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Short message service (SMS) surveys assessing pre-exposure prophylaxis (PrEP) adherence and sexual behavior are highly acceptable among HIV-uninfected members of serodiscordant couples in East Africa: A mixed methods study.

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Abstract

Short message service (SMS) surveys are a promising data collection method and were used to measure sexual behavior and adherence to HIV pre-exposure prophylaxis (PrEP) among HIV-uninfected partners of serodiscordant couples enrolled in a sub-study of the Partners Demonstration Project (an open-label study of integrated antiretroviral therapy and PrEP for HIV

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Declaration of Interests

We declare that we have no conflicts of interest.

Ethical Statements

The study protocol, informed consent forms, recruitment materials, and other requested documents and any subsequent modifications were reviewed and approved by the Uganda National Council of Science and Technology and the Kenya National Council of Science and Technology, Massachusetts General Hospital, and the University of Washington.

The funders had no role in data collection or analysis and the results and interpretation presented here do not necessarily reflect the views of the study funders.

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prevention in Kenya and Uganda). Questionnaires were completed by 142 participants after study exit. Median age was 29 years; 69% were male. Ninety-five percent (95%) felt SMS surveys were “easy” or “very easy”, 74% reported no challenges, and 72% preferred SMS surveys over in-person study visits. Qualitative interviews involving 32 participants confirmed the ease of responding to SMS surveys. Participants also indicated that surveys acted as reminders for adherence to PrEP and condom use and were experienced as support from the study. SMS surveys were generally found to be acceptable in this population and provided real-time context of PrEP use.

Resumen

Las encuestas del servicio de mensajes cortos (SMS) son un método de recopilación de datos prometedor y se utilizaron para medir el comportamiento sexual y la adherencia a la profilaxis previa a la exposición al VIH (PrEP) entre los socios VIH-no infectados de las parejas serodiscordantes inscritas en un subestudio de la Proyecto de Demostración de Partners (estudio de etiqueta abierta de la terapia antirretroviral integrada y PrEP para prevention del VIH en Kenia y Uganda). Los cuestionarios fueron completados por 142 participantes después de la salida del estudio. La edad mediana era 29 años; 69% eran varones. El 95 por ciento (95%) consideró que las encuestas de SMS eran “fáciles” o “muy faciles”, 74% no reportaron ningún dificultades y 72% prefirieron encuestas de SMS sobre visitas de estudio en persona. Las entrevistas cualitativas que involucraron a 32 participantes confirmaron la facilidad de responder a encuestas SMS. Los participantes también indicaron que las encuestas actuaron como recordatorios para la adherencia a la preparatión y el uso del condón y se experimentaron como apoyo del estudio. Por lo general, se encontró que las encuestas por SMS eran aceptables en esta población y proporcionaban un contexto en tiempo real de uso de PrEP.

Keywords

Adherence; SMS; PrEP; Serodiscordant Couples; East Africa

Introduction

Multinational studies have demonstrated that antiretroviral medications, when used as pre-exposure prophylaxis (PrEP), are highly efficacious for HIV prevention (1-3). However, in studies where adherence was low, efficacy was not demonstrated (4, 5). Adherence is, therefore, key to PrEP effectiveness (6, 7). Self-report during study visits is the most common means of adherence measurement; however, it is subject to recall bias and social desirability bias (8, 9). Innovative methods to collect adherence data are clearly needed.

Given the wide availability and use of cellular phones globally for voice and short message service (SMS, or text messaging) communication (10, 11), SMS surveys are a promising method for data collection in research studies. SMS offers several advantages for data collection compared with face-to-face interviews. First, SMS can be completed at the convenience of study participants, thus obviating the need for transportation, time off work, and other potential structural obstacles. Secondly, SMS can collect data frequently and in real-time, which may reduce the recall bias commonly associated with infrequent study

visits (12). Also, the relative anonymity of technology-based data collection may reduce social desirability bias (12-14). Furthermore, airtime or money may be sent via phones in real-time, which may serve as a strong incentive to participate.

