Supporting Treatment of People Living with HIV / AIDS in Resource Limited Settings with IVRs

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ABSTRACT

We developed an interactive voice response (IVR) system called TAMA (Treatment Advice by Mobile Alerts) that provides treatment support to people living with HIV / AIDS (PLHA) in developing countries, who are on antiretroviral therapy (ART). We deployed TAMA with 54 PLHA in 5 HIV clinics in India for a period of 12 weeks. During the study, we gathered feedback about TAMA's design and usage. Additionally, we conducted detailed qualitative interviews and analysed usage logs. We found that TAMA was usable and viable in the real life settings of PLHA and it had many desirable effects on their treatment adherence. We developed insights that inform the design of TAMA and some of these can be generalised to design of other long-term, frequent-use IVR applications for users in developing countries in the healthcare domain and beyond.

Author Keywords

IVR; HIV; AIDS; healthcare; developing countries; treatment support; frequent-use applications; TAMA

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

Human Immunodeficiency Virus (HIV) affects 35 million people worldwide and is a cause of about 2 million deaths annually. A large majority of these people live in developing countries. In India there are about 2.4 million people living with HIV / AIDS (PLHA), and about 170,000 people die each year due to HIV [16, 35].

HIV is not curable yet, however it is manageable. The treatment of HIV is called ART. ART drugs suppress the replication process of HIV. Once a PLHA gets stabilised on ART, viral load reduces and gets suppressed, her immunity increases (which is tracked by CD4 counts) and can lead a productive life [11, 34]. However, the PLHA needs to be adherent to ART and needs to continue taking the medication for life. It is also important to take the medication on time. ART drugs stay in the blood for a limited amount of time. A drop in the drug level gives HIV opportunities to replicate and to develop resistance to the drug. If and when the virus develops resistance, the PLHA needs to take the next "line" of ART drugs, which suppress another part of the process of HIV replication. Though several lines of ART medication have been developed, the first line is the cheapest, the most widely available, and gives the PLHA the best chance for a simple regimen with a long term treatment success [34]. With high adherence, a large majority of PLHA can stay on the first line of ART for several years.

Over the last two decades, ART drugs have become available all over the world. Costs too have come down significantly, and in several countries, including developing countries, the first two lines of ART medication are available for free. It is therefore a surprise that though the treatment is available and affordable, many PLHA die each year. Could information and tools help in this situation?

The last decade has seen a rise in the use of mobile phones in developing countries. In this paper, we investigate whether it is possible to support the treatment of the PLHA with the help of mobile phones that they already own. A technology commonly available on all mobile phones is IVR. However, IVRs are not normally associated with personal, frequent-use applications. We designed an IVR ap-

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plication called TAMA for the PLHA, and a web-interface for the clinician. As a pilot study, we deployed TAMA for 12 weeks with 54 PLHA in 5 clinics across India and collected feedback about its design and usage.

The next section reviews the related work. After that we describe the design of TAMA and our study. The fourth section describes our findings, followed by discussions and conclusions.

RELATED WORK

There have been several studies that describe why PLHA from developing countries have poor adherence to ART. Costs of ART and financial status of the patient are important reasons for discontinuing medication and poor adherence [5]. However, giving away free medication does not work either. A study reports that respondents receiving free drugs had lower adherence [28]. Severe depression, less education, being unemployed, high CD4 count, hospitalisation, side effects, and pill burden were the other factors associated with lower adherence. Reasons for missed doses were ran out of pills, travelling away from home, simply forgot, busy with work, or intolerable side effects [37].

There is some literature about ways of supporting treatment. Klein et al. describe an "adherence loop" wherein a patient needs to believe that she has a disease, to develop a mental model of the condition and the therapy, to know what she needs to do, and to act and to have the ability to do so [10]. While their work was not specific to HIV and was done in developed countries, other studies corroborate the importance of patient education, and social and emotional factors. Patient's knowledge about side effects, belief towards ART, having developed reminder tools for taking medication, and patient's trust and confidence in the doctor improves adherence [37]. Studies have shown a positive correlation between family support and adherence [3], though family support is usually less in case of PLHA because of the stigma.

There has been work related to using technology for treatment support. Computer-based and mobile-based interventions were found to be effective in developed countries because of lower cost and higher flexibility than human-delivered interventions [17, 20, 31, 33, 36]. SMS-based HIV preventions strategies were found to be particularly useful in developing countries, including Uganda [4], Kenya [12] and South Africa [6, 25]. SMS-based systems have also been used for daily or weekly adherence reminders and for collecting adherence feedback in Africa [22].

However, SMS content is not secure and hence not suitable in case of PLHA who have not yet disclosed their HIV status to their family members, which limits the use of SMS. Further, SMS-based systems cannot reach everyone in developing countries because of low literacy. A specific problem in the context of India is that even literate people are unable to input text, and hence do not use SMS.

