implementation space, office supplies, and tools. The Cyber Health Educator should have office space in the clinic where they can recruit participants during clinic visits and implement the social media intervention. The Cyber Health Educator should have a computer with ready access to EMR to prescreen to determine whether patients coming in for clinic visits

meet eligibility criteria. The Cyber Health Educator should also have a cell phone and/or tablet that supports Facebook, texting, and GPS-based mobile app use.

Marketing/Social Marketing

A colorful flyer that contains a brief description of the intervention and eligibility criteria and friendly pictures of the Cyber Health Educator should be prepared and placed in locations (e.g., health departments, LGBT centers, HIV service agencies, and testing sites) where potential participants will see the flyers. English and Spanish versions of the flyer should be created and distributed.

For additional outreach, an adaptation of the project flyer can be developed and used as a sponsored post (ad) on Facebook. To make this type of post, an intervention-specific Facebook page must be created. This type of page lets users choose the ad's placement (in the News Feed or Mobile News Feed, groups, on the right hand column of the page, etc.), the amount of time it will remain posted, and how many people can be reached (which depends on the budget allocated to spend on Facebook promotion). The text in the flyer may need to be abbreviated to conform to Facebook's guidelines for promoted post images.

Another version of the flyer can be published in the Volunteer section of local Craigslist pages as well as in local LGBTQ newspapers.

The flyer is titled "Wake Forest Baptist Health" at the top left. In the center is the "weCare" logo, which features three stylized human figures in red, blue, and green, with a red ribbon symbol below them. Below the logo, the text reads "Join us!" followed by an invitation to participate in a research study for transgender women, gay, and bisexual men ages 13 to 34 to:

- RECEIVE SUPPORT and information related to:
 - Your medical visits
 - Taking your medication
 - Other needs
- Using APPS that you prefer

A row of colorful icons for various mobile applications is shown, including WhatsApp, Kik, Facebook, Instagram, Snapchat, and others. Below this, another bullet point states:

- You can also be part of an optional private Facebook page to:
 - Meet and get support from other transgender women, gay and bisexual young men like you

The text "All your information will be kept private." is printed below. On the bottom left, there is a small photo of a man and a box containing contact information: "FB: Eli Arellano", "Text me: 336 816-5706", and "KIK me: weCareNC". On the bottom right, there is a small box with the text: "IRB# 00035181", "Principal Investigator Dr. Scott D. Rhodes: 336-713-5080", and "Wake Forest Institutional Review Board: 336-716-4542".

Wake Forest[®]
Baptist Health

weCare

¡Únete!

Te invitamos a participar en un estudio de investigación para mujeres transgénero y jóvenes gay y bisexuales 13 a 34 años para:

- Recibir APOYO e información referentes a:
 - Tus citas médicas
 - Tomar tus medicamentos
 - Otras necesidades
- Usando APPS que tu prefieras

También puedes ser parte de una página opcional privada de Facebook para:

- Conocer y recibir apoyo de otras mujeres transgénero y jóvenes gay y bisexuales como tú

Toda tu información se mantendrá privada.

FB: Eli Arellano
Text me: 336 816-5706
KIK me: weCareNC

IRB# 0003518.1
Principal Investigator Dr. Scott D. Rhodes: 336-713-5080
Wake Forest Institutional Review Board: 336-716-4642

Outreach and Recruitment

In addition to the distribution of flyers, collaboration with agencies that provide HIV services, such as Disease Intervention Specialists from a local Public Health Department who follow-up with persons with or exposed to HIV, can be useful to help get the word out about the intervention and recruit participants. Also, in order to reach participants throughout the catchment area, intervention staff may choose to advertise the intervention on the GPS-based mobile apps used in the intervention and encourage potential participants to communicate with the Cyber Health Educator.

To recruit participants within the clinic, the Cyber Health Educator prescreens patients coming in for clinic visits. When a patient who meets eligibility criteria (potential participant) arrives for their medical appointment, a nurse or patient navigator briefly introduces the project to them and asks them if they would like to speak with the Cyber Health Educator about enrolling in the intervention. Then, the Cyber Health Educator meets the potential participant, explains the project to them, and, if they agree to participate, enrolls them.

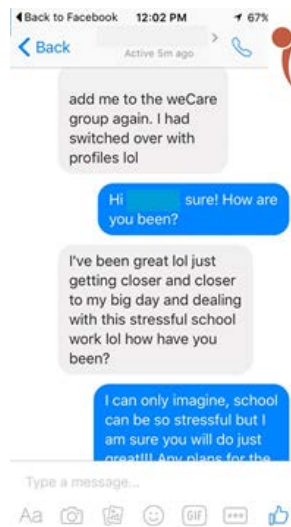
Procedures/Protocols

Participant enrollment and tracking procedures. After eligible participants consent to participate in the intervention, the Cyber Health Educator completes an enrollment form for each participant to record the participant’s demographic and contact information and the social media platform(s) that the participant selects to use as a mode of communication (see Appendix 3). The Cyber Health Educator keeps records of each participant’s enrollment information.