While promising, potential challenges also exist with using SMS for collecting self-reported data. For instance, the SMS may come at inconvenient times, thus disrupting an individual's routine and/or resulting in lack of a response. The SMS may be read by others, particularly in settings where cell phones are commonly shared (15) and may result in disclosure of study participation. The content of the SMS may also raise unwanted questions (e.g., survey questions may be misinterpreted as coming from an intimate partner). Moreover, technical failures may occur, including cellular network outages and handset damage, resulting in variability in system performance (16, 17).

In light of these potential benefits and challenges, a few studies to date have assessed the acceptability of SMS-based self-report. One study of SMS surveys for antiretroviral therapy (ART) adherence in Uganda showed high acceptability, although completion rates were poor and participants expressed frustration with the data collection process (15). A more recent study of SMS surveys for the collection of PrEP adherence and sexual behavior within the Partners PrEP Study (a phase III randomized placebo-controlled clinical trial of tenofovir-based oral PrEP) found high acceptability over 5 months (18). Further studies, particularly those involving other study designs and with longer follow-up, are needed.

This study presents quantitative and qualitative assessments of experiences with periodic daily SMS surveys that were sent within a sub-study of the Partner's Demonstration Project —an open-label, pilot demonstration project of antiretroviral-based HIV prevention among high-risk HIV serodiscordant African couples.

Methods

The Partners Demonstration Project

The overall goal of the Partners Demonstration Project was to evaluate a scalable, integrated, and pragmatic delivery approach for ART and time-limited PrEP with targeted counseling, brief adherence promotion, and frequency of follow-up designed to reflect approaches suitable for public health settings in resource-limited settings (19). Eligible couples were ≥18 years of age, sexually active, and intending to remain as a couple at enrollment. Visits took place at enrollment, Month 1, Month 3 and every 3 months until Month 24. Participants were encouraged to take PrEP until their HIV-positive partner had been taking ART for at least six months at which time the risk for HIV acquisition was low assuming good ART adherence. All participants in the Partners Demonstration Project received face-to-face counselling on PrEP adherence and risk reduction counselling at every study visit.

The Partners Mobile Adherence to PrEP (PMAP) study

The PMAP sub-study was designed to assess PrEP adherence and concurrent risk for HIV acquisition via SMS surveys and was implemented at 2 study sites (Thika site in Kenya and Kampala site in Uganda). The Kampala site is located in Kasangati (a town about 16 kilometers north of the capital) and is affiliated with the Infectious Diseases Institute;

Kampala has an HIV prevalence of 6.9% (20). The Thika site is located about 42 kilometers northeast of Nairobi and is affiliated with the Kenya Medical Research Institute; the local HIV prevalence rate is 4.7% (21). In both sites, the main social economic activities of participants include trade, farming, casual labor, and some degree of professional work. Although both sites are located in peri-urban settings, study participants were recruited from diverse settings, including urban, peri-urban, and rural environments. HIV-negative partners were eligible for the sub-study if they had ≥3 months of planned PrEP use, owned a mobile phone using a service provider compatible with the SMS platform (i.e., *Safaricom* in Thika; *MTN* and *Airtel* in Kampala), were literate, were able to receive and send SMS, and had regular access to electricity for charging their phone (note, the electricity access could be in any location and not necessarily the household of the participant). Eligible participants completed a 1-week trial period of daily surveys and were enrolled if they completed ≥3 daily surveys; additional training was provided as needed.

In addition to procedures for the Partner's Demonstration Project study visits, PMAP study participants also received SMS surveys that were sent daily for 7 days before and 7 days after each study visit in the Partners Demonstration Project. Surveys were sent at participant-selected times and were available for responses for 23 hours after delivery. Each survey was initiated only after receipt of a 4-digit password and consisted of 7 questions with branching logic on sexual activity and PrEP adherence in the prior 24 hours (see Appendix 1). Depending on skip patterns, questions about general health behaviors (e.g., drinking boiled water) were used to ensure each survey consisted of 7 questions, thus discouraging responses leading to shorter surveys. Participants were incentivized with approximately $0.50 of airtime for each completed survey, which was automatically delivered to their phones. SMS surveys were sent while participants were eligible to take PrEP and held during protocol-defined holds (e.g., drug toxicity). Study staff reviewed responses in real-time to assess for technical errors or potential need for additional training with the SMS system; participants were contacted as needed. During prolonged cellular network outages, additional SMS surveys were sent to affected participants so approximately 14 surveys were sent around each study visit.