Intuitively, IVR systems seem to have several advantages over SMS. IVRs are suitable in oral cultures, can be richer in communication than text, and because the content is stored at the server end, IVRs can be potentially made more secure. IVRs have been traditionally used for customer service. More recently, applications based on IVRs have been used as a mechanism to enable citizen journalism in rural areas [15], for broadcasting audio messages to commercial sex workers [27] and as an agricultural information service [19]. The IVR platform has been extended as a "Spoken Web" with many applications [1].

IVRs have also been used in the healthcare domain. DocTalk attempts to extend doctors' visits by allowing them to share pre-recorded messages on IVRs [23]. In a recent study, IVR was used to provide thrice a week adherence reminder for a daily pill, and report a small improvement in Hb levels of intervention group over control group [18]. Authors speculate that the findings were not significant due to small sample size. But another possible reason could be that the calls were "about the adherence" and not actual daily pill-time reminder calls. They also provide a systematic review of healthcare studies using technology.

In recent times, IVRs have been used to support HIV treatment, mainly for adherence reminders. IVR has been used to collect adherence data [7]. IVR was found to be better than SMS for weekly adherence calls [26]. Tucker et al used IVRs to provide self-monitoring of adherence for up to 10 weeks to PLHA who were substance users in rural USA [31]. They found that daily reports were correlated positively with 4-day and 7-day recall reports, though 7-day recall yielded higher adherence claims.

In our prior study with 65 PLHA in 5 clinics across locations in India, we found that while adherence is important, there is a need and an opportunity to do more [9]. While most PLHA are counselled on initiation of ART, these efforts are not sufficient. We suggest a more holistic intervention that repeats, localises and personalises information, provides conceptual clarity in addition to factual and procedural knowledge, complements current efforts in clinics, leverages the social position of treating doctors, and discreetly supports PLHA who have not disclosed their HIV status to family members.

However, increasing the features of an IVR system carries the risk of making it complex and unusable. In a follow-up experimental study, we reported that the IVR systems with these levels of complexity could be made usable even by low-literate users [24]. However, a product that works in a lab with healthy users need not be as effective in real-life settings with PLHA. The objective of the current study is to evaluate the design in a real-life setting with PLHA.

TAMA (TREATMENT ADVICE BY MOBILE ALERTS)

We designed a system called TAMA to complement and extend the care provided by the HIV clinics. TAMA consists of an IVR for the PLHA and a web-interface for the

clinics. It provides pill-time reminder calls to PLHA, allows them to look up recommendations for common symptoms, plays short informational messages called "health tips" and reminds about appointments (figure 1).

Pill-time Reminders

It is important that a PLHA is adherent to her ART regimen and takes her doses on time. TAMA calls the PLHA to remind her to take her pills. The PLHA can choose to get daily or weekly reminder calls. If the PLHA chooses daily calls, TAMA calls her just after the pill time and asks if she has already taken her dose, if she plans to take it later, or if she will not be taking the dose (figure 1A). If the PLHA indicates that she has taken the dose, TAMA gives feedback about her adherence over the last 28 days.

At times the PLHA may be busy or away from her pills at pill-time, and may report that she will take the pill later. At other times, the pill-time call may not go through because of range or battery issues. In such cases, TAMA calls back after 30 minutes. TAMA repeats such calls for up to 2 hours after the first scheduled pill-time call. The PLHA is free to proactively call TAMA at any time (either before or after the pill-time) to report her dose. This is useful if the PLHA does not want to be disturbed at pill-time.

If the PLHA reports that she will not be taking the current dose, the doctor's voice comes on the line and gives feedback about the importance of adherence. When the PLHA misses her dose for the first time, (or if her adherence level has been generally high), the feedback is a gentle reminder. For frequent *pill-missers* (and for those with low / falling adherence), the feedback gradually gets sterner and reminds about several negative consequences, including possible viral resistance, and the risk of needing more expensive medication in future.

Those who feel that daily pill-time calls may intrude their lives too much can opt for a weekly call. The PLHA indicates a "best call time" (e.g. Sundays at 5 pm) for an unhurried call once a week. In that case, TAMA calls the PLHA once a week, reminds about adherence, and collects self-reported adherence feedback based on a 4-day recall.

Symptoms and Recommendations

ART drugs are known to cause side-effects. However, not every symptom is a side effect of ART. A symptom may also be caused by an opportunistic infection, by a condition called immune reconstitution syndrome, or due to treatment failure of the ART drugs. Currently, the PLHA needs to visit the clinic to manage a symptom. Symptoms require varied interventions. Some symptoms require no action as they disappear within a few weeks as the body gets used to ART. Others require minor lifestyle adjustments (e.g. taking

