Demonstration Site Summary

Text Messaging to Improve Linkage, Retention and Health Outcomes among HIV-positive Young Transgender Women: Text Me, Girl!

Friends Research Institute, Inc.

Los Angeles

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

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

Principal Investigator: *Cathy J. Reback, Ph.D.*,
reback@friendsresearch.org

December 2019

This publication was made possible by award number H97HA28889 from the U. S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV/AIDS Bureau's Special Projects of National Significance Program. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the U.S. government.

INTERVENTION SUMMARY

Text Me, Girl! is a 90-day theory-based, trans-specific, automated text-messaging intervention designed to improve health outcomes along the HIV Care Continuum, with the desired outcome of viral suppression among HIV-positive young transgender women, aged 18-34, who are not linked to care, or not retained in care, or not prescribed ART, or non-adherent to ART, or not virologically suppressed. Over the course of the 90-day intervention, participants receive 270 theory-based text messages (three messages daily) that are targeted, tailored, and personalized specifically for HIV-positive young adult transgender women. Each day participants receive a message that corresponds with three components of the HIV Care Continuum: 1) HIV positivity/physical and emotional health; 2) linkage/retention in HIV care; and, 3) ART medication adherence/viral load suppression (again, three messages daily, one along each component of the HIV Care Continuum). Text messages can be delivered to either a participant's cell phone or email inbox. Following the 90-day *Text Me, Girl!* intervention, participants can opt-in or opt-out of continued weekly post-intervention text-messages for ongoing retention and engagement support from HRSA's UCARE4LIFE text-message library. The per-participant text-messaging cost is estimated to be $3 to $5 per participant. *Text Me, Girl!* was developed and evaluated as part of the HRSA HIV/AIDS Bureau's Special Projects of National Significance (SPNS) Social Media Initiative. The *Text Me, Girl!* intervention demonstrated significant outcomes in ART uptake, ART adherence, and viral suppression.

THEORETICAL BASIS

Text Me, Girl! uses three theories of behavior change that have demonstrated efficacy across more than three decades of empirical research, and have proven to be particularly effective for technology-based HIV prevention: Social Support Theory,[1-5] Social Cognitive Theory,[6,7] and the Health Belief Model.[8,9] Technology-based interventions that employ more than one theoretical mechanism of behavior change produce superior results. [10,11,12] Each of the three daily text messages were grounded in one of the three theories guiding established principles of behavioral change applied to steps in the HIV Care Continuum.

- **Social Support Theory** informed messages encouraged instrumental, emotional, and informational assistance.
- **Social Cognitive Theory** informed messages worked to enhance self-efficacy (i.e., the belief/perception that one is able to achieve desired outcomes).
- **The Health Belief Model** informed messages targeted individuals' beliefs regarding threats to their health and their beliefs that specific health behaviors can reduce these threats.

INTERVENTION DEVELOPMENT

The *Text Me, Girl!* text-messaging library was developed in collaboration with young adult transgender women who were staff at Friends Community Center in Hollywood, California, and member of the Friends Community Center's transgender Community Advisory Board (CAB). Several reiterations were made as staff and CAB members wrote, edited, and revised each text message. Following that process, the research team reviewed the messages to ensure that each message reflected a stage in the HIV Care Continuum and each message had a theoretical foundation. The text messages were then evenly distributed across the HIV Care Continuum and the theoretical foundations. To further ensure cultural responsiveness, after the research team edited for HIV Care Continuum and theoretical content, the text-message library was again returned to the transgender staff and CAB members for their final review and approval.

INTERVENTION COMPONENTS AND ACTIVITIES

Text Me, Girl! text messages are transmitted through an automated simple message service (SMS) gateway, such as Twilio or Qualtrics. The intervention requires minimum staff time to enroll participants and to administer, as the text-messages are sent automatically and there are no responses from participants to monitor or respond to. The 270 text messages were uniformly designed to transmit scripted text messages to each participant across: 1) the HIV Care Continuum; and, 2) the theoretical foundation of each message (see Table 1). The intervention serves to remind, educate, motivate, and encourage behaviors supporting retention in care and mediation adherence. Sample text messages are presented in Table 2. Entry to the intervention includes an initial welcome message. This initial message is not a HIV care message but, rather, is used to determine that the technology platform system is registered to the participant's cell phone or email inbox, and that transmission is successful (e.g., "Thanks for your participation!" or "Welcome to Text Me, Girl!"). All text messages are transmitted every day including weekends, in real-time, within a 10-hour period (i.e., an outgoing text message approximately every five hours). The optimum text-messaging hours were determined to be daily at 12:00 PM, 5:00 PM, and 10:00 PM. However, a participant may alter the predetermined default text-messaging schedule by personalizing a 10-hour texting period to fit her individual schedule. To maintain interest and enthusiasm for the intervention, participants do not receive the same scripted text message twice. Participants can further personalize their intervention by choosing which platform they would like to receive the text messages: by text message to her cell phone or to her email inbox.