Quantitative data collection and analysis

Exit surveys were administrated to a convenience sample from the PMAP study. We asked about participant experiences with the study and SMS surveys, including challenges, likes, dislikes, privacy concerns, and preferences (see Appendix 2). Response options were read to participants. Demographics and survey outcomes were summarized descriptively. Differences between those who did and did not participate in the exit questionnaire and exploration of survey outcomes by participant gender, age, years of education and socio-economic status (as inferred from the presence of electricity in the household) were conducted using Fisher's exact test for categorical comparisons and the Kruskal Wallis test for continuous comparisons. Statistical significance in the former was considered at $p<0.05$, while that for the latter was at $p<0.0013$ after a Bonferroni correction for the 38 comparisons involving gender, age, years of education and socio-economic status.

Qualitative data collection and analysis

PMAP study participants were purposively selected for in-depth qualitative interviews based on gender, age (greater than versus less than 30 years), and reported challenges with SMS during the course of the study (yes versus no). Participant experiences with the SMS surveys were explored with the following domains of interest: likes, dislikes, challenges, assistance obtained to participate, privacy concerns, and preferences and suggestions for future SMS surveys. Interviews took place in a quiet, private location and were conducted in the participant's preferred language (English, Luganda, Swahili or Kikuyu). The interviews were digitally recorded for transcription purposes. All in-depth interviews were audio-recorded, transcribed, and translated into English by the study team and analyzed using an inductive and deductive approach (22). The codebook was developed through an iterative process by two coders GK and BN which was applied to all transcripts using Dedoose software 7.0.23. Authors KN and BB reviewed a quarter of emergent themes with the coders to ensure accuracy and consistency of interpretation. This approach allowed exploration of the experiences from the participants' point of view, what the participants believed rather than testing a pre-existing theory. Inconsistent results were reviewed by the coders until consensus was reached.

Ethical considerations:

We obtained ethical approval from the institutional review boards at Partners Healthcare/ Massachusetts General Hospital, Kenya Medical Research Institute, Uganda National Council for Science and Technology and the University of Washington. All participants provided written informed consent.

RESULTS

Participant characteristics

A total of 373 individuals enrolled in PMAP.A mean of 47 (SD 29) SMS surveys were completed per participant over a mean of 4.6 (SD 2.2) 14-day reporting windows, reflecting a mean of 9.8 (SD 6.0) months of study participation (23).

A total of 142 PMAP participants completed exit questionnaires (83 from Kampala and 59 from Thika). As shown in Table 1, the median age was 29 years (IQR 25, 36). The proportion of females in this sample and that in the overall PMAP population was 35% and 29% (p=0.94), respectively. Median schooling years was 9 years (IQR 7, 12) in the sample compared to 10 (8, 12) in the general PMAP population (p=0.02). Fifty-nine percent of the sample and 42% of the general PMAP population were from Kampala (p=0.002).

Quantitative assessment of experiences with the study and SMS surveys

Table 2 indicates participant assessments of the SMS survey experience. Nearly all participants found SMS survey participation to be "very easy" or "easy" and the majority reported no challenges with the SMS surveys. When asked about advantages of the SMS surveys, most participants endorsed a reminder function, most commonly a reminder to take PrEP. Approximately a quarter of participants endorsed liking the incentives. Few participants reported dislikes or needed assistance with the SMS surveys. While

approximately one-quarter of participants reported that others saw their SMS survey questions, nearly all felt neutral or positive about the experience.

Differences in SMS survey experiences by gender, age, socio-economic status, education and study site

There were a number of differences when comparing Thika to Kampala participants. Those in Kampala were more likely to report being reminded by surveys to take PrEP and use condoms ($p<0.001$), to like study incentives ($p<0.001$), and to be less willing to receive periodic SMS for more than 6 months ($p<0.001$). No other statistically significant ($p<0.0013$) differences were seen in comparisons of SMS survey experiences by gender, age, socioeconomic status or education.