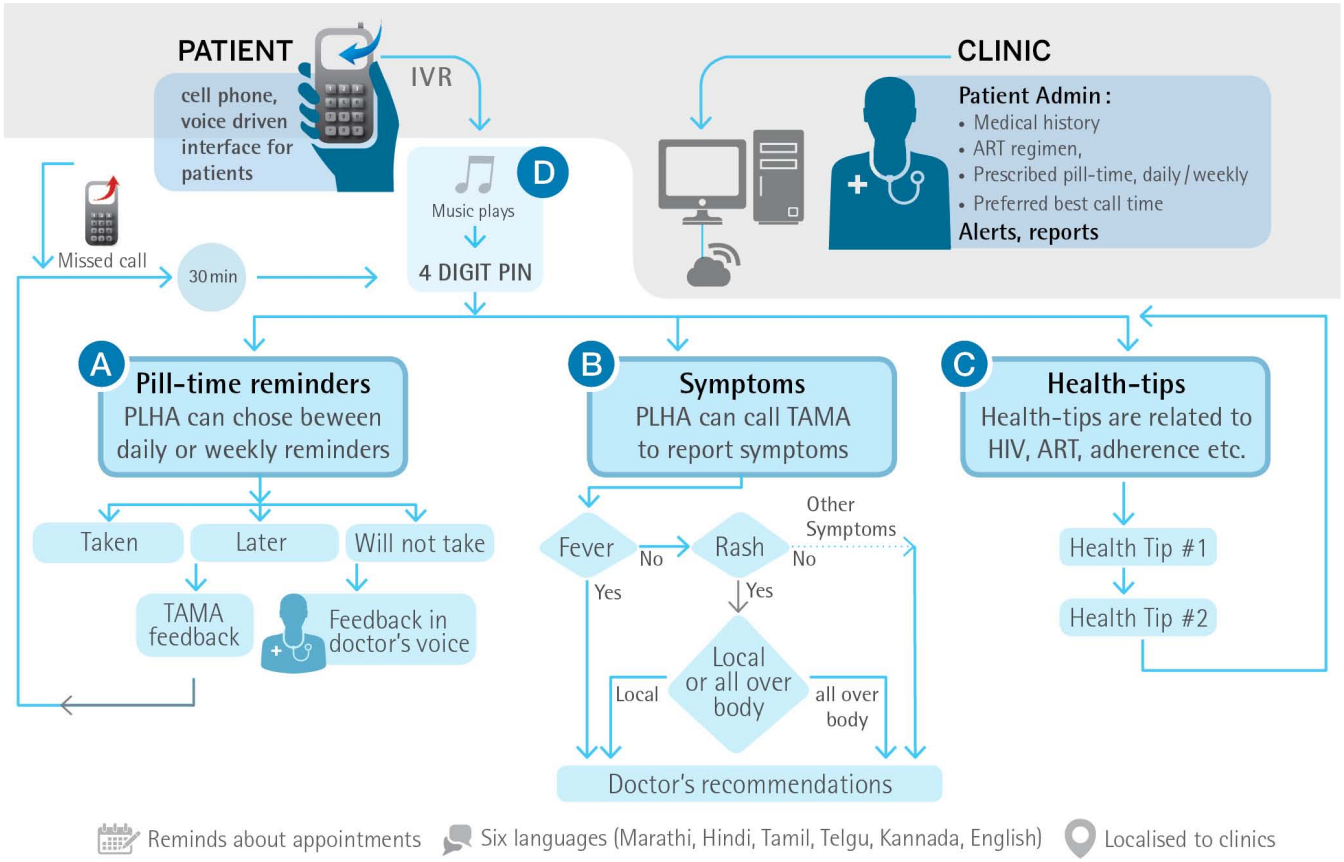

Figure 1. TAMA patient services daily (A) pill-time reminder, (B) symptoms look-up, (C) health tips, and (D) PIN.

medication half an hour before dinner). Others require symptomatic medication for a short duration that is available over the counter without a prescription in most drug stores (e.g. paracetamol). Some symptoms may require the PLHA to stop or change her ART regimen. Some symptoms require urgent medical attention.

If the PLHA is not feeling well, she can call TAMA (figure 1B). TAMA asks her about a probable symptom (e.g. "fever"). If the PLHA answers "no", TAMA asks about the next probable symptom (e.g. "rash"). If the PLHA answers "yes", TAMA may ask the PLHA for further details (e.g. "is the rash all over the body, or is it localised"). Depending on the PLHA's answers, TAMA makes one of four possible recommendations: ignore the symptom for now but discuss it with the doctor on the next visit, take *x* over-the-counter medication for *y* days, a lifestyle change, or meet the doctor immediately. In each case, TAMA also advises on whether or not to continue ART. In critical cases, TAMA connects the PLHA directly to a doctor for further management. The symptoms, their sequence, and the recommendations are based on an algorithm that is personalised depending on factors such as regimen of ART, age, gender, BMI, baseline CD4, hypertension, diabetes etc. This algorithm was created by a panel of practicing HIV specialists.

TAMA dialogues and algorithms are designed to err on the side of safety, and at times at the cost of usability. As a result, some dialogues are long, and in some cases, the PLHA is screened through less frequent but riskier symptoms before the recommendation for a more frequent but less risky symptom is played.