Intervention exposure form. The Intervention Exposure Form is used to record the interactions that the Cyber Health Educator has with each participant, including the date and the type of interaction (e.g., a reminder to reschedule their appointment they canceled) and the number of messages exchanged between the Cyber Health Educator and the participant (see Appendix 4).

Role and responsibilities of the Cyber Health Educator. Summarized, the roles and responsibilities of the Cyber Health Educator include:

- To interact with participants within the social media platforms
- To establish rapport and start building trust with participants in-person and through social media
- To be supportive to participants but not intrusive
- To send messages to check in with participants to maintain contact; further build rapport; and assess and address potential barriers to linkage, retention and viral suppression (see example below)
- To offer support and resources to deal with stigma and fears of rejection
- To remind participants to bring questions for their providers to their appointments
- To remind participants of upcoming appointments
- To follow-up immediately with participants who do not attend a scheduled clinical appointment (to check on them and encourage them) as well as with those who do attend their appointments (to acknowledge them for taking care of their health)



At a minimum, the Cyber Health Educator should contact participants twice a month, but ideally more often. The decision to contact participants more often will depend on the Cyber Health Educator's perception of the level of contact a participant would like to have and would benefit from.

Some participants may not feel comfortable receiving messages that include words such as "clinic" or "medication". The Cyber Health Educator should ask the participants at enrollment what word(s), if any, they would like not be included within the message(s) they send.

If the participant shares with the Cyber Health Educator an issue or a situation that the Cyber Health Educator perceive is urgent, the Cyber Health Educator should encourage the participant to call their provider. In the case that the participant shares a situation that is alarming or critical, the Health Educator should encourage the participant to contact the Emergency Room or dial 911 for help.

The Cyber Health Educator does not supplant the existing roles of those within the clinic. Instead, the Cyber Health Educator continually uses social media to communicate with each participant to reduce and reframe barriers and bolster facilitators of linkage to and retention in care. The Health Educator communicates in English or Spanish language, depending on the preferences of each participant.

Partners

A CBPR approach was used initially to develop the weCare intervention to ensure that it was developed to be the most relevant, culturally congruent, and promising intervention, with the potential for sustainability, as well as the highest level of acceptability and meaningfulness among racially and ethnically diverse YMSM and YTG women, ages 16-34, living with HIV. The weCare team established partnerships comprised of community members representing racially and ethnically diverse YMSM and YTG women; community-based organization representatives; medical providers and clinic staff, including patient navigators; and health department representatives. These partners help to ensure the intervention is based in ongoing service delivery and the real-world lived experiences of community members. The Cyber Health Educator should work closely with the clinic medical providers and staff to thoroughly understand the process of accessing HIV care clinical services within the clinic and the potential barriers faced by racially and ethnically diverse YMSM and YTG women.

Staffing Roles

Project Director: Responsible for all aspects of the project, including intervention implementation and evaluation; budget and fiscal oversight; and recruitment and retention benchmarks.

Evaluator: Responsible for implementation of evaluation activities for the project, including development of data collection instruments and systems, and coordination of analysis and interpretation of process and outcome data.

Cyber Health Educator: Responsible for identifying and recruiting participants, and implementing the intervention according to the protocol.

Data Manager: Responsible for training data collectors, managing and reporting data, and coordinating the cleaning and storage of evaluation data.

Data Analyst: Responsible for planning and executing statistical analyses, providing statistical guidance on recruitment and data collection processes, and writing up and reporting results of statistical analyses.

Key Staff Attributes

Project Director: Experience in HIV prevention and care interventions conducted in partnership with vulnerable populations, including self-identified gay and bisexual men and other MSM; transgender persons; African American/Black and Latino communities; and persons living with HIV.

Evaluator: Experience in public health evaluation; program management; social media technology; and data collection (using mixed methods), analysis, and interpretation.

Cyber Health Educator: Experience in health education related to HIV prevention and care with racial and ethnic minority communities including African American/Black and Latino, and MSM and transgender communities.

Data Manager: Experience in community-based data collection, data cleaning, and dataset preparation.

Data Analyst: Experience in public health evaluation and statistical analysis, including longitudinal, behavioral, and intervention research.

