

Considerations in using text messages to improve adherence to highly active antiretroviral therapy: a qualitative study among clients in Yaoundé, Cameroon

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Abstract: Poor adherence to highly active antiretroviral therapy (HAART) is a major hindrance to the reduction of mortality and morbidity due to HIV. This qualitative study used focus groups to explore the views and experiences of HIV patients on HAART with adherence reminders, especially the text message (SMS [short message service]). The ethnographic data obtained were used to design a clinical trial to assess the effect of motivational text messages versus usual care to enhance adherence to HAART among HIV patients in Yaoundé, Cameroon. Participants appreciated the idea of a timely SMS reminder, and cited the physician as a role model. They expressed concerns about privacy. Long-term life goals were a motivating factor to adhere. Overall, text messaging was viewed positively as a tool with a dual function of reminder and motivator. Messages coming from the attending physician may have a stronger impact. Trials investigating the use of text messages to improve adherence to HAART need to consider the content and timing of SMS, taking into account technical challenges and privacy.

Keywords: focus groups, adherence, highly active antiretroviral therapy (HAART), text message, short message service (SMS), human immunodeficiency virus (HIV)

Introduction

Highly active antiretroviral therapy (HAART) has greatly reduced morbidity and mortality due to HIV.¹ However, the battle is not yet won, as multiple barriers to adherence are common in all groups of people living with HIV.² It was initially thought that near perfect adherence is an absolute necessity for optimal viral load suppression.³ Recent findings suggest that some viral load suppression can occur at less than 95% adherence, even though this may depend on the specific regimen, the duration of follow-up, and the way adherence is measured.⁴⁻⁶ Poor adherence is a gateway for the development of drug-resistant strains of HIV.^{4,7} It is also associated with disease progression and mortality.^{8,9} Generally speaking, high rates of adherence are desirable and should be promoted. It is of particular importance to investigate ways of improving adherence by providing support and counseling, sending reminders, or using easy-to-take regimens. However, the literature on aids to adherence in resource-limited settings is rather scarce, and most often involves interpersonal techniques like encouragement, medication delivery, nutrition, and housing support.¹⁰

Adoption and use of mobile phone technology is experiencing its greatest growth rate in Africa.¹¹ The mobile phone text message, or SMS (short message service), has

been investigated as a tool for improving adherence to HAART, in different settings, with different message timings and content.^{12–14}

The Cameroon Mobile Phone SMS (CAMPS) trial (ongoing) is investigating the use of weekly motivational mobile phone text messages to improve adherence to HAART in Cameroon.¹⁵ This paper investigates clients' perception of their difficulties with adherence, the applicability of the intervention, and how it can be adapted to the local setting. As the literature on the use of mobile phone technology to improve adherence to HAART is growing, its applicability will depend not only on its efficacy but also on how well it responds to clients' needs. Before testing the efficacy of the SMS, a broader sense of its utility, content, and timing is required.

We used focus group discussions with participants drawn from the waiting rooms of the Yaoundé Central Hospital (YCH) Accredited Treatment Centre (ATC), a large urban HIV clinic, and collected data from clients. The overall aim of the interviews was to investigate patient experiences with adherence and adherence reminders focusing on the use of the SMS as a potential reminder. We also explored patient views on the content of the text message, role models as motivators to take medication, personal motivating factors to adhere, and practical issues concerning the use of the SMS.

Methods Framework

We based our research on the premise that humans have free will and strive to achieve their maximum potential, even though external help is often necessary (humanism).¹⁶ In broad terms, our research investigates the individual living with HIV and a specific intervention to improve adherence to medication and thus health and well-being. We used ethnographic methods to capture and interpret the phenomena surrounding adherence to medication, with specific focus on the SMS as a potential tool. The ethnographic approach was deemed significant for this study because of its focus on groups (people living with HIV) and its ability to elucidate lifestyles (adherence), within the subcultural context in which they are enacted.¹⁷ Our findings are the results of direct contact with group members.

Ethical considerations

We obtained permission to conduct the interviews from the administration the YCH-ACT. Ethical clearance was obtained from the Cameroon National Ethics Committee.

Following the discussions about the purpose of the study, we obtained verbal consent from all patients who volunteered to participate in the focus groups. Persons aged below 21 years were not included, as they were below the age of legal consent. They were assured of protection of privacy, confidentiality, and anonymity in reporting the results of the focus group. The notes were taken in a register, which was kept in a secure location.