Information

It is important that a PLHA develops a conceptual understanding of HIV and ART in addition to having procedural and factual knowledge. But few reliable channels of information are available to them. Majority of the PLHA in India do not have access to the internet. Those who do, do not always find localised and personalised information that is relevant, and do not always trust the information they find. Currently, PLHA are counselled on initiation of ART. However, counselling is hard as a lot of information needs to be given and the PLHA is not in a condition to absorb it.

TAMA provides information in a question and answer format in short chunks of about 30 seconds each on demand. We call these "health tips". In the version used in the study, TAMA had 32 such health tips related to HIV, ART, adherence, tracking CD4, nutrition, family, children, disclosure etc. When a PLHA selects the option, two health tips are played back to her (figure 1C). The sequence is based on when she is likely to need that information. For example, the initial health tips have information relevant to those who are new to ART (e.g. adherence, tracking CD4 etc.), while the later ones are related to nutrition or family.

Security

PLHA are not likely to trust a system that has the slightest risk of an accidental disclosure. An accidental disclosure could lead to strain in the family, a loss of job, and / or public disgrace. TAMA is protected by a 4-digit personal identification number (PIN) (figure 1D). The PLHA chooses her PIN when she registers into TAMA. When TAMA calls a PLHA, or when the PLHA calls TAMA, a piece of music is played without any instruction. To access TAMA, the PLHA inputs her PIN. If the PIN is incorrect, the music is played again, and the PLHA tries again. If the PIN is correct, the relevant menu of TAMA begins.

Other Design and Technology Aspects

PLHA are often lost to follow up by clinics. Based on the last clinic visit date, TAMA reminds the PLHA to fix up an appointment for the next clinic visit. Once an appointment is fixed, TAMA reminds about the appointment itself.

In this study, TAMA was made available in 6 languages (Marathi, Hindi, Tamil, Telugu, Kannada and English). The scripts of TAMA were written in a conversational style. Translations (especially symptoms) were carefully localised and reviewed. Apart from languages, TAMA was also localised to clinics. This was done to leverage the trust that the doctors enjoy with patients. The opening greeting mentions the name of the clinic and / or the name of the treating doctor. E.g. "Welcome to PQR clinic", or "Welcome to Dr. Xyz's clinic". A "voice of the doctor" gives feedback when the PLHA misses a dose. This voice also gives recommendations when the PLHA reports symptoms. While using the actual doctors' voices would have been ideal for this, it was not feasible as the doctors are not fluent speakers in all languages. (We must remember that India is a multi-lingual country).

As Indian languages do not have robust text-to-speech or automatic speech recognition technologies, all dialogues in TAMA are recorded in human voices. Input is received through touchtone navigation. For outgoing calls, TAMA IVR is accessed by dialling a toll-free number. Incoming calls in India are free.

Clinical Tools

TAMA provides a web interface for clinics to register and maintain patients. During registration, the clinic enters the PLHA's medical history, the ART regimen, the prescribed pill-time (e.g. 10 pm daily), the preference to receive daily or weekly calls, and the preferred best call time (e.g. Sundays at 5 pm). As the PLHA uses TAMA, the web interface raises alerts about symptoms or falling adherence so that clinics can track patient progress and follow up in critical cases.

To help the clinics train the PLHA for using TAMA, an 18-minute long video was produced. With the help of scenarios, the video demonstrates the use of TAMA, including the use of the PIN, adherence reporting, symptoms look-up, and health tips. The video also shows some best practices

such as taking one's pills on time and proactively calling TAMA rather than waiting for TAMA's call. Like TAMA, the videos too are localised in languages and to the clinics and include photographs of local doctors. (As a clinical trial is currently underway, and it uses the same videos, these have not been referenced here.)

THE STUDY

IVRs work on all mobile phones, and hence have a wide reach. However, IVRs are not easy to use and are not typically used as a personal, frequent-use application for providing holistic treatment support. The key question that we wanted to answer was, "*Can TAMA IVR with as many features be safely used for supporting treatment of HIV in a real-life setting in a developing country?*" Further, we wanted to investigate which design decisions worked, why, and what can be learnt beyond the immediate context of supporting HIV treatment?

We deployed TAMA in five well-known HIV clinics in four large cities and one small town in India (Mumbai, Pune, Bangalore, Chennai, and Chirala). The locations were selected in high HIV prevalence states and to represent the diversity in languages and the types of clinics. Clinics often got patients who spoke different languages. Hence localised versions of TAMA IVR and the training videos were developed for each location for each language spoken there. In all, 16 localisations of TAMA IVR and training videos were created. Since all clinicians could speak, read, and write English fluently, only the English version of the web interface was developed. At least two doctors and / or clinic staff in each clinic were trained to use the web interface and to administer the protocol for the study.