Training

The Cyber Health Educator should be trained by the project team based on this Intervention Manual and the Health Education Intervention Training Guide, which includes didactic, interactive, and skills-building modules. During this training, the Cyber Health Educator is additionally trained on how to interact within the social media platforms, how to build trust with individuals through social media, and how to be supportive to participants but unobtrusive, among other topics.

The training components should cover the following:

- Introduction to the intervention and its approach, including how to facilitate engagement in care through theory-based messages.
- Role-playing exercises, which provide opportunities to practice skills and receive feedback to enhance the Cyber Health Educator's effectiveness in applying theory-based messages. This should include conducting mock conversations via Facebook messenger, texting, and app-based instant messaging using study team members or other volunteers as participants.
- Practice in crafting, delivering, and following-up on conversation triggers.
- Education on social cognitive theory and theory of empowerment education and how they relate to this social media intervention and the logic underlying the intervention, implementation strategy, and behavior change methods.

The Cyber Health Educator should be evaluated pre- and post-training and the results should be used to tailor supplemental training to meet needs. They also should meet with the project team every week in-person to provide updates and identify additional training needs, as well as offer insights and suggestions to the project team to improve implementation and evaluation.

Lessons from the Field

Successes

Recruitment and retention. In the initial implementation of the weCare intervention, 198 participants were recruited for the study and most of them were retained over the period of 18 months. The team credits its high recruitment and retention rates to the rapport built and connections established between the Cyber Health Educator and participants.

The Cyber Health Educator used strategies that facilitated enrollment through building rapport by getting to know potential participants and easing into a description of the project. The Cyber Health Educator also recruited and retained participants by tapping into participants' "good

will” and their sense of commitment to their community by explaining the importance of the project for improving engagement in care and health outcomes among YMSM and YTG women and emphasizing that their participation could benefit others like them. The Cyber Health Educator shared that findings could lead to further research and future programming designed for YMSM and YTG women living with HIV. Participants felt a sense of commitment and more than 95% of those invited agreed to participate.

The study team provided gift cards for participants to thank them for their time when completing baseline and follow-up evaluation assessments, which also helped as an incentive for recruitment and retention.

Role of the Cyber Health Educator. Several factors contributed to the Cyber Health Educator’s success in providing support to intervention participants related to care linkage, retention, and health outcomes. First, the Cyber Health Educator was a person who was similar to many participants (e.g., demographics, sexual orientation, and life experiences), which allowed the Cyber Health Educator to build trust with participants and understand their needs, concerns, and priorities.

As described previously, the Cyber Health Educator was based in the clinic where participants received care, and recruited participants and implemented the social media intervention within the clinic. The Cyber Health Educator established excellent rapport with the clinic staff, and complemented, rather than supplanted, the existing roles and services of the staff (e.g., patient navigators, interpreters, etc.). The Cyber Health Educator’s role was that of an additional resource within the clinic.

In addition, the Cyber Health Educator was trained to thoroughly understand the process of accessing HIV care clinical services within the clinic and understand the barriers faced by racially and ethnically diverse YMSM and YTG women. The project team has found that this firsthand experience is invaluable to facilitate access to services among those with real and perceived barriers.

The Cyber Health Educator also developed a strong sense of camaraderie with participants. Participants in the original implementation of the intervention indicated that they were thankful for the “check-ins”, information about resources, support for resolving challenges, and reminders the health educator sent using social media. When participants first enrolled in the intervention, it was often the Cyber Health Educator who initiated social media interactions. However, after some time, participants began initiating contact, once trust had been established and participants realized that the Cyber Health Educator was a resource who could help them overcome their challenges related to HIV medical care, particularly those participants who struggled to stay in care.

One example of a success story is about a participant who had developed AIDS and was also infected with Hepatitis C. The participant was not attending his medical appointments and was not responding to calls or messages from the clinic. His life-threatening conditions required urgent care and it was imperative that he be seen by medical providers. It was only after the Cyber Health Educator contacted him and explained to him the urgency of his situation that he

agreed to be seen by the providers and his life was saved. The patient at first was in denial about the seriousness of his condition but the Cyber Health Educator helped him to understand and both the participant and the clinic staff were grateful to the Cyber Health Educator for this involvement and support.

Challenges/Barriers

Recruitment. The project experienced a number of challenges related to participant recruitment. Some potential participants were hesitant about enrolling because they thought participation would take up too much of their time. The project team addressed this challenge by explaining that, after enrollment, participation in the intervention itself required very little time commitment (i.e., that it only involved receiving social media messages from the Cyber Health Educator) and by providing gift cards as a token of appreciation for the time participants spent completing baseline and follow-up assessments, which may not be needed in a replication of this intervention.