Following the 90-day theory-based, trans-specific text-messaging intervention, participants can opt-in or opt-out of continued weekly post-intervention messages for ongoing retention and

engagement support derived from the HRSA-funded UCARE4LIFE library, which are designed for a broader audience of youth and adults living with HIV.

Table 1: Text Message Intervention Design by HIV Care Continuum and Theoretical Foundation

Theoretical Foundations	# HIV Positivity/ Physical & Emotional Health Messages	# Linkage/ Retention in HIV Care Messages	# ART Med. Adherence/Viral Load Suppression Messages	Total Messages per HIV Care Continuum & Theoretical Foundations
# of Social Support Theory Messages	**30**	**30**	**30**	90
# of Social Cognitive Theory Messages	**30**	**30**	**30**	90
# of Health Belief Model Messages	**30**	**30**	**30**	90
Total:	**90**	**90**	**90**	270

Table 2: Sample Text Messages by HIV Care Continuum and Theoretical Foundation

Theoretical Foundations	Sample HIV Positivity/ Physical & Emotional Health Messages	Sample Linkage/ Retention in HIV Care Messages	Sample ART Med. Adherence/ Viral Load Suppression Messages
Sample Social Support Theory Messages	*Trans women, living positive, loving life.*	*When you stay in HIV care you can expose your heart, not your partner.*	*HIV meds work, your trans beautiful body is worth protecting.*
Sample Social Cognitive Theory Messages	*Make no compromise. You can protect yourself, girl.*	*Stay on top of your numbers with your doctor's help, now that's Trans Pride.*	*You can take care of yourself and your trans community, take your meds.*
Sample Health Belief Model Messages	*One night of fun, a lifetime with herpes.*	*Missing an HIV appointment can mean missing out on life.*	*HIV meds can keep your trans body strong and healthy.*

EVALUATION RESULTS SUMMARY

Data from *Text Me, Girl*! (N=130) revealed that most participants were between the ages of 30-34 (59%), most self-reported their race/ethnicity as Hispanic/Latinx (43%) or African-American/Black (40%), a quarter had achieved a greater-than-high-school education (25%), and half earned less than $500/month (50%). Almost half (44%) reported current housing instability or were experiencing homelessness.

At baseline, only 35% of participants were virally suppressed, and only 5% reported their ART medication adherence as "Excellent." By 12-month distal follow-up, half (49%) of participants were fully virally suppressed and 38% had achieved "Excellent" ART adherence (both χ^2 $p < 0.001$). Overall levels of ART uptake also significantly increased from 49% at baseline to 72% at 12-month distal follow-up (χ^2 $p < 0.001$). Multivariate analyses indicated that increased engagement in the *Text Me, Girl!* intervention was associated with significantly increased likelihood of attending a HIV care visit in the past six months, as well as increased probability of achieving an undetectable viral load (both $p < 0.01$). Multivariable results also indicated that retention in the *Text Me, Girl!* intervention was associated with significantly improved ART adherence, and significantly increased likelihood of achieving an undetectable viral load (both $p < 0.05$).

ADOPTING, ADAPTING, AND IMPLEMENTING

Implementing *Text Me, Girl!* is relatively simple. A community based organization or clinic can access the text-message library by contacting the Principal Investigator. The text-message library is provided to a SMS gateway provider that the organization contracts with, which can be done relatively easily through websites. Then frontline staff with participant contact can enroll a participant in the messaging gateway system (more details below).

Community based organizations/clinics may want to vet the messages with their transgender women participants and CAB to ensure the messages are relevant to their specific local population. We recommend maintaining the same structure and core content of the messages, i.e., HIV Care Continuum and theoretical foundation content, and only adapting language to local idioms or slang, as suggested by their transgender women participants and CAB.

STAFFING REQUIREMENTS & FUNCTIONS

Text Me, Girl! core intervention staff needed to implement the project include a Project Coordinator and the clinic or agency staff who will enroll participants in the intervention. The total amount of hours per year will depend upon the total number of participants annually.

However, enrollment takes about five minutes per participant to describe the intervention, answer questions, and register her phone number or email address. If informed consent or release forms are required by the implementing organization, additional time will be needed. A brief follow-up after a few days is suggested to touch base with the participant to ensure messages are being received and that there are no technical complications to problem solve, and to answer questions and assuage any concerns the participant might have, which should take less than five minutes. Finally, a staff person should be assigned approximately 30 minutes each week to monitor the text-message and email logs from the messaging gateway service provider (e.g., Qualtrics, Twilio) to identify potential problems in the message delivery system, and if participant's phone numbers may have changed or if messages were blocked. This information could be used to prompt follow-ups with patients to address concerns and assist in patient retention.