During the study, TAMA IVR was provided for use at home for a period of 12 weeks to PLHA who had been on ART for 0-6 months, and who volunteered participation. On recruitment, participants were trained by the clinic with the help of the video and demonstrations. While recruitment was open to all eligible PLHA, we requested the clinics to ensure variability in terms of gender, languages, income groups, education, and age. In the first four weeks, all participants were required to be on a daily pill-time calls option. After that if the clinician found that the participant has been adherent, he could move her to a weekly call on request. The participants were followed up after weeks 2, 4, 8 and 12. A buffer of ± 2 days was allowed to account for convenience. If a follow-up happened beyond this window, the data from that participant for that follow-up was not considered for the purposes of the study (though the medical treatment continued as usual). The study took 9 months.

Our objective was to evaluate TAMA in a real-life setting. Apart from training the doctors and clinic staff on TAMA, we did not provide any additional administrative assistance. Apart from TAMA and TAMA training, the participants received the "standard of care" (i.e. the same treatment at the same cost as they would have otherwise got). Specifically, we did not provide any medication or cost of medication

Qualitative Interviews

Authors conducted semi-structured qualitative interviews with a subset of the participants. Before each interview, the interviewers reviewed TAMA logs. The interviewers asked the participants several open-ended questions to identify design problems or difficulties faced while using TAMA. Participants were encouraged to share experiences, opinions, and feedback about TAMA's design and usage and were asked for suggestions about how TAMA could be improved. Interviewers followed up on specific incidents noticed in usage logs. Interviewers probed about perceptions of effects on adherence and accuracy of information provided by TAMA. Interviews typically lasted 40 minutes. After a gap of a few weeks, interviews were repeated with some of the participants to explore if perceptions changed over time.

Quantitative Questionnaires

During each follow-up, the participants answered a questionnaire. The first 10 questions were the same as the System Usability Scale (SUS) questionnaire [2], which were modified only to replace the words "the system" with the word "TAMA", and translated. An additional set of 12 questions were asked to elicit feedback about TAMA's design and the participant's usage. The questionnaire was orally administered by a trained clinic staff or a treating doctor in the language of the participant's choice. The administrator read out the questions to the participant. In case the participant did not understand a question the administrator repeated the question, but did not give additional explanation.

The study was done ethically. It was done only in clinics specialising in treating HIV patients. Apart from the phone number and the medical history, no other personal data was collected from the PLHA. Patient data of a particular clinic was only handled within that clinic. PLHA interviews were scheduled by clinic staff and were conducted by researchers within the clinic premises. The design of TAMA and the study were approved by ethics committees of all participating organisations.

PARTICIPANTS

Initially doctors found it difficult to recruit women, rural participants, and those with less education. However, in due course doctors managed to recruit participants with reasonable variability. A total of 54 PLHA (35 male, 19 female) were recruited. Each clinic recruited between 5 to 15 PLHA. There were 28 urban, 10 small town, and 11 rural participants. 15 participants chose TAMA IVR in Telugu, 14 in Marathi, 8 in Tamil, 8 in Hindi, 6 in Kannada, and 3 in English. 9 participants had less than 4 years of school education, 10 from 4 to 7 years, 15 from 8 to 10 years, and 20 had more than 10 years of education. Their mobile phone experience ranged from 6 months to 17 years (mean 6.6 years, SD 4.5 years).

A total of 50 qualitative interviews (including 15 repeat interviews) were conducted with 35 participants. 12 of these were conducted after 2 weeks of TAMA usage, 12 after 4 weeks, 11 after 8 weeks, and 14 after 12 weeks. 10 participants interviewed were of the age 23 to 30, 16 of age from 31 to 40, and 9 of age 40 to 64.

FINDINGS

The overall qualitative feedback on TAMA was very positive. TAMA was found to be usable even by people with few technology skills. A participant could not unlock her own phone, but could answer TAMA calls by herself.

Many participants, and particularly those who had no other support system, liked TAMA. They felt that through TAMA someone was keeping track of their treatment like a family member, taking care of them, and giving them knowledge, advice and counselling. Participants consistently agreed with the statement "When I use TAMA, it feels like I am in touch with my HIV clinic" (4.30/5 to 4.44/5 across weeks 2-12). A large majority of participants said they were willing to pay for such a service. The minority who said they wouldn't, said so either because they could not afford to pay or because they were financially dependent on someone else. When asked what might be the effect once TAMA was shut down after the study, some said they would miss TAMA, and it might make them miss their pills. Others said they will have to manage without TAMA by making alternative arrangements such as mobile alarms.

The qualitative interviews produced detailed feedback about specific features and design aspects of TAMA.

Pill-time Reminders

Many participants said that their adherence to ART regimens had improved because of TAMA. Some participants said they now were more "serious" about adherence than earlier. Four participants believed that they had been adherent earlier, but even they thought that TAMA served as a backup "in case I forget – which is bound to happen at times". Three participants who had used mobile alarms for pill times said that TAMA was better "because it calls several times". The 30 minute gap between calls was considered to be ideal. Many thought that a larger gap would make them late, and a shorter gap too much of a nag. Logs indicate that for 6,904 pills scheduled to be taken by participants, they received 5,787 incoming pill-time reminder calls (84%). It is interesting to note that 8,203 pill-time calls attempted by TAMA were either not completed (possibly due to range or battery issues), or missed, declined, snoozed, or left incomplete by participants. Thus, the remind-me-in-30-minutes feature got used extensively.