Other challenges involved identifying and reaching potential participants. As mentioned previously, to implement the study, the project partnered with the clinic to screen and invite patients who met the eligibility criteria to participate. However, many potential participants did not show up for their medical appointments at the clinic, so the project team was not able to recruit them. However, the project team supported clinic efforts to follow up with no-shows to reschedule their appointments, which allowed another potential opportunity to recruit potential participants if they attended the rescheduled appointment.

The project team had also expected to recruit and enroll participants from outside of the clinic in community-based locations. The project team met and partnered with staff from local testing sites, health departments, various organizations that serve people living with HIV, and Disease Intervention Specialists to discuss processes for referring newly diagnosed YMSM and YTG women with HIV to the intervention. The project team also posted flyers with information about the intervention on bulletin boards and distributed those flyers to community members to spread the word to potential participants. In addition, digital versions of the flyers were posted on Facebook, Instagram, and Craigslist. However, very few participants were recruited through these efforts due to a variety of factors, including concerns from organization representatives about confidentiality issues related to making referrals and communication challenges.

Engagement in the intervention. Overall, most participants responded to the social media messages that the Cyber Health Educator sent, and trust and rapport were established. There were a few participants, however, who did not respond or rarely responded and had little interaction with the Cyber Health Educator. Many of these participants still showed up for their medical appointments, so the messages may still have been effective even if participants did not respond.

Retention. Some participants were difficult to retain in the intervention over time. Some moved out of the area to another city or state and transferred their care to another clinic, which represented another challenge since the Cyber Health Educator was unable to view their appointment information and the study team was not able to abstract data from participants' EMR to track their retention in care and viral load. Through perseverance, the study team was

able to locate most participants who moved and, for those who were no longer getting their medical care at the clinic, the Cyber Health Educator continued to send messages to check-in with them and evaluation data was collected over the phone.

Another challenge occurred when participants who had selected to be contacted by text messages changed their cell phone numbers and forgot to give the study team the new one, which made it difficult to contact them and to continue supporting them via social media. The study team was often able to track these participants down using alternative channels, such as contact information for friends or family that they had provided at enrollment and/or social media platforms they chose as secondary alternatives for contact.

Similarly, some participants selected to be contacted via only limited media platforms, in some cases, only one platform (text messaging or Facebook were the most common). These limited selections made retention more challenging. Few participants chose GPS-based apps as platforms for contact, even if they used them, which further limited the Cyber Health Educator's options for contacting them if they did not respond to messages sent via text or Facebook.

Tips for Future Implementation

Several key activities supported successes and helped in overcoming barriers:

1. The Cyber Health Educator's initial interaction with participants was "in person", which helped to establish rapport and trust.
2. The Cyber Health Educator offered sound advice, exhibited good judgment, and was discrete and relatable to most participants given that they had some characteristics in common, such as sexual orientation and age. For those participants whose first language was Spanish, the Cyber Health Educator was also fluent in this language.
3. The Cyber Health Educator worked in collaboration with the clinic's patient navigators to assist participants in accessing resources and overcoming obstacles to care (e.g., insurance; referrals for housing, food, and other medical needs such as dental care; and transportation).
4. As part of the trust-building process, the Cyber Health Educator sent personalized messages and reminders using language and abbreviations many young people like to use (e.g. "I can't wait 2 c u tomorrow morning"). The Cyber Health Educator also sent personalized messages to participants on their birthdays and for holidays such as New Year's Eve, Christmas, and Thanksgiving, as well as regular messages to "check-in" with participants to see how they were doing and provide assistance to overcome barriers related to their care.
5. As part of the study, participants completed follow-up assessments at 6, 12 and 18 months; however, this may not be required in a replication of the intervention. Once trust and rapport had been established, other strategies were identified for participant retention by the implementation team, including flexibility and adaptability in terms of timing and location for assessments to accommodate participants' schedules and changes in plans.
6. Perseverance, creativity, flexibility, and the use of various recruitment and retention strategies simultaneously were critical. The project team tailored strategies to potential participants' priorities. The project team did not assume that one strategy would work to recruit and retain all potential participants, but a combination of strategies.

Monitoring and Evaluation

Aims for Local Evaluation

Our local evaluation sought to:

1. Determine whether the weCare tailored social media intervention improved engagement in medical care and health outcomes (i.e. reduced viral load) among YMSM and YTG women with HIV using an intervention-control (usual care) group design;
2. Document the mode of intervention delivery, dose, and messaging (i.e., the social media used, how often, and what types of messages were utilized); and
3. Explore qualitatively changes over time in engagement in medical care and health outcomes for YMSM and YTG women with HIV as well as perceptions about the intervention, including ways to improve the intervention and facilitators of and barriers to engagement in medical care.

