# "It´s time for your life": How should we remind patients to take medicines using short text messages?

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## ABSTRACT

*The objective of this paper is to characterize effective patient care reminder strategies for people living with HIV/AIDS (PLWHA) to improve antiretroviral therapy (ART) adherence) using short message service (SMS) based on patient perspectives. We conducted a qualitative study with adult PLWHA in a community-based clinic in Lima, Peru using focus groups. 26 HIV-positive individuals participated in four focus groups (20 men, 6 women). The participants expressed positive perceptions towards receiving reminders via SMS, but specified certain characteristics they wanted them to have (such as being simple and concise). It was also important that the messages maintained confidentiality and privacy by using coded words or phrases ("Remember, it is the time of your life") instead of "sensitive" words (HIV or antiretroviral). This study suggests that patients want healthcare SMS that appropriately notify them, deliver a careful crafted message, and assess the context in which they are received.*

## INTRODUCTION

Adherence to antiretroviral treatment (ART) is critical for treatment success of people living with HIV/AIDS (PLWHA). Near perfect (≥95%) compliance is required for both immediate and long-term clinical success.[1] Non-adherence to ART, however, ranges from 33%–88%.[2] Several informatics interventions aimed at improving adherence by influencing patient behavior have been tested and have also evaluated electronic reminders to influence decision-making.[3,4]

A 2008 systematic review on the use of electronic reminder devices to improve adherence to ART concluded that there is insufficient evidence supporting the effectiveness of electronic reminders (including via cell phones and pagers) as strategies for improving patient adherence to ART.[5] A potential limitation of the existing published data is that they overlook the key role of the reminder message. The data are limited by a lack of understanding how patients process such messages in a healthcare setting and how they may influence their decision-making.[6]

Several researchers have proposed various characteristics of effective reminders. Norman suggests that all reminders have two essential aspects: the signal or notification modality (that there is something to remember) and the message (this is what to remember).[7] In addition, an effective reminder should also have the capability to assess the right context to judge the best moment for reminding.[8]

These characteristics of messages have the potential to be effectively implemented and leveraged using mobile devices such as cell phones. Context-aware mobile devices are an emerging research area that can address reminders not only from the technological point of view,[9] but also research related to human-computer interaction and privacy issues[10]. Currently there is not a comprehensive list of recommendations for reminder messages targeted to improve adherence for PLWHA.

The objective of this paper is to characterize effective ART reminder strategies for PLWHA in Lima, Peru using SMS based on patient perspectives. SMS is a potentially powerful tool that meets many of the criteria to be effective reminders, including providing a signal and a message. The study setting provides an excellent opportunity to utilize SMS because of the high penetration of cell phones in Peru (79.3% by June 2009). A better understanding of message processing and an exploration of the factors that effect acceptance of such request may help improve adherence of interventions aimed at those patients.

## METHODS

Participants were recruited at a community-based clinic (Via Libre) in Lima, Peru that serves mostly HIV-positive individuals. Four focus groups were conducted at the clinic. Three of the focus groups were conducted exclusively with males and one group exclusively with females.

Individuals were recruited using flyers and purposive sampling and were required to be HIV-positive adults receiving ART who owned a cell phone. Eighty-three patients were invited to participate in the study and 56 consented to determining their eligibility. Seven of those consented were not receiving ART and four did not own a cell phone and thus were ineligible. Those eligible were invited to attend one of the four focus groups and were offered 30 Peruvian nuevos soles (about $10 US dollars) and a light meal for participating. Of the 45 individuals scheduled for a focus group, 26 (58%) actually attended.

The focus group guide was adapted from previous formative work[11] to specifically assess culturally-appropriate reminder messages. HIV consultants in Lima reviewed the topic guide to determine the content validity. The groups were conducted in Spanish at the community clinic by a professionally trained moderator with experience in formative research and co-moderated by the first author (WHC). The groups lasted about one to one and a half hours, were digitally recorded, and a research assistant took notes.