TAMA helped people develop good adherence habits. Participants strongly agreed with the statement "TAMA helps me take my medicines on time" (4.47/5 to 4.74/5 across weeks 2-12). Distractions (festivals, work etc.) still affected some people's pill-times, but TAMA's calls prod them to be punctual. Some started associating their pills with routine activities like dinner. In the questionnaire, participants were asked whether their adherence would have been less or more than current had they not been using TAMA. Their opinion changed marginally over the 12 weeks. After the first 2 weeks of TAMA usage, the participants' opinions tended towards somewhat less than current adherence (2.26/5). By the 12th week, the opinions had drifted towards somewhat more than current adherence (2.53 in week 4, 2.67 in week 8, 2.77 in week 12). Though the differences are not statistically significant, the drift is consistent

The adherence percentage feedback seems to have worked. Several participants could recall their current adherence percentage. Some participants could explain correctly what the numbers meant, though a majority was confused. One participant asked, "Does it mean that I am late?" Some participants felt that TAMA underestimated their adherence. And yet, in all cases, their "daily scores" seemed to prod them on towards better adherence. They were keen to find out their adherence levels and waited to hear their current percentage before hanging up the call.

We were interested to find out if people "cheated" TAMA (i.e. answered that they had taken the pill, but actually took it later). A majority of participants said they did not do so. One remarked, "Why should I do that? It is about my life after all". Six participants admitted to have cheated TAMA, and at least one of these admitted that once he had forgotten to take his pill after he reported it as taken.

We were interested to find out if participants called TAMA proactively to report doses. If a user calls proactively, it could mean that she is not overly dependent on TAMA's reminder calls. Surprisingly, as per the logs, as many as 52/54 participants made at least one outgoing call to record adherence. For 6,904 scheduled pills, 1,095 (16%) such outgoing calls were made. But many participants did not want to call TAMA proactively every time and said it was "too tedious". Some asked why they should bother, as "TAMA calls for the purpose of reminding". One said, "I will call TAMA only if I have a problem". Even the participants claiming that that they took their pills before TAMA calls them said they waited for TAMA to call. Twelve participants said that they "called back" after TAMA had called them once at their pill-time. Three said that they called TAMA if a later call from TAMA was likely to disturb their work or sleep, or if they were likely to be in company. Only one participant called TAMA routinely, and he too missed on occasions.

A related issue was the toll-free number. Though many users did have TAMA's toll-free number "written down somewhere", only one tech-savvy participant had saved it in his phone. Most preferred to call back the same number that TAMA called from (a toll number).

Opinions were mixed about whether TAMA calls were intrusive. When TAMA's call came in front of others, some thought that was intrusive but most participants managed to

answer TAMA calls in public or in company. To the statement "I often get disturbed in my work when TAMA calls" participants disagreed consistently (1.62/5 to 2.17/5). In contrast, participants reported that weekly calls by TAMA (the "best call time" calls) were not useful and were intrusive. The few participants who were set to receive weekly calls opted out when they found out they could. Only one participant asked to be switched from daily pill-time reminders to a weekly call.

Symptoms and Recommendations

Some participants reported that they did not have any symptoms, and naturally many of these did not access the symptoms menu. Among those who had symptoms, six preferred to call or visit the doctor first, either in cases where the doctor was easily accessible, or because the participants were not sufficiently trained to use the symptom menu in TAMA. (This happened in case of some early participants in the study.)

But a majority of participants called TAMA first. Logs show that 42/54 participants accessed the symptoms menu in a total of 216 calls. Among these 75 were outgoing calls made by 31/54 participants (presumably calls because of a symptom or out of curiosity). 33/47 participants reported one or more symptoms in TAMA through 100 calls. (*Due to a technical difficulty, this part of the data is available for 47/54 participants.*)

Of the 100 reported symptom calls, in 40 calls TAMA diagnosed the case as critical and attempted to connect to a doctor after giving the recommendation. In 29 of these 40 calls, TAMA could connect the 14 participants to a doctor successfully. In many of the clinics, more than one doctor was set up to receive such escalated calls in a sequence. In spite of this, TAMA could not complete calls to doctors in 11/40 cases for 10 participants. This data reflects the real life. Doctors typically get hundreds of calls from patients every day, and they do miss many calls. In the study, TAMA was deployed to a small fraction of the patients in each clinic, thus it did not have any 'triaging' effect on the number of calls that doctors receive. Hopefully when TAMA is deployed to all patients in the clinic, some of the problems will be resolved by the system, thereby allowing doctors to handle more calls that are critical.

During the interviews, many of those who accessed the symptoms menu said they trusted in TAMA's recommendations, but some still needed a reconfirmation from the doctors. Eight participants reported that they had "explored" the symptoms menu out of curiosity even when they did not have any symptoms. Two participants admitted that they had reported a "fake" symptom, and were surprised to find that it was taken seriously. TAMA gave them a recommendation and even connected them to a doctor. While it is not desirable to have fake symptoms reported, exploration helped three participants report a real symptom. They explored all the available symptoms in one pass, and reported a true symptom in a second pass soon after.