Monitoring Progress

Intervention reach. The target was to enroll 192 YMSM and YTG women who were newly diagnosed, not linked to care, out of care, or not virally suppressed to participate (96 in the intervention group and control [usual care] group), and to implement the social media intervention with participants in the intervention group for 12 months. Participant recruitment was completed by the end of May 2018 and intervention implementation will be completed by the end of May 2019.

Effective activities. We used the following as indicators of the effectiveness of the intervention:

1. The number of MSM and TG women, ages of 16-34, with HIV who attended a routine HIV medical care visit within 3 months of HIV diagnosis.
2. The number of MSM and TG women, ages of 16-34, with an HIV diagnosis who had at least one HIV medical care visit in each 6-month period within the 24-month measurement period.
3. The number of MSM and TG women, ages of 16-34, with an HIV diagnosis who were prescribed ART in the 12-month measurement period.
4. The number of MSM and TG women, ages of 16-34, with an HIV diagnosis who filled their ART prescription.
5. The number of MSM and TG women, ages of 16-34, with an HIV diagnosis with a viral load of <200 copies/mL at last test.

Costs and results of different activities. The assessment of cost for the intervention can be divided into 3 phases: development costs; implementation costs; and dissemination costs. Throughout this project, the project team documented all costs to develop a summary of costs by phase. Intervention development costs included the time and effort of the project team to develop and “manualize” the intervention; the time and effort of the project steering committee; the training of the Cyber Health Educator; and preparing the project-specific social media profiles and private Facebook group. Implementation costs included the time and effort of the project team to implement the intervention; the time and effort of the steering committee; and the time and effort of uncompensated project partners who coordinated with the project team. In addition, fees associated with the use of text messaging and apps and travel expenses (to facilities and agencies in the community to recruit community members for the project, as well as for team members to collect follow-up data from participants if data could not be collected in

the clinic) were included. Dissemination costs included providing technical assistance to other sites who wished to implement and/or adapt the intervention within a new context and providing copies of materials.

Keeping the Intervention on Schedule. For the most part, the intervention was kept on schedule; some changes in the recruitment timeline were made due to the timeline of the development of multi-site evaluation and due to challenges recruiting participants from community-based settings.

Participants/Sample for Local Evaluation

The project team identified potential participants at the clinic, local testing sites, and community organizations that provide services for people living with HIV, and selected those who met the eligibility criteria to invite to participate.

Local evaluation participants were randomized into the intervention group (which was part of the multi-site evaluation) or control (usual care) group (which was not part of the multi-site evaluation).

Methods for Local Evaluation

Surveys. Participants in the intervention and control (usual care) groups completed a brief ACASI questionnaire at baseline enrollment, and 3 more times (at 6-, 12- and 18-month follow-up). The questionnaire included all items for the multi-site evaluation as well as items specific to our local evaluation on barriers to care and experiences of discrimination.

Intervention exposure. The Cyber Health Educator documented all social media messages and interactions using the Intervention Exposure Form programmed into REDCap, a secure web-based application designed to support data capture for research studies. Data collection included date of the conversation, who initiated contact (the participant or Cyber Health 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” (i.e., transportation and insurance/benefit assistance), “enrollment questions,” and “participant seeking other information/help.”

Medical chart data. Data were abstracted from the clinic’s EMR system, Epic’s “WakeOne”, for those in the intervention and control (usual care) groups. Data abstracted included: medication lists, treatment history, appointment information, and lab results.

Several data analysis methods were used to evaluate out project objectives using medical chart data:

- 1) Increase the number of MSM and TG women, ages 16-34, with HIV who attended a routine HIV medical care visit within 3 months of HIV diagnosis.

Method (for objective #1): The project team used Chi-square analysis to compare care linkage between the intervention and control (usual care) groups.

- 2) Increase the number of MSM and TG women, ages of 16-34, with an HIV diagnosis who had at least one HIV medical care visit in each 6-month period within the 24-month measurement period.
- 3) Increase the number of MSM and TG women, ages of 16-34, with an HIV diagnosis who were prescribed ART in the 12-month measurement period.
- 4) Increase the number of MSM and TG women, ages of 16-34, with an HIV diagnosis who filled their ART prescription.
- 5) Increase the number of MSM and TG women, ages of 16-34, with an HIV diagnosis with a viral load of <200 copies/mL at last test.

Method (for objectives #2-5): The project team conducted a between-group analysis to compare the intervention and control (usual care) groups using a logistic regression model with a covariate term for intervention. Logistic regression model was fit using SAS PROC LOGISTIC.