The group sessions were transcribed by the research staff and reviewed by a Spanish-speaking investigator (WHC). Data were entered into Atlas.ti version 5.2 qualitative data management software (Scientific Software Development, Berlin, Germany). Two different Spanish-speaking researchers (WHC, DAQ) coded transcripts independently using a content analysis approach. After coding each group the researchers discussed codes came to an agreement on the final coding. A list of codes was created based on the first two groups and then applied to the other two groups. Based on the number of shared themes between groups, we estimate that we reached a saturation of themes of at least 80%. The inter-rater reliability between the coders had a Kappa of $0.8289$ (standard error= $0.0903$, P<0.0005). Summaries were compared and discussed until a consensus was reached on which themes were most salient to participants. We then reviewed the transcripts to confirm our findings and identified quotes that best illustrated common themes. Quotes were translated and edited for ease of reading, but were not substantially altered. The institutional review boards of the University of Washington, Universidad Peruana Cayetano Heredia, and Via Libre approved the study. All participants signed an informed consent previous to the participation to the study.

## RESULTS

### Demographics

During March-April 2008, 26 PLWHA (20 male, 6 female; mean age=37 years, SD:8.5) participated in focus groups at the Via Libre Clinic. All participants (12 heterosexual, 14 gay) were on ART at the time of recruitment and participation. Most of them (88%) had completed high school. The majority of participants were frequent users of the Internet and cell phones (including SMS).

### Signal-Related Features

The participants preferred text messages over recorded voice messages or phone calls as reminder alerts because they are easier, more confidential, and more readily-available ("I think that a text message would be better because you are sometimes in the car and the recorded message does not play well or you cannot hear it very well…a text message could be read quickly and it reminds you"). One participant pointed out also that "I do not know how to retrieve the voice messages…so, it´s easier to read a text message."

### Message-Related Features

*Perceptions towards reminder messages*

Overall participants were in favor of receiving medication reminders on their cell phones ("I believe that [the reminder alert system] is important because sometimes…when you are feeling better, or at work, or due to any other reason…you forget to take your medicines … so, having somebody to remind you is very important").

*Characteristics of reminder messages*

The most preferred characteristic for the reminders was that they be motivational ("Remember, it is time for your life"). One participant felt these types of messages were important because "we experience sadness, happiness, and if I receive this message (reminder)…somebody cares about me! This encourages me to move ahead." Another participant also pointed out that receiving motivational reminder could help to assuage feelings of loneliness ("I practically do not have anybody…I sometimes feel a

bit depressed"). At least one participant, though, felt that motivational type reminders could be overly dramatic ("My life has so many, so many sides that I would not like the reminder alerts to be so dramatic...").

Some other characteristics that the participants thought were important are conciseness ("The reminder could be short, direct"), simple ("I believe that the message should be something simple"), and shareable ("We sometimes receive messages that we share with friends, relatives, coworkers or with anyone ").

Some participants felt that it would also be important to have reminders that had a spiritual tone ("Though I am not a believer, receiving a message like 'Thank God for the time of your life' meets our needs very well. First, it reminds you, and, second, it is completely confidential").

## Context-Related Features

*Frequency of change*
Most of the participants thought it would be a good idea to change the messages with some frequency in to prevent monotony and boredom with them ("You should change the message…because it might become monotonous otherwise…it's the same as how I tire of taking my pills every day"). Some suggested that the messages should change weekly and others preferred daily. Changing the messages frequently was also suggested because "people may be under different kinds of mood, so the messages should be different."

*Anthropomorphic features*
"I like the idea (of a reminder alert system) … enough that receiving a message via cell phone is not emotionless, it is something that reminds you of something very important. I think it is excellent." The participants often anthropomorphized the system with human characteristics such as thinking of it as a "friend," a "guide" or even an "angel." Along with these characteristics was the idea of establishing a long-term relationship with the system.

*Confidentiality and privacy issues*
Keeping the medication reminders confidential was the most important concern that many, though not all, participants expressed. They did not want "sensitive" words (e.g. 'HIV', antiretroviral, etc.) related to HIV included in the system. A suggested alternative to "sensitive" words was using code words or phrases so that only the participants will know what the reminder refers to ("The [message] should be a little more

discreet…for example, 'It is time for your candy,' something simple but you know what it is"). A couple of participants also suggested erasing the reminder after receiving it.

## DISCUSSION

Our participatory design approach gave us many insights about key culturally-specific issues in the development of reminder messages for ART adherence using SMS among PLWHA in Lima, Peru.

