Development of a personalized bidirectional text messaging tool for HIV adherence assessment and intervention among substance abusers

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ABSTRACT

We describe the development of a two-way text messaging intervention tool for substance users who are non-adherent with HIV medications, and examine message flow data for feasibility and acceptability. The assessment and intervention tool, *TxText*, is fully automated, sending participants mood, substance use, and medication adherence queries by text message. Participants respond, the tool recognizes the category of response, and sends the personalized intervention message that participants designed in return. In 10 months, the tool sent 16,547 messages (half initial, half follow-up) to 31 participants assigned to the TxText condition, who sent 6711 messages in response to the initial messages. Response rates to substance use ($n = 2370$), medication ($n = 2918$) and mood ($n = 4639$) queries were 67, 69, and 64%, respectively. Responses indicating medication adherence, abstinence from substances, and good moods were more common than negative responses. The *TxText* tool can send messages daily over a 3 month period, receive responses, and decode them to deliver personalized affirming or intervention messages. While we await the outcomes of a pilot randomized trial, the process analysis shows that *TxText* is acceptable and feasible for substance abusers with HIV, and may serve as a complement to HIV medical care.

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Lifesaving medication regimens for HIV disease can result in increased life expectancy with lower rates of illness for patients living with HIV. The Achilles' heel of antiretroviral therapy (ART) is the requirement of very high medication adherence to avoid viral mutation, medication resistance, and failure of treatment (Chesney, 2003). While adherence to HIV regimens is a well-researched challenge, active retention in adequate care has been more recently identified as a source of morbidity and mortality (Kempf et al., 2010; Mugavero et al., 2009). It is now clear that both regular attendance at clinic appointments and regular, as-directed dosing of HIV medications are required to optimize health.

Some groups are at particularly high risk for non-adherence and disengagement from care. These include those newly diagnosed with HIV, but also those who experience barriers to care. In the U.S., this second group is disproportionately filled with people of color, from rural areas, from the South, with fewer financial resources, lacking transportation, and residing in communities where stigma about HIV disease is strong (Kempf et al., 2010; Konkle-Parker, Erlen, & Dubbert, 2008; Reif et al., 2011; Sandelowski, Voils, Chang, & Lee, 2009; Sandelowski, Voils, Chang, & Lee, 2009; Sayles, Wong, Kinsler, Martins, & Cunningham, 2009; Yannessa, Reece, & Basta, 2008;

Young & Bendavid, 2010). All of these social factors undermine access to care and ART adherence. Additionally, mental disorders and substance use can reduce adherence; both depression and active alcohol and drug use can be related to periods of ART nonadherence (Berg, Cooperman, Newville, & Arnsten, 2009; González-Guarda, McCabe, Florom-Smith, Cianelli, & Peragallo, 2011; González-Guarda et al., 2011; Malta, Strathdee, Magnanini, & Bastos, 2008; Tucker, Burnam, Sherbourne, Kung, & Gifford, 2003).

Nonadherence to ART regimens is closely related to treatment failure (Flandre et al., 2002; Paterson et al., 2000), and in response, researchers have developed interventions to improve adherence. Unfortunately, these interventions tend to come too late, after a period of nonadherence has already resulted in viral replication and reduced immune health. Additionally, most tested HIV medication adherence interventions have modest and ephemeral effects (Simoni, Amico, Pearson, & Malow, 2008; Simoni, Pearson, Pantalone, Marks, & Crepaz, 2006). There is a clear need to develop interventions that can identify nonadherence and other behaviors that threaten adherence as they occur, in real time, and deliver an appropriate intervention immediately.

Mobile phone technology, commonly called mHealth, has the potential to address many of the concerns outlined above. Mobile phones have been spreading rapidly in the U.S. market, with near complete saturation expected by 2014 (Lenhart, Ling, Campbell, & Purcell, 2010). More African-Americans (93%) have mobile phones

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than other groups, and this subset of the population uses more mobile phone minutes per month (Brenner, 2013). Rural areas in the U.S. generally have some access to cellular signals as coverage extends into remote sections of the country. Therefore the reach of the technology, and its familiarity to many people, are potential advantages. Additionally, an mHealth intervention may fit the preferences of non-urban people living with HIV. Many people living with HIV express preferences for technology with which they are already familiar and may already use, such as text messaging, rather than Internet materials accessed from a computer; these options are seen as more private and more accessible by non-urban HIV patients living in the U.S. South (Farrell Carnahan, Fabbri, & Ingersoll, 2011). Thus, a simple mobile-phone-based intervention might be acceptable to this patient subpopulation, and could potentially overcome some of the health disparities they experience. Because of variable cellular signal strength, a text messaging (SMS) mHealth tool might be particularly appropriate because text messages can often be received and sent even in areas where voice telephone calls have inadequate signal strength.