Qualitative Interviews. The project team conducted qualitative interviews at pre- and post-implementation with providers and clinical and testing site staff (n=20 at pre-intervention and n=20 at post-intervention) to explore changes over time in care linkage and retention processes and health outcomes for young MSM diagnosed with HIV. The project team also interviewed intervention participants post-implementation whose viral load was reduced (“stories of success”; n=15) and whose viral load was not reduced (“stories for learning”; n=15) to explore perceptions about the intervention, including ways to improve the intervention and facilitators of and barriers to care linkage and retention.

In-depth interview guides were developed iteratively by the project team and refined and approved by the project steering committee. Interview data were analyzed using constant comparison, an approach to grounded theory. Analytical steps included:

- After each interview, documenting general impressions about its content and potentially emerging themes and new areas of information;
- Listening to the digital recording and taking general notes;
- Having digital recordings professionally transcribed verbatim and then verified;
- Entering transcriptions will into the Nvivo software (Chicago, IL) for purposes of data management;
- Developing a common coding system and data dictionary;
- Coding all transcripts using this common coding scheme, while allowing for new codes to emerge. Special attention was given to differences across role (e.g., participant, healthcare provider, and social worker). Similarities and differences across transcripts were examined and codes and themes revised accordingly.
- Presenting findings to the project steering committee for final review, revision, and

interpretation.

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APPENDIX 1

Messages Related to Linkage & Retention

Theory	Construct	Enrollment	Check-in	Following-up on previous conversation	Overcoming barriers	Appointment reminder
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!	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?
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?	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
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)	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?
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?	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?
SCT	Vicarious learning	I know it is scary 2 think 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	Some guys like me to check n with them 2 help out. Anything I can do 4 u?	Sometimes it takes ongoing communication for people 2 feel comfortable asking 4 help. Do u need any help around (e.g., making appt, getting meds)?	For some it is helpful 2 go 2 a 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?	Sometimes people miss their appointments and then are less healthy. I don't want u to be one of them!
	Persuasion / social support	Hi great to meet u 2day 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?	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?
SCT	Incentives	I 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!	How did things go with...? Wow! Sounds like u had success!	U r doing wonderful showing 2 all of ur appointments, even when I know u have 2 work	After ur appt do, treat urself to [something that the cyber health educator knows that the

Theory	Construct	Enrollment	Check-in	Following-up on previous conversation	Overcoming barriers	Appointment reminder
			[include happy/congrats emoji]		and go 2 school, treat urself this weekend	participant values/wants and is reasonable and within reach]
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?	There are a lot of things that stop us from getting the care we need	Missing ur appt can hurt ur health. R u gonna to make it tomorrow?
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?	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

SCT: Social cognitive theory

ET: Empowerment theory

VL: Viral load

U=U: Undetectable=Untransmittable

Messages Related to Retention

Theory	Construct	Missed appointment	Prescription reminder	Medication adherence	Reinforcing
SCT	Information	I think u missed ur appointment 2day. Do u need the scheduler's phone #?	ur prescriptions r ready 2 pick up 2day. 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.	Is great that u r helping ur friends. Our friends often need the same info that we once needed.
SCT	Outcome expectancies	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?	How do u feel about today? Do you feel like u met ur objective? I am proud of ur progress.
SCT	Self-efficacy	Hey, we missed u 2day. 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?	One more success that should help u feel more confident about managing ur health, right?
SCT	Direct experience	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.	U did it! How do u feel?
SCT	Vicarious learning	Let's get ur missed appt rescheduled. Most people feel better when they get back in2 a routine	Some people put their meds in different bottles so that no one knows that it is these meds. Does that sound like something u could do?	Try this app: Care4today, is 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?	All the other people I talk to say that staying n care helps them stay healthy. & talking 2 me helps them 2!
	Persuasion / social support	Hi, did u have a chance 2 call the clinic yesterday? U know	It's normal to forget ur meds once n a while. Don't beat	U have overcome so many challenges. U can handle this	How can I help u care 4 urself?

Theory	Construct	Missed appointment	Prescription reminder	Medication adherence	Reinforcing
		that this is so important, right? How can I help u?	yourself up about it. But u'll be better off if u take regularly! Text me if u want some ideas to help u	too. How can I support u take them as directed?	
SCT	Incentives	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]	If u make this appointment, pat urself on your back. U are doing it right. U r making me proud.
ET	Critical consciousness	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	Gotta get to appointments and take meds as prescribed to get to U=U
ET	Action	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?	Ur staying in care is making a difference for your health. Don't u think so?