Information

Logs indicate that 42/54 participants accessed health tips in 718 calls. Among these, 158 calls (22%) were proactive outgoing calls made by 32/54 participants, the rest being incoming calls. Information was perceived to be useful and believable. Over the 12 weeks, participants consistently agreed with "TAMA is helping me to know more about ART and HIV" (4.15/5 to 4.51/5) and disagreed with statements "TAMA does not give useful information" (1.31/5 to 2.00/5) and "I find the information given by TAMA hard to believe" (1.77/5 to 2.44/5).

A majority of those who had heard health tips remembered them. The health tips that could be readily recalled were actionable. They were regarding nutrition, about not sharing ART pills, that there are multiple lines of ART, about how HIV can and cannot spread, and why one should track CD4 regularly. However, six participants could not recall any health tip, though logs indicate that they had heard some of them. The participants who heard health tips demanded more of actionable health tips. They wanted to know about the "latest research", more about children and family issues, sexual behaviour, nutrition, about the "real" differences between ART medications available at various prices and in different clinics, about alcohol, smoking, becoming "negative", life expectancy, and prognosis. Those who had reported symptoms wanted personalised health tips related to those symptoms. Several participants report a change of behaviour after hearing health tips. Participants said they often had questions after hearing a health tip. Perhaps there could be a "discussion board" around each health tip.

24 participants accessed 10 or more health tips in a single call at least once (looping through the menu 5 or more times). This behaviour was not anticipated. Some participants said that they had heard "all" the health tips available. A particular rule in TAMA is that once a health tip is played, it is not repeated within 15 days. So those who heard many health tips "ran out". Perhaps this rule is not needed, as repetition is useful.

Five participants who never heard health tips said they did not know that TAMA had this feature. Eight participants had heard health tips only once or twice. Surprisingly, when we asked these participants what could be added to TAMA, they often asked for "more information" (often of the type that was already present in TAMA).

Other Issues

While participants were concerned about accidental disclosure, almost all felt that the PIN was secure enough. Over the 12 weeks they consistently disagreed with the statement "TAMA will cause un-wanted disclosure – people who don't know about TAMA suspect something" (1.62/5 to 2.00/5). Participants reported surprisingly few PIN malfunctions. One user pressed the "green button" after entering the PIN once. Another user "backspaced" a wrong PIN to correct it (like one can do on a handset). But users learnt to get over these problems quickly.

While most participants said that TAMA calls reminded them of their pills, one participant said it reminded her of her disease. We found that while some people learned to "barge in" the IVR menus, many continued to wait till the menu was completed.

We discovered some operational issues related to the study during the interviews. In some cases, participants' data was not completely entered in TAMA, which prevented TAMA from playing health tips. We found that participant training was inconsistent across clinics particularly for early participants. When the training was improved, later participants faced fewer issues. Some problems were related to the mismatch between the doctor's advice during consultation and the settings in TAMA.

Quantitative Feedback

The mean SUS score across all participants across 12 weeks is 83.73 (SD 13.8, 95% CI 81.7 to 85.8). SUS scores above 81 convert to a percentile rank of above 90% of reported studies [29, 32]. We present the detailed SUS scores grouped by weeks, languages and clinics in an appendix online [30]. The quantitative questions were analysed by comparing the responses of participants against a uniform distribution using the Kolmogorov Smirnov goodness of fit test for ordinal variables with a D statistic. All questions returned significant results at $p < 0.05$. We present the details of these quantitative findings also in the appendix [30].

DISCUSSIONS

It is known that low literate users lack several abstraction skills and find it difficult to navigate hierarchies [14]. While it is true that many of our users needed to be trained to use IVRs, we found that a small amount of training helped the participants overcome the initial barriers and use TAMA effectively over the longer term. Though such training may not be feasible for one-time use applications, it makes sense for long-term, frequent-use applications. Future research could focus on evaluating the costs and benefits of training low-literate users for such applications.

While providing technology support for a routine task such as pill-taking, we must remember that it should mainly serve as a backup. There is always the risk that people may get too dependent on technology. A study showed that adherence could drop due to over-dependence on technology or due to device failure [13]. The participants' opinion about what their adherence would have been without TAMA drifted from "somewhat less than their current levels" after 2 weeks of usage to "same as current levels" after 12 weeks. Though the differences are not statistically significant, the drift is consistent. A possible reason could be that TAMA's pill-time reminders were useful to the beginners, but as the participants got used to ART they became less dependent on them (at least in their perception). A design feature that possibly contributed to this trend was that TAMA calls the participant 5 minutes *after* the scheduled pill-time. A focussed study is required to confirm this trend empirically.