Precollection material

We developed a group discussion guide listing specific topics to be addressed and providing a framework for the moderator to ask questions (Table 1). This guide covered questions related to difficulties with adherence, timeliness of medication taking, reminders, content of the text message, role models as motivators to take medication, personal motivating factors to adhere, and practical issues concerning the use of the SMS. The guide was reviewed by a group of experts that included two anthropologists, a sociologist, and the moderator of the group discussions. We pilot tested it on five volunteers for clarity. The guide ensured that the same themes were covered in all the group discussions.

Study setting

The YCH-ATC is the largest HIV clinic in the country, with about 40 new patients every week and 6500 regular clients. Waiting times at the YCH-ATC vary from 30 minutes to 2 hours, based on arrival time and physician availability. There are hundreds of patients waiting for as few as eight physicians. Yaoundé is the capital city of Cameroon, situated in

Table 1 Focus group discussion guide

Adherence

Do you have difficulties in taking your medication?

Do you sometimes miss doses?

What can make you miss a dose?

Is there any way the hospital can help you to improve your adherence?

Do you have any specific ways to improve your adherence?

Do you think any of these approaches work?

The SMS

What do you think about use of SMS as a reminder strategy?

When and how often do you think SMS should be sent?

What kind of message do you think would be useful if one were to use SMS as a reminder tool?

Role models

Do you have a role model?

Who is your role model?

Do you think having an SMS message associated with this individual could be an effective motivator to help people adhere to treatment?

Life goals and motivation to take medication

What motivates you to take your medication?

What are your top goals for the next 5 years?

the center region and comprising a mostly urban community. In 2004, the prevalence of HIV in Yaoundé was estimated to be 8.3%.¹⁸

Data collection

Clients found in the waiting room were approached by the interviewer and asked whether they were willing to discuss their adherence to HAART. Consenting persons were then grouped in a separate room free from external distractions and interviewed. The interview team was made up of an experienced moderator (a medical anthropologist) and a note-taker, both in plain clothes and neither of whom was staff of the hospital. Five group interviews were performed during the period October 15–19, 2010. Interviews lasted between 45 minutes and 60 minutes and were conducted in French. Participants were seated such that they could see each other and the moderator. Discussions were based on open-ended thematic questions prespecified in the group discussion guide. The moderator asked additional questions to clarify specific areas of interest. Despite the interview taking place in a hospital setting, participants freely discussed the problems they had with adherence and how the SMS could help. The participants were identified by their groups and individual numbers. Only gender was noted. All treatment regimens provided at the time of this study were twice-daily regimens. We carried out group discussions using the discussion guide to keep the responses from derailing from our topics of interest, and stopped the discussions when no new ideas were forthcoming. Once saturation was met, the notes were read to the participants to ensure accuracy and to confirm the quotes. Data collection was set to end when no new ideas were forthcoming, thus delimiting our sample size. Qualitative samples are often small and data gathering usually stops when no new information can be obtained.¹⁹

The participants

The participants were selected from the YCH-ACT. By so doing we obtained information from people belonging to the parent sample from which the CAMPS trial would recruit and who had experience with the phenomenon under study. No hospital staff were involved in the recruitment or interviewing process. We included patients who were HIV positive, regularly received treatment from the YCH-ACT irrespective of the duration, were present in the waiting room on the days of the group discussions, and were willing to participate. Verbal consent was a prerequisite to recruitment. We excluded patients who were not regulars at the clinic and those aged less than 21 years.

Thirty-two people participated in six group discussions. The average group size was five people. We considered only participants who took part in the discussions from start to finish, excluding those who left midway or joined the group later on. Two people were excluded from the analysis on this basis. The small groups permitted the moderator to elicit responses from everyone. Two-thirds of the population were women. The common characteristic of the participants was that they were all living with HIV and taking HAART from the same clinic. They were a subset of the population from which we wished to obtain information and could provide insights into the challenges they faced with adherence, reminder mechanisms, and motivation to adhere.