Project Director

The Project Director is responsible for:

- Project implementation
- Participant safety
- Overseeing all program management tasks
- Assisting with staff hiring and training
- Assisting in training all project-related staff
- Conducting in-service trainings at local community based organizations and networking with community gatekeepers to enhance community awareness of *Text Me, Girl!*
- Supervising the Research Coordinator

Frontline Staff

Frontline staff with direct participant contact would ideally be assigned the task of offering the intervention and enrolling each participant in the messaging system. These staff might be nurses, case managers, navigators, peer educators, or even physicians since the effort to enroll is less than five minutes.

COSTS

Staffing costs will vary based on geographic location, experience of staff, and percentage effort. The text-messaging costs will also vary by the per-message fee from the text-message gateway provider, but tends to range from 1 to 2 cents per message. At 270 messages for the core *Text Me, Girl!* intervention, the per participant cost is estimated to be between $3 and $5 over the

90 day intervention period. The UCARE4LIFE messages are typically sent one time per week, per domain. There are a total of 12 content domains in the full UCARE4LIFE message library; however, the *Text Me, Girl!* project only utilized the two domains that have content directly related to the HIV Care Continuum. Cost for implementing the UCARE4LIFE message library will depend upon the number of domains used and the number of weeks the text messages are delivered. However, the same 1 to 2 cents per message can be used in this calculation.

RESOURCES

Publications:

- Reback, C.J., Fletcher, J.B., Fehrenbacher, A.E., Kisler, K. Text Messaging to Improve Linkage, Retention, and Health Outcomes among HIV-positive Young Transgender Women: Protocol for a Randomized Controlled Trial (Text Me, Girl!). JMIR Research Protocols. DOI:10.2196/12837 RR1-10.2196/12837

Websites:

Friendscommunitycenter.org

Contact info:

Cathy J. Reback, Ph.D.

323-463-1601

reback@friendsresearch.org

REFERENCES

1. Reilly T, Woo G. Social support and maintenance of safer sex practices among people living with HIV/AIDS. Health & Social Work. 2004; 29(2): 97-105. doi: 10.1093/hsw/29.2.97
2. Wohl A, Galvan F, Myers H, et al. Do social support, stress, disclosure and stigma influence retention in HIV care for Latino and African American men who have sex with men and women? AIDS and Behavior. 2011; 15(6): 1098-1110. doi: 10.1007/s10461-010-9833-6
3. Woodward EN, Pantalone DW. The role of social support and negative affect in medication adherence for HIV-infected men who have sex with men. Journal of the Association of Nurses in AIDS care. 2012; 23(5): 388-396. doi: http://dx.doi.org/10.1016/j.jana.2011.09.004

4. Glick S, Golden M. Early male partnership patterns, social support, and sexual risk behavior among young men who have sex with men. AIDS and Behavior. 2013; 1-10. doi: 10.1007/s10461-013-0678-7
5. Scott H, Pollack L, Rebchook G, Huebner D, Peterson J, Kegeles S. Peer social support is associated with recent HIV testing among young black men who have sex with men. AIDS and Behavior. 2013; 1-8. doi: 10.1007/s10461-013-0608-8
6. O'Leary A, Wolitski RJ, Remien RH, et al. Psychosocial correlates of transmission risk behavior among HIV-seropositive gay and bisexual men. AIDS. 2005; 19: S67-S75.
7. Mausbach BT, Semple SJ, Strathdee SA, Zians J, Patterson TL. Efficacy of a behavioral intervention for increasing safer sex behaviors in HIV-positive MSM methamphetamine users: results from the EDGE study. Drug and Alcohol Dependence. 2007; 87(2): 249-257.
8. Carpenter C J. A meta-analysis of the effectiveness of health belief model variables in predicting behavior. Health Communication. 2010; 25(8): 661-669. doi: 10.1080/10410236.2010.521906
9. van der Snoek EM, de Wit JBF, Götz HM, et al. Incidence of sexually transmitted diseases and HIV infection in men who have sex with men related to knowledge, perceived susceptibility, and perceived severity of sexually transmitted diseases and HIV infection: Dutch MSM–Cohort Study. Sexually Transmitted Diseases. 2006; 33(3): 193-198. doi: 110.1097/1001.olq.0000194593.0000158251.0000194598d.
10. Reback CJ, Fletcher JB, Shoptaw S, Mansergh G. Exposure to theory-driven text messages is associated with HIV risk reduction among methamphetamine-using men who have sex with men. AIDS and Behavior. 2015; 1-12.
11. Reback CJ, Grant DL, Fletcher JB, et al. Text messaging reduces HIV risk behaviors among methamphetamine-using men who have sex with men. AIDS Behav. 2012; 16(7): 1993-2002. doi: 10.1007/s10461-012-0200-7
12. Webb T, Joseph J, Yardley L, Michie S. Using the internet to promote health behavior change: a systematic review and meta-analysis of the impact of theoretical basis, use of behavior change techniques, and mode of delivery on efficacy. Journal of Medical Internet Research. 2010; 12(1): e4.