First, we found it very interesting that our participants preferred receiving a readable message rather than a phone call or a pre-recorded voice message. This is related to the literature on calm technologies[12]. Text messages are less obtrusive and interrupting than receiving a phone call. They have the advantage of being easily used in a variety of daily activities[5]. Mobile devices that allow patients to receive and send messages also have several attributes that make them very attractive to healthcare providers and researchers, including always being on and with the patients, inexpensive, the potential for surveillance, and geographical positioning[13]. Overall, mobile technologies have the potential to effect behavior change by enabling access to information and communication in novel ways.

The fact that the participants preferred informative and motivational reminder messages reveals that they are interested in not only receiving a reminder, but also something that lifts their self-esteem and gives them encouragement. Previous studies have shown that automated, telephone-based interventions emphasizing social cognitive concepts (e.g. motivation, self-efficacy) have demonstrated short- and longer-term efficacy[14,15].

Some important context-related issues were mentioned by the participants. We found confidentiality issues were very important to most participants. Lester et al. considered confidentiality issues to be of the utmost importance in any strategy to use cell phones in healthcare[16]. Some of the participants were very concerned about the wording of the messages. The fears they shared with us about confidentiality are likely related to social issues such as empowerment, stigma towards those with HIV/AIDS, and discrimination; the same issues we have found in a previous study[17].

An interesting finding of this study was the use of anthropomorphic characteristics to describe the cell

phone system that sends the messages. The anthropomorphization of inanimate objects is a common habit in our everyday lives and has been fairly well studied in human-computer interactions[18].

We found that the subjects would like to experience the cell phone reminder system as a friend. The portability of "always ready" devices in combination with the messaging interventions can create a synergistic feedback loop between patient and device as evidenced by Milch's finding that "several of the patients allowed that the pager became a trusted friend[19]." The successful mobile interaction through messages should promote an intensive, positive relationship between the user and the mobile application, like a longstanding and comfortable friendship[20]. This is an important feature that should be investigated in future research studies.

An important limitation of our study is its applicability to the general population since our study population was limited to a convenience sample of PLWHA in urban population of Lima. The participants in this study cannot be considered representative of PLWHA throughout Peru or elsewhere. This limitation is somewhat balanced in that we are confident that we reached saturation as many of the responses were similar among participants[21].Also, the age characteristics of our population are very similar to the national profile of adult PLWHA on ART in Peru[22]. Another bias to consider is the potential for giving socially desirable responses in focus group settings, though we found that while the participants were ready to agree on many topics, they also strongly disagreed on a number of topics. We believe that many of the ideas and themes we heard during these groups are applicable in other settings, and would encourage other researchers to explore this subject and to tailor our findings to the needs and preferences of the populations they study.

Based on previous research and our findings, our recommendations for designing and using SMS reminders for ART adherence are:

1. Use only reminders that have been carefully crafted to ensure credibility, to maintain calmness, and to appropriately ensure privacy and confidentiality.
2. Messages should be worded such that the intended content of the message is conveyed clearly to the user because text-only messages lack the intonation and expression of cues that would normally assist in interpreting such information.
3. Formulate messages that minimize ambiguity.

4. Recommend that users delete the reminder after reading it.
5. Messages should be tested with a small group of the target population to ensure acceptability before widespread implementation and use.

In addition to these suggestions, we would also encourage healthcare providers and researchers to consider Fogg's Principles of Mobile Persuasion for the use of mobile technologies for encouraging behavior change. These include sending messages at the right moment, delivering relevant and current information[20].

Our focus groups allowed us to develop messages that can potentially meet the needs of our target population. In addition, our focus groups gave us important evidence not only for an intervention study, but also for other researchers that want to implement such a system in the developing world or in other settings.

## CONCLUSION

In conclusion, the results reported in this paper have created a basis to develop a dynamic, personalized and confidential messaging system that can meet the prevention and adherence needs of PLWHA in Lima, Peru. Though previous research is inconclusive regarding the use of electronic reminder devices for ART adherence, these results indicate that the characteristics of the reminder (notification modality, the message, and the context) could play an important role in interventions to improve patient adherence to ART.

Future interventions using SMS for improving healthcare and changing behavior should also consider other emerging mobile technologies, such as Multimedia Messaging Service (MMS) or Enhanced Messaging Service (EMS) to further enrich these types of patient-provider interactions.

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