Preferences and recommendations for future SMS survey

As shown in Table 3, most (59%) of the participants found the number of surveys “just right” and over one-third would answer more. The majority (73%) preferred SMS surveys to face-to-face study visits. Preferences for the timing of the SMS surveys (i.e., daily versus periodic) and duration of the surveys were mixed. Nearly all (93%) participants would be willing to participate in another survey and would recommend this form of data collection to a friend.

Qualitative findings

Qualitative data was collected through 32 in-depth interviews with 21 HIV-uninfected men and 11 women in HIV serodiscordant relationships. The main themes that emerged from the data were related to (i) ease of answering questions, (ii) SMS as reminders, (iii) SMS perceived as an act of concern, (iv) sharing SMS responses and (v) challenges of answering questions through SMS.

Ease of answering questions

Many of the participants reported that it was easy to respond to the questions through SMS because the questions were easily understood and the responses were in number form (i.e., 1 for “yes”, 0 for “no”), which were easily answered by participants with limited literacy. Participants also reported that the initial training and follow-up support they received at the clinic helped to ease the process.

> The messages were not so bad because I knew some of the things. They used to ask you about something you know… They explain to you how to do it. That if it is yes, you press number 1 and if it is no, you put 0. (Female aged 28, Kampala)

> They are good questions which are normal and I know them and I am now supposed to answer them depending on how I have been asked and they are not those hard questions. It is easy, easy questions. (Male aged 22, Thika)

SMS as reminders

Although the surveys were meant to be data collection tools, participants reported that responding to questions related to adherence and condom use reminded them to adhere to

PrEP and to use condoms. Because the messages came close to their next clinic appointment, they served as clinic visit reminders as well. One participant also reported that the SMS survey alerts acted as reminders for the HIV-infected partner to adhere to ART.

> …it was easy for me to remember that I have to take PrEP and the time for going to the clinic. It was easy for me to remember that I am about to go back to the clinic and whenever they started sending me questions, I would even check on my card to see the remaining period of time I have to go back. Those are some of the good things I gained. (Male aged 29, Kampala)

> I used to enjoy the messages because they used to ask me… my husband took long to initiate ARVs but they would ask me "Did you have sex with condoms?" It is true, even when I was about to have sex without using condoms, I could think 'oh! Let us put on a condom', yet I could have forgotten about that.But the messages saved me so much to make sure that I put on a condom. It saved me. (Female aged 29, Kampala)

SMS perceived as an act of concern

Some study participants reported that they felt that the clinic staff were sending the SMS because they were concerned about their health and welfare. Others stated that the purpose of the SMS was to follow-up on how they were doing before their next study visit.

> I thought that they (clinic staff) always think about me that I am alive and they remember me. So, that is why they are able to send me messages on my phone and I am able to respond. (Female aged 29, Kampala)

> …but this one (PMAP study) you see they were doing follow up so even if.… you are forgetful…..you feel that you need to take them because even the one who has prescribed it (PrEP) for you is concerned. So why should you ignore it (chuckles)? (Male aged 46, Thika)

Sharing SMS responses

Most participants stated that they did not disclose PMAP participation to people other than their sexual partners with whom they were participating in the Partners Demonstration Project. Some participants specifically reported intentionally sharing the responses with their study sexual partners. The fear of other people learning of their participation in the study made the participants only answer the questions in private places where no one would suspect what they were doing. Most participants also reported that having a password and being prompted to delete the messages after completing the survey were important aspects of the study.

> No, no. I have been very keen about it, so secretive about it and even before, if I know the time for the questions… you are heading to time of those questions, I will walk out with my phone even if I am going to the toilet. So, I was very keen about it because I didn't want somebody to know what was going on. (Male aged 30, Thika)

> There is no one I have ever told because even when that message is delivered, it requests for a password and there isn't anyone who has the password and even my wife doesn't have. (Male aged 22, Thika)

Challenges of answering questions through SMS

The main challenge that participants reported was insufficient time to answer questions especially if messages came while the participant was away from home.

> Sometimes the questions would start coming in when am still busy in town whereby I had to hold on responding to them until when I get home. (Male aged 25, Kampala)

There were also issues related to charging the phone battery which made responding to SMS difficult. A few participants found the daily questions repetitive and those related to sexual behavior too personal.