SCT: Social cognitive theory

ET: Empowerment theory

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APPENDIX 2



Eli Arellano Hall shared a link.

January 29, 2018

Ever thought about talking to your doctor about anti-depressants, but not sure how? Maybe this could help!"

¿Alguna vez pensó en hablar con su médico acerca de los antidepresivos, pero no está seguro de cómo? ¡Tal vez esto podría ayudar! "

See Translation



HIVPLUSMAG.COM

How to Have the Antidepressant Medication Conversation with your Doctor



Eli Arellano Hall shared a link.

October 13, 2017

We know an HIV diagnosis can be a scary thing, but we're here to tell you that it will all be okay. You are in control, not HIV. You can rock your treatment plan and start your journey to a happier, healthier life today. 🙌

💎💎 What does that look like? 😊

✓ Getting educated on HIV and how it affects your body — and how your meds are the key to living a healthy life 🧐

✓ Getting into treatment and staying there 💊

✓ Getting to a support group on the regular 🙌💎💎

✓ Practicing sa... See More

See Translation



POSITIVEPEERS.ORG

Signs you're rocking your HIV treatment

HIV can be scary. But you can overcome your fear and rock your HIV...

APPENDIX 3

HRSA SPNS Study Enrollment Sheet

Eligibility

1. Is the participant HIV-positive?
 - Yes
 - No [*STOP; this person is not eligible to participate in the study*]
2. Does the participant self-identify as male or transgender?
 - Yes
 - No [*STOP; this person is not eligible to participate in the study*]
3. Does the participant report ever having sex with men?
 - Yes
 - No [*STOP; this person is not eligible to participate in the study*]
4. What is the participant's age (in years)? _____
[*If age is <16 or >34 years, STOP; this person is not eligible to participate in the study*]
5. Which, if any, of the following criteria does this person meet? (*select all that apply*)
 - Newly diagnosed (i.e., tested HIV positive for the first time within the last 12 months)
 - Not linked to care (i.e., aware of their HIV infection status but have never attended an HIV medical visit* after being diagnosed)
 - Out of care/not fully retained in care (i.e., diagnosed with HIV more than 12 months ago, but has a gap in attending HIV medical visits* of more than 6 months within the last 24 months)
 - Not virally suppressed (i.e., had a viral load \geq 200 copies/mL at last lab test)

* HIV medical visits are defined as seeing an HIV medical provider.
[*If answer obtained by participant self-report, confirm by chart review prior to collecting baseline data. If, after chart review, none of the criteria are met, this person is not eligible to participate in the study.*]

Contact information

6. Name: _____
7. Date of birth (MM/DD/YYYY): _____
8. Cell phone number: _____
9. Is it okay to send texts to this number?
 - Yes
 - No
10. Other phone number: _____
- 10a. Is it okay to send texts to this number?
 - Yes
 - No
11. E-mail address: _____

11a. Is it okay to contact you via Facebook messenger?

- Yes
- No

11b. Facebook username: _____

12. Name of at least one other person who would know how to get in touch with the participant:

13. Relationship of this person to participant: _____

14. Cell phone number of this person: _____

15. Is it okay to send texts to this number?

- Yes
- No

16. Other phone number of this person: _____

17. E-mail address of this person: _____

Social media preferences

“As stated on the consent form, participants will be randomized either into weCare, a tailored social media-based program, or to receive usual care at the Wake Forest School of Medicine Infectious Diseases Specialty Clinic. Randomization means that you are put into a group by chance. It is like flipping a coin. Neither you nor the study staff can choose the group you will be in. You will have an equal chance of being placed in either of the 2 groups. If you are randomized to be part of weCare, a trained Cyber Health Educator (‘CHE’) will interact with you one-on-one using social media such as Facebook messenger, text messaging, and/or GPS-based mobile applications (‘apps’), based on your preferences. The Cyber Health Educator (‘CHE’) will communicate with clinic staff as needed to ensure that he can best support you and your health.”

18. Preferred method(s) of communication if participant is randomized to be part of weCare (*select all that apply*):

Method and contact information/username:

- Text (cell phone) _____
- Text (Kik) _____
- Text (Whatsapp) _____
- Facebook _____
- Adam4Adam/Radar _____
- Badoo _____
- Grindr _____
- Jack’d _____
- Scruff _____
- Other (specify) _____

“The weCare program also includes an optional secret group on Facebook. The secret group is interactive and provides information about HIV care and the clinic and an opportunity to get support from other gay and bisexual men and transgender women like you. All aspects of the secret group are invisible to people who are not members of the secret group. Only participants in the weCare program and weCare program staff are allowed to be members. If you are randomized to be part of weCare and choose to be part of the secret group, other members of the secret group will be able to see that you are a member and anything that you post within the secret group, but nobody else who is not part of the secret group will be able to see. Being part of the secret group is optional and you can be part of weCare without being part of the secret group.”