To further wean people away from over-dependence on TAMA, we originally considered that it might be better if PLHA were to proactively call TAMA to report adherence instead of waiting for TAMA's call. While that may still be the better option, after the study we are convinced that TAMA is usable and viable in real life settings, and it could be reliably used by PLHA for pill-time reminders. Though many participants occasionally called TAMA, routine proactive calling for reporting pill-time adherence does not seem feasible to most users.

Surprisingly, participants found the *weekly* "best call time" calls more intruding than the *daily* pill-time reminders. By hindsight the reason is clear. The daily pill-time calls are actionable ("take your pill now") and fit into a routine, and hence do not intrude. While the weekly calls remind about the importance of adherence, they are pedantic. They do not actually help adherence, and hence are found intrusive.

Trust is an important factor to consider while disseminating information on sensitive topics. Literature in agricultural domain suggests that though users say they prefer to get information from an expert, they tend to act more often on an IVR message from a peer rather than an expert [19]. Our experiment with PLHA peer group discussions also indicates that peers are trusted [8]. However, PLHA also have tremendous trust in the local doctors. We tried to leverage that trust in the doctors by localising TAMA and the training videos to clinics, and by using "the voice of the doctor" to give critical advice. We found that the recommendations were usable, useful and trusted. After the study, our sense is that the participants trusted TAMA recommendations only because these came from the doctors. Perhaps trust is a function of the domain (agriculture vs. healthcare) and type of task (practical agriculture vs. treatment).

The proportion of participants who reported symptoms in TAMA seems to be somewhat larger than in the clinical practice. Though we did not investigate this systematically (and two participants did admit to reporting fake symptoms), the difference indicates that the participants may be reporting minor symptoms that they may have otherwise ignored, perhaps because TAMA makes reporting symptoms easy. This calls for more investigation in future.

Dialog design in IVRs should be related to frequency of use. In TAMA the symptoms menu is meant to be used rarely. The symptoms menu was accessed in only 216 calls, and a symptom was reported in only 100 calls. This suggests that such menus should allow for exploration at the same time they should not lead to wrong entries of medical data. Balancing these requirements and yet keeping such dialogs usable by less educated users has been a challenge. On the other hand, for frequently used IVR menus (e.g. pill-time reminder menus), length of dialogs is an important design consideration. Our prior work suggests that longer, expansive menus help novices understand prompts better [24]. However, not many of our participants had learnt to barge in after 12 weeks. For long-term, frequent-use IVR

applications, menus could be progressively shortened to improve speeds of experienced users, with longer menus could act as backup.

Some of the participating doctors were surprised to see the popularity of health tips and the demand for even more despite the extensive counselling that they provide. However, we believe that more could be done to help PLHA understand their disease and its treatment, and to give them emotional and social support. The participants who did not access health tips too were keen for more information. A reason they did not access the existing information could be the health tips had to be "pulled". In contrast, the adherence feedback (which was "pushed") was always heard. People with less exposure to digital technologies are not used to active "information foraging" as is understood traditionally [21]. For them, perhaps the cost of interaction is too high compared to the utility of information gained. They prefer to stumble upon information by serendipity (e.g. friends, TV etc.) and would readily hear pushed information.

For the clinics, TAMA is an enabling tool rather than an automated system. When it is scaled up TAMA needs to be better integrated with the operations of the clinic. This may include activities such as more extensive patient training, saving TAMA numbers in their phones, tracking their usage routinely, follow-up in cases of poor adherence or symptoms etc. In a way, it may increase the clinic's work, though it also allows them to extend their care beyond the clinic.

CONCLUSIONS

IVRs can reach a large majority of human population today and are particularly suitable for countries like India with many languages and several low-literate users. IVRs are known for poor user experience and are usually associated with pesky customer service calls. However, in a study in five HIV clinics with 54 PLHA for 12 weeks we found that it is possible to improve adherence and build a deeper relationship between PLHA and the clinic using a holistic, well-designed, localised, personalised IVR application. Our study shows that TAMA was usable and works in real-life settings. The quantitative feedback reassured us about the appropriateness of our broader design approach to TAMA. The qualitative interviews unearthed the insights of why things work, what can be improved, what failed, and why.

While some of these lessons are specific to TAMA, we find that many of these can be generalised to other frequent-use IVR applications in the healthcare domain. We found that a 4-digit PIN on IVRs is usable and provides sufficient perception of security to HIV patients. It should be sufficient for most other ailments. We found that a daily pill-time reminder call is not considered intrusive as it is actionable, while even a weekly call may be intruding if it is pedantic. Our 30-minute duration between follow-up calls turned out to be just right for the users. Patients suffering from serious health conditions are hungry for authenticated, personalised, and localised information beyond what they receive from clinicians and caregivers. The delivery of such information needs to fit their information seeking behaviour. Pushing information to them may be better than asking them to pull it.

Our immediate next step in this project is a randomised clinical trial, wherein biological outcomes of a cohort of HIV patients using TAMA will be compared with a control group. Looking beyond, several such long-term, frequent-use applications based on IVR technologies seem feasible for a wide range of users in developing countries, though many unanswered questions call for more research.

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