> Maybe the phone is off, it is not charged. You find that at that time you cannot answer because it has no charge, and if it reaches 12 o'clock, you cannot answer. (Male aged 23, Thika)

> …….those questions… Asking you today "how many times did you have sex? Had you already had sex at this time? Remember the person who told me to send me messages is a man. I thought perhaps they are at the clinic laughing at me …so that thing used to piss me off and I wondered, "Why have they asked me such a thing?" They ask you about it (sexual behavior) every day, over and over. (Female aged 28, Kampala)

Discussion

This mixed methods study indicates that SMS surveys to assess PrEP adherence and sexual behavior were highly acceptable among HIV-uninfected members of serodiscordant couples in East Africa. An accurate understanding of adherence is important for PrEP given the close relationship between adherence and effectiveness (6, 7). Unlike face-to-face study visits, SMS allow for the collection of behaviors and other situational information at the time PrEP is (or is not) taken. This context is critical for understanding if PrEP adherence aligns with the risk for HIV acquisition a concept known as prevention-effective adherence (23).

The high acceptability of SMS data collection in our study could be at least partially explained by the fact that most of the participants found the SMS data collection easy. One key factor appears to be the clear training they received and the support of the study staff. Indeed, participants saw the SMS as an expression of support from the study staff. Surprisingly, only a quarter of participants in this resource-limited setting reported liking the incentives, suggesting that they had other motivations for participation (24).

Acceptability of SMS data collection has been attributed by others to the anonymity offered by the mobile technology relative to face-to-face study visits (8, 9, 25), as well as the protections used for privacy (23). Although participants in this study reported few concerns that the SMS system would compromise their privacy, sharing of SMS responses was

uncommon. When done, sharing was only among sexual partners who were also enrolled in the Partners Demonstration Project. Similarly, participants chose to only answer the questions in private locations and liked the fact that the surveys were password-protected. Participants in another recent study involving SMS surveys also reported that having a password increased their sense of privacy (17). Attention to privacy protection should thus be a priority in future studies using SMS-based data collection.

Although SMS surveys are designed to collect data, they may have important interventional effects. For instance, the survey data in this study could have been used by the study staff to trigger risk reduction counseling or participant follow-up. The study was observational by design, so the research staff only reviewed the responses to ensure proper functioning and participant understanding of the SMS system. Even though the observational nature of the study was explained to participants during the consenting process, they reported experiencing the SMS surveys as reminders for PrEP adherence and study retention. Such effects have been seen in trials of SMS reminders used explicitly for those purposes (24, 26). This potential intervention effect should be considered carefully if SMS surveys are planned for future, purely observational studies. Randomized controlled trials could be conducted with and without SMS surveys to determine the extent of any intervention effects. Additional studies could also explore if prolonged SMS data collection could lead to dependence, especially in instances where participants indicate that SMS surveys are useful as adherence reminders (27, 28).

SMS surveys may also influence participant experiences in a study. Participants reported perceiving the SMS surveys as support from the study staff and some expressed concern with how the staff would interpret their responses. These experiences should also be considered in future studies; participants should be informed as to who will see the data and how it will be used. In cases of two-way SMS, content should be reviewed regularly in case follow-up may be expected or needed. Such ancillary-care obligations could have important implications on study design and operations (29).

For frequently changing behaviors, innovative methods that allow for real-time data collection, such as those delivered by mobile technology, are needed (18). However, several aspects of SMS surveys require further exploration. First, there is a need to evaluate the relative accuracy of data collected via SMS compared to other methods of data collection (14), such as comparing SMS self-reported adherence with objective measures like electronic adherence monitoring and drug concentrations. Moreover, the frequency of these surveys and content need to consider participants' preferences. For example, in our study, nearly half of participants would be willing to participate for 6 months or more, despite some participants finding the SMS survey questions to be 'too repetitive'. To optimize the use of SMS data collection, some challenges such as the issue of sufficient battery charge, which has also been reported in other studies in resource-limited settings, need to be addressed (30). Solar-powered phones, for instance, could be considered. In this study, challenges with SMS surveys were reported more commonly by women and relatively older participants. These populations may require additional attention during training for SMS surveys. Notably, these findings are consistent with other literature (31).