Data analysis

Data were analyzed for 30 participants. Analysis was limited to the content of the discussions. A verbatim transcript of the discussion was noted in a register by the note-taker. Coding was done manually by placing the data into categories, based on the themes in the discussion guide, namely adherence, text message reminders, role models, life goals, and motivation. RCBM coded the data. They were verified by LM. RCBM, LM, and LT verified the manuscript for consistency with the original notes. Disagreements were resolved by discussion.

Results

We included 19 females and eleven males. All were aged 21 years or above and resided in the Yaoundé. They were all taking HAART from the same clinic (YCH-ACT).

Adherence

Adherence was deconstructed using questions investigating difficulty in taking medication, timeliness of taking medication, and personal approaches to improving adherence.

A third (ten of 30) of the patients declared that they had some difficulty in following the prescribed medication. They claimed that their adherence improved with time and “experience”. There was an initial period of forgetfulness at the onset of therapy, and then later on the medication became more habitual. Missed doses were caused by incidental events like journeys and running out of pills. Financial difficulties leading to inability to afford regular meals were also raised as a reason for not taking medication. Some reported being abandoned by their family members, poor clinical response to medication, and side effects as reasons for missing doses.

Most of the participants (17 of 30) acknowledged not being able to take medication on time, with a delay

time varying from a few minutes to several hours, and appreciated the idea of a reminder. Only a quarter (seven of 30) of the patients had a systematic reminder method for their medication. They felt that it would establish a new routine and remove the stress of having to remember when to take medication, leaving the responsibility to external forces. For those who used reminders, they cited alarms, meal times, mobile phone beeps from close ones, personal verbal reminders by individuals, and prayer times for Muslims.

"I have no problem, I just use prayer hours." (Group 2, Participant 4)

Their most preferred reminders were beeps, alarms, text messages, or personal verbal reminders from their entourage. Preferences for the different types of reminders varied greatly among the participants.

"I forgot my telephone at home. I would prefer something I can hang around my neck." (Group 1, Participant 3)

"... I set my telephones to remind me ..." (Group 3, Participant 6)

A few described the difficulties they faced with the current methods they were using.

"I set my phone to ring when I am supposed to take my medication, but sometimes I don't hear it." (Group 3, Participant 3)

"Sometimes I am 30 minutes late." (Group 2, Participant 1)

"You should provide counseling to encourage patients." (Group 4, Participant 2)

The SMS

Half (15 of 30) of the participants believed that the SMS could help them take their medication but that the value of the SMS would depend on the sender. Some preferred that the SMS should come from their physician.

"I think it's a good idea." (Group 5, Participant 7)

There was no consensus as to the content of the message.

"It's time to take your medication." (Group 1, Participant 3)

"The content is not important." (Group 1, Participant 4)

"A beep is sufficient because there are people who go through other people's phones." (Group 3, Participant 2)

"Call to order." (Group 1, Participant 1)

"It's time." (Group 1, Participant 1)

"The SMS may expose the privacy of the patient; therefore, not everyone should be able to understand it." (Group 5, Participant 6)

"The SMS should be coded." (Group 2, Participant 4)

The number of messages participants wanted also varied. Some preferred to receive two messages – one in the morning and in the evening. Others preferred to receive four messages per day: ie, 15 minutes before time and one exactly on time for medication (twice daily).

Role models

Very few patients declared to have role models. Only three of the 30 participants declared to have role models and found the idea of using role models as message senders interesting. However, most still preferred to have the message come from their physician, and identified him/her as the figure they looked up to. The three who had role models each had a different one Samuel Eto'o Fils (soccer player), Akon (musician,) and Barack Obama (US President).

"My idol is Eto'o. A message coming from him would be good!" (Group 2, Participant 1)

"I don't have a role model, so for me it is not interesting." (Group 6, Participant 7)

"Role models are good in motivating people to take their medication. For example, when Barack Obama went to Kenya he did a public HIV screening test and it motivated many Kenyans to do screening tests." (Group 7, Participant 7)

Life goals and motivation to take medication

For most participants, their motivation to take medication was based on the hope of finding a cure sometime in the future, or the fear of falling sick. Some expressed the desire to achieve personal goals such as having kids, raising their kids, and building houses.

"When I see how other people on medication are faring well, it motivates me to take mine too." (Group 3, Participant 4)

"I don't have any side effects. This motivates me to take my medication." (Group 2, Participant 2)

Additional issues

We also recorded additional comments of interest. Some participants brought up pertinent points regarding the use of text messages, such as poor network, possibility of dependence on the SMS, and poor adherence in its absence.