Studies of HIV-related mHealth interventions range from descriptions to observational studies to randomized trials. Most studies focus on medication adherence as the sole intervention target, with interventions delivered by SMS/text messaging, smart phones, or computers (Pellowski & Kalichman, 2012). A recent Cochrane review covering studies published through 2011 found only two good quality mHealth intervention studies (Horvath, Azman, Kennedy, & Rutherford, 2012). These studies examined weekly SMS adherence interventions conducted in Kenya, and found that weekly text messaging enhanced ART adherence and improved suppression of viral load. In March 2013, we found 26 studies published after that review with the keywords text messag* and HIV abstracted on PubMed. Most of these were focused on HIV prevention ($n = 7$), or assessed the feasibility of an mHealth intervention to target varied HIV risk behaviors in a particular population ($n = 8$) such as Latinos (Leite et al., 2013), African American teens (Cornelius et al., 2012), Chinese men who have sex with men (MSM) (Nehl et al., 2012), or US MSM (Reback et al., 2012), while two were secondary or process analyses of other studies, and four were reviews of various aspects of mHealth in the HIV field.

There were five intervention studies among people living with HIV. Three studies tested variations of one-way standardized text messaging. In a pilot RCT, text message medication dosing reminders sent to eight Brazilian women were related to higher ART adherence by self-report, pill-count, and MEMS than in the control group ($n = 13$) (da Costa et al., 2012). In an RCT of weekly standardized motivational one-way text messaging versus usual care in Cameroon, there was no impact on ART adherence among 200 patients (Mbuagbaw et al., 2012). In contrast, in a single-arm cohort study in Bangalore India, weekly picture text messaging paired with weekly interactive voice messaging for 6 months among 150 patients increased optimal ART adherence over 6 months (Rodrigues et al., 2012).

Two studies tested variations of two-way and tailored text messaging. In a proof-of-concept study of tailored text messaging for ART adherence among MSM adults, investigators sent dynamically tailored text messages, primarily medication dosing reminders, over a 3 month period, with weekly adherence queries that the participants answered by two-way messaging (Lewis et al., 2013). Participants liked the text messaging intervention, and ART adherence, viral load, and CD4 count improved among those who were nonadherent at study entry. Among youth living with HIV, investigators pilot tested text messages as medication reminders and queries about dosing in a two-way text messaging intervention (Dowshen, Kuhns, Johnson, Holoyda, & Garofalo, 2012). They found that mean Visual Analog Scale adherence scores and AIDS Clinical Trial Group questionnaire 4-day recall increased at 12 and 24 weeks compared to baseline, with a

trend towards improved CD4 and viral load markers. They reported good retention and acceptability to the adolescent sample living with HIV. While preliminary, these studies show that both one-way and two-way text messaging are promising for improving ART adherence.

Importantly, none of these text messaging intervention studies assessed nor intervened upon other phenomena that undermine ART adherence. In the U.S., symptoms of depression and active substance use often correlate with periods of ART nonadherence (Carrico et al., 2011; González-Guarda et al., 2011; González-Guarda et al., 2011; Malta et al., 2008; Tucker et al., 2003). In response to this pattern of related behaviors, a few studies have tested face to face ART adherence interventions among substance abusers, and have found that addressing nonadherence and substance abuse together is a promising approach that results in both improved adherence and reduced drinking and drug use (Ingersoll et al., 2011; Parsons, Golub, Rosof, & Holder, 2007; Parsons, Rosof, Punzalan, & Di Maria, 2005). Similarly, a few investigators have developed dual target interventions addressing both depression and adherence, with promising results (Daughters, Magidson, Schuster, & Safren, 2010; Safren et al., 2012). While these face to face interventions targeting ART adherence and depression or substance use had good outcomes, their reach is limited. It seems logical to extend a text messaging adherence intervention to target active substance use and poor moods that threaten adherence.

The purpose of this paper is to describe the formative, iterative development process used to create a two-way text messaging intervention tool that assesses ART adherence, substance use, and mood daily, and delivers self-created personalized intervention messages for each targeted behavior nearly immediately. Additionally, we will assess the tool's feasibility and acceptability to participants. Then, we will examine the process data available to date. Last, we will summarize the feasibility of the text messaging tool to address ART adherence, depressed mood, and active substance use.

1. Methods

The overall procedures used to develop the personalized bidirectional text messaging tool follow. First, the study team reviewed data from a small preliminary study we had conducted of a one-way SMS system. These data included participant perceptions of receiving self-designed, personalized messages encouraging ART adherence as highly motivating (Delgado et al., 2009). A subset of the preliminary study team identified desired features of a new tool. These included capability to assess nonadherence, substance use, and poor mood in real time, and to send an intervention message in real time. Additionally, the team wanted to make the tool scalable, sustainable, and cost effective, and determined that it should be as automated as possible, with an easy interface for administration and data retrieval.

We sought input from the target population of patients through a series of individual and small group interviews. Nineteen participants completed questionnaires on their demographic, substance use, adherence, and mobile phone characteristics. After showing a short presentation of the goals of the study and many possible options for a text messaging tool, we elicited their feedback about potential draft components, utility, and appeal. We also interviewed health care providers who were HIV clinicians, pharmacists, or health department AIDS Drug Assistance Program (ADAP) coordinators. Fourteen professionals provided information about their HIV treatment experience and participated in a 20 minute interview about their perceptions of barriers to HIV care engagement and medication adherence, misconceptions patients have about medications and treatment, major reasons patients report for missing appointments or failing to pick up medications, and the strategies patients used to overcome the barriers. After these interviews, we