19. If participant is randomized to be part of weCare, would he/she like to be part of the optional secret Facebook group at this point?

- Yes
- No

20. If participant is randomized to be part of weCare, how far in advance would he/she like appointment reminders (*select all that apply*):

- 1 week before the appointment
- 1 day before the appointment
- Other: _____

21. If participant is randomized to be part of weCare, would he/she prefer that messages from the Cyber Health Educator **NOT** use any of these terms (*select all that apply*):

- Clinic
- Medication
- Prescription
- Doctor
- Nurse
- Pharmacy
- Appointment
- Provider
- Other: _____

“As a reminder, regardless of whether you are randomized to be part of weCare, throughout the research study information will be reviewed and recorded from your medical records, including demographic information, medication lists, treatment history, and appointment information. Your pharmacy will also be called to collect information on the medications that you are prescribed. You will also be asked to do a brief questionnaire. The questionnaire will be done 4 times, once at the beginning of the study (now), again in 6 months, in 12 months, and in 18 months. Questions ask about your age, education, and experiences with health care and technology. You will receive \$15.00 for completing the first questionnaire at the beginning of the study, \$20.00 for completing it again in 6 months, \$25.00 for completing it in 12 months, and \$40.00 for completing it in 18 months, for a total of up to \$100.00.”

For study staff use only

22. Date enrolled (MM/DD/YYYY): _____

23. Enrolled by: _____

24. Where was participant recruited from?

- Testing site
24a. If so, please specify which one: _____
- DIS (Disease Intervention Specialist) worker
- Wake Forest School of Medicine Infectious Diseases Specialty Clinic
- Other: _____

Date and time of next HIV medical visit (if known):

25.1 Date (MM/DD/YYYY): _____

25.2 Time: _____

26. Wake Forest Baptist Health medical record number: _____

27. Unique ID number: _____

28. Which group was participant randomized to?

- weCare intervention
- Usual care

APPENDIX 4

Social Media Intervention Exposure Form

Q1. Interviewer ID (Staff ID)

Q2. Site name

Q3. Participant ID _____

Q4. Date ____ / ____ / ____

- Q5. Type of contact: (check all that apply)
- In-person
 - Phone/voice
 - E-mail
 - Facebook
 - Text messaging (cell phone or computer)
 - Kik
 - WhatsApp
 - A4A / Radar
 - Badoo
 - Grindr
 - Jack'd
 - SCRUFF
 - Mobile app – chat
 - Other: _____

Skip to Q7 unless Q5 = 'In-person'

- Q6. Location of in-person contact:
- Medical office
 - Non-medical office
 - Outside (e.g., on the street, at an event)

- Q7. Who initiated contact:
- Staff
 - Participant

Skip to Q10 if Q5 = 'In-person' only; skip to Q8b if Q5 = 'Phone or Voice' only

WF_Q8A. Total number of messages sent today: (does not include phone calls) ____

WF_Q9A. Total number of messages received today: (does not include phone calls) ____

Skip to Q10 unless Q5 = 'Phone or Voice'

WF_Q8B. How many calls did staff make to the participant? ____

WF_Q9B. How many calls did participant make to the staff? __ __

- Q10. Topics discussed: (Check all that apply)
- Regular check-in
 - Following up on previous conversation
 - Appointment reminder
 - Missed appointment
 - Retention in care
 - Viral suppression
 - Prescription reminder
 - Medication adherence
 - Participant seeking information
 - Problem-solving / overcoming barriers to care
 - Utilization of support services
 - Health literacy
 - Skills building
 - Social support
 - Enrollment in project
 - Referral provided: _____
 - Appointment scheduling (e.g., reminding participant to schedule or reschedule appointment, helping participant to schedule appointment, etc.)
 - Acknowledging participant for attending HIV care appointment
 - Other: _____

- WF_Q12. Language(s) used:
- English
 - Spanish
 - Both

WF_Q13. Did intervention staff attend a clinic appointment with this participant today?

- Yes
- No [**Skip to Q14**]

WF_Q13a. Total length of appointment (in hours): __ __

WF_Q13b. Total length of appointment (in minutes): __ __

WF_Q14. Next medical appointment date and time: __ __ / __ __ / __ __ __ __ __ __ : __ __

WF_Q15. Next other appointment date and time (e.g. housing, mental health, etc.): __ __ / __ __ / __ __ __ __
__ __ : __ __

Q11. Other notes: _____