"There is no network in my quarter!" (Group 3, Participant 1)

Discussion

This paper directly explores the issues surrounding the use of mobile phone text messages to improve adherence to HAART among people living with HIV, and raises serious questions concerning the applicability of such a technique in low-resource settings. We collected data from the focus groups until we achieved data saturation: ie, no new ideas were forthcoming.

The interviewer and note-taker played a central role in the data collection process. They have experience with ethnographic research in the same clinic and knowledge of the dynamics within the environment. They employed personal empathy to put the participants at ease and hence be more willing to divulge information. Their relationships with the participants were not affected by status or conflicting roles, as they were not medical or social staff of the clinic.

The overall impression is that participants appreciated the idea of a text message reminder, if it was timely enough, irrespective of the content. The physician was the figure they identified with the most as a role model. They expressed concerns about privacy and the possibility of disclosure of status. Long-term goals stood out as additional motivation to take treatment. We also identified a clear need for support from peers, family, or health personnel. Poor mobile provider services may hinder the technical applicability of such an intervention.

Despite the nearly ubiquitous nature of the mobile phone, its formal application to improve adherence to HAART is relatively new. A study in India found that participants were very interested in mobile phones for improving adherence to HAART, and often used their phones to contact their health provider.²⁰ In this study, disclosure of status was not a deterrent to the use of text messages.²⁰ A systematic review on the use of mobile phone technology in South Africa found that it could play an important role in the control of HIV/AIDS by supporting adherence and other interventions.²¹ In a survey of HIV-positive patients in Ghana, a majority of the patients agreed that a mobile phone-based reminder system would be helpful in improving adherence to HAART.²² HIV-positive patients were also willing to use their mobile phones to receive reminder text messages in Peru.²³

The potential role that the SMS can play need not undermine the importance of family and peer support. Another ethnographic study reports additional motivation to adhere beyond the desire to be healthy but rather to conserve social capital.¹⁰ This highlights the role that peers and family can play in promoting adherence.

The implications of such findings to the conduct of a text message trial are clear. As a reminder, text messages and

beeps may be helpful. For motivational purposes, role models may not work. The paternalistic approach to medicine is still prevalent in this context and may explain the important position of the physician as a potential role model.²⁴ Measures to protect privacy and disclosure of status should be employed. Impersonal messages may help to protect privacy, but on the other hand may lose the motivational effect that can be obtained by personalization. Building on long-term goals, motivations, and family ties can provide new avenues for improving adherence.

Lessons learnt for the CAMPS trial

Based on the information obtained from this study, the CAMPS trial did not use role models to motivate participants to adhere to HAART.¹⁵ They used empathic and friendly messages inviting the participants to report any difficulties with medication. Different messages were sent on a weekly basis. The content of the message did not disclose HIV status or the kind of medication taken. These messages were sent from the research center and were not outsourced to a mobile phone company. A phone number was provided for trial participants who wished to talk to a physician. The CAMPS trial also used the delivery report function to determine whether the messages were received.

Limitations

This study has some limitations that are worth noting. The open nature of the interviews may have caused some participants to reserve their comments. We also think that patients may be uncomfortable with discussions about adherence in the hospital setting, even though we endeavored to make the interviews as informal as possible using plain-clothed and nonstaff interviewers. To reassure the participants of confidentiality and anonymity, only gender-related information was collected. Age was used only to determine eligibility. Additional sociodemographic data were not collected, because the participants in this study and the participants in the CAMPS trial were drawn from the same population. We have no reason to believe that these two groups will differ significantly as to create concerns about external validity. We cannot ascertain that these findings would apply in a different setting. Finally, notes were taken manually (without a video or audio recorder). Even though the quotes were reread to the participants to ensure accuracy, there is always the possibility of human error.

Conclusion

People living with HIV experience difficulties related to treatment and need support in order to adhere to treatment.

The text message is an acceptable means of providing support and motivation. How it can be tailored to suit individual needs or adapted to suit the majority of the patients is a subject for further research. The physicians' status in this context can be used to encourage adherence. The possibility of disclosure of status, loss of privacy, and technical difficulties must also be addressed before text messages can be used on a large scale.

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Disclosure

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