This study had several strengths, including a relatively large sample of women and men who had participated in multiple SMS-based surveys. The prospective mixed methods approach enabled us to rigorously explore participants experience with SMS survey. Our findings, however, can only be generalized among men and women in African serodiscordant relationships who own cellular phones; experiences may differ in other populations. Additionally, the convenience sample included more participants from Kampala and a lower level of education compared to all PMAP participants and thus may not reflect the overall study experience.

Conclusions

Most participants reported positive experiences with SMS surveys to answer questions related to PrEP adherence and sexual behavior. Collecting data through SMS may also promote PrEP adherence and safer sexual behaviors. Future work should optimize challenges with the technology, as well as assess the accuracy of this self-reported adherence data.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1;

Characteristics of PMAP participants completing versus not completing the exit interviews. Values indicate N (%) or median (IQR).

	Participants completing exit interviews	Participants not completing exit interviews	p-value
Age (years)	29 (25, 36)	29 (26, 35)	0.94
Female	49 (35%)	68 (29%)	0.30
Education (years)	9 (7, 12)	10 (8, 12)	0.02
Kampala	83 (58%)	97 (42%)	0.002
Electricity in home	86 (61%)	- *	- *
# Persons in household	3 (2, 4)	- *	- *

* Electricity and #persons in household was asked at the interview and therefore is missing for those who did not participate in the interviews

Table 2;

Experiences with the PMAP study and SMS surveys (N=142 participants). Multiple responses were possible for all but the first question.

Questions	**Responses read to participants**	**N (%)**
Feeling about study participation	Very easy	59 (41%)
	Easy	76 (54%)
	Neither easy nor difficult	6 (4%)
	Very difficult	1 (1%)
Challenges with SMS surveys	Yes (*indicate which challenges*)	30 (21%)
	Cellular network	10
	Phone	9
	Airtime incentive	5
	Time spent	1
	Other	11
	No	112 (79%)
Likes of the SMS surveys	Surveys remind me to take PrEP	109 (78%)
	Questions remind me to use condoms	58 (41%)
	Surveys remind me to return to the clinic	49 (35%)
	Incentives	38 (27%)
	Other	22 (16%)
	None	8 (6%)
Dislikes of the SMS surveys	Questions were too repetitive	4 (3%)
	Questions were offensive	3 (2%)
	Too many technical problems	2 (1%)
	Other	5 (4%)
	None	129 (92%)
Assistance with SMS surveys	Yes (*indicate from whom*)	12 (8%)
	Partners	11
	Friend	1
	Relative	1
	Other	0
	No	130 (92%)
Surveys seen by others	Yes	33 (24%)
	Indicate by whom	
	Partners	29
	Friend	1
	Relative	3
	Other	0
	Feeling about it being seen	
	Bothered	2
	Neutral/no strong feeling	12
	Glad	18

Questions	Responses read to participants	N (%)
	Seen or read without permission	
	Yes	1
	No	32
	No	107 (76%)

Table 3.

Preferences and recommendations for future SMS surveys (N=142 participants).

Questions	Responses	N (%)
Number of questions asked per survey	Would answer more	47 (33%)
	Just right	83 (58%)
	Too many	12 (8%)
Preference for periodic daily SMS surveys versus in person study visits	SMS surveys	102 (72%)
	In person	40 (28%)
Preference for daily versus periodic SMS	Daily	70 (49%)
	Periodic	56 (39%)
	Either/no preference	16 (11%)
Preference for duration of daily SMS surveys	Up to 1 month	38 (27%)
	Up to 3 months	38 (27%)
	Up to 6 months	22 (16%)
	More than 6 months	43 (30%)
Preference for duration of periodic * SMS surveys	Up to 1 month	36 (26%)
	Up to 3 months	34 (24%)
	Up to 6 months	21 (15%)
	More than 6 months	50 (35%)
Willingness to participate in future SMS surveys	Yes	132 (93%)
	Maybe/not sure	5 (4%)
	No	5 (4%)
Willingness to recommend SMS surveys to a friend	Yes	132 (93%)
	Maybe/not sure	3 (2%)
	No	7 (5%)

* The term “periodic” refers to consecutive daily SMS separated by several weeks without SMS, as was done in the PMAP study.