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## Mobile phone use for a social strategy to improve antiretroviral refill experience at a low-resource HIV clinic: patient responses from Nigeria

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### ABSTRACT

In sub-Saharan African areas where antiretroviral (ARV) drugs are not available through community pharmacies, clinic-based pharmacies are often the primary source of ARV drug refills. Social pressure is mounting on treatment providers to adjust ARV refill services towards user-friendly approaches which prioritize patients' convenience and engage their resourcefulness. By this demand, patients may be signalling dissatisfaction with the current provider-led model of monthly visits to facility-based pharmacies for ARV refill. Mobile phones are increasingly popular in sub-Saharan Africa, and have been used to support ARV treatment goals in this setting. A patient-centred response to on-going social pressure requires treatment providers to view ARV refill activities through the eyes of patients who are negotiating the challenges of day-to-day life while contemplating their next refill appointment. Using focus groups of five categories of adult patients receiving combination ARV therapy, we conducted this cross-sectional qualitative study to provide insight into modifiable gaps between patients' expectations and experiences of the use of mobile phones in facility-based ARV refill service at a public HIV clinic in Nigeria. A notable finding was patients' preference for harnessing informal social support (through intermediaries with mobile phones) to maintain adherence to ARV refill appointments when they could not present in person. This evolving social support strategy also has the potential to enhance defaulter tracking. Our study findings may inform the development of ARV refill strategies and the design of future qualitative studies on client-provider communication by mobile phones in under-resourced HIV treatment programmes.

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### KEYWORDS

Antiretroviral therapy; ARV refill; mobile phone; social support; focus groups; sub-Saharan Africa

## Introduction

In sub-Saharan Africa, significant social shifts are apparent in the ubiquity of mobile phones. Evidence abounds that mobile phone communication between patients and antiretroviral treatment (ART) providers in Africa can improve adherence to ART (Lester et al., 2010; Mbuagbaw et al., 2011; Okuboyejo, Ikhu-Omoregbe, & Mbarika, 2012; Pop-Eleches et al., 2011; Wise & Operario, 2008). Recent estimates indicate that over 450 million mobile phones are in use in Africa (Prækel Foundation, 2014), and many providers have recognized their use as a relatively inexpensive means of communication to support ART goals (Lester et al., 2010; Okuboyejo et al., 2012; Wise & Operario, 2008). However, in settings with high HIV stigma, maintaining a valid database of clients' phone numbers can be frustrating because of the attitude of patients with concerns about inadvertent

disclosure (Kinyua et al., 2013). Such ART patients may also be wary of community distribution centres out of dread of community-level disclosure (Rasschaert et al., 2014). Some studies have reported evolving compromises for antiretroviral drug (ARV) refills through self-forming patient groups, dispensing several months' supply of drugs per clinic visit, or extending ARV delivery systems through home-based care teams (Braitstein et al., 2011; Decroo, Telfer, & Biot, 2011; Harries, Zachariah, Lawn, & Rosen, 2010).

As increasing numbers of ART patients successfully lead active and busy lives, their demand for creative ARV refill options will rise, and with it the pressure to adjust prevailing refill protocols to suit indigenous systems of social support. To investigate how ARV refill practices may leverage the increasing popularity of the mobile phone, we explored for modifiable gaps between the expectations and perceptions of adult patients

regarding the use of mobile phones in ARV refill service at a large public clinic in Nigeria.

## Methods

Eligible participants were consenting adults with mobile phones who had been receiving ART for at least six months at the HIV Clinic, University College Hospital, Ibadan (UCH). During clinic enrolment, patients provide their contact details (including mobile phone number) and also nominate one treatment supporter from their relationship pool to support their treatment experience. Mobile phone numbers of clients are stored in a database for care-related use. All patients undergo clinical and laboratory assessment once every six months to determine whether virologic/immunologic goals are being met. At the time of this study, 5200 patients obtained ARV refill once every month at the clinic-based pharmacy. ARV refill by “intermediaries” (family, friends, or clinic staff) was permissible on patient’s request. The term “intermediary” is used here to describe ARV refill helpers, and to distinguish them from clinic-mandated “treatment supporters”.

We used purposive sampling with participant stratification by sex and age (18–24; 25–40; and > 40 years) to achieve five groups with seven participants per focus

group. Participants were approached individually (face-to-face) by a co-investigator during recruitment. All groups were gender-specific, except for the 18–24 years age group (by participants’ preference). Each group met once on different dates spanning seven weeks in October–December 2013. All groups responded to a study-specific focus group discussion (FGD) guide prepared in English and Yoruba (the dominant local language, duly back-translated into English). The FGD guide was pilot-tested, and focused on submission of mobile phone numbers to providers; reliability of submitted phone numbers; the role of ARV refill intermediaries; and suggestions for preventing ARV refill abuse. Trained HIV clinic staff (physicians, nurses, and adherence counsellors familiar to participants) conducted closed-door FGD sessions at UCH. We effected de-identified audio recordings and verbatim transcription of group discussions, and performed content analysis by meta-coding. Transcripts were not reviewed by contributors, but participants were debriefed during follow-up clinic visits. Ethical approval was obtained from the University of Ibadan/UCH Ethics Committee.

## Results

Out of 60 potential participants who were approached, 35 enrolled in the study. Four enrolees eventually failed to participate in the FGD because of competing engagements. The mean duration of FGD sessions was 133.20 minutes. Nobody manifested emotional distress as a result of participation. Some participants’ quotes are presented in [Table 1](#).

**Table 1.** Participant quotes from FGD.

FGD guide sub-topic	Participant quote	Participant’s sex/age
Disposition to submission of mobile phone numbers	“Since I know that it (phone number submission) is for my good in case I stop my treatment, how can I be against it?”	Male, 19 years
Reliability of submitted mobile phone numbers	“See, I have two phones ... one for the village, and one for the city. So, if one phone is not working (reachable by calls) today, it doesn’t mean I have abandoned it. I will still go back to it tomorrow.”	Male, 38 years
Suggestions for updating clients’ phone numbers in clinic database	“Why won’t I make sure that my phone is reachable if I know this will allow a friend to help me collect my (antiretroviral) tablets from the clinic?”	Female, 32 years
Perception of role of ARV refill intermediaries	“I already know how to take my tablets. So, why would you people (ART providers) need to discuss anything with somebody just collecting my drugs for me?”	Female, 52 years
Suggestions for preventing abuse of ARV refill through intermediaries	“If I send somebody to collect my medicine for me, it will be somebody I trust, and I will be waiting for a (phone) call from that person, or from the clinic.”	Female, 47 years

### *Disposition to submission of mobile phone numbers*

No respondent reported negative feelings about submitting their personal mobile phone number for inclusion in the clinic database. Participants all assumed that the main purpose of obtaining clients’ phone numbers was for defaulter tracking. They demonstrated awareness that defaulter action was undesirable treatment behaviour with bad consequences.

### *Reliability of submitted mobile phone numbers*

Several participants admitted to being unmindful that submitted mobile phone numbers may no longer be valid for contacting them. None had updated their phone details in the clinic database. Some admitted that they had acquired new mobile phone lines after clinic enrolment, but defended such changes as a necessary adaptation to telecommunication service constraints.

No respondent reported deliberate deactivation of a submitted phone number from feeling insecure. The dominant opinion was that invalid phone numbers would cease to be an issue when ART providers guide patients to realize that benefits (such as refill privileges) are tied to the maintenance of a functional client–provider phone connection.

### **Role of ARV refill intermediaries**

Only a few participants reported that they had never used an intermediary (family or friend) for ARV refill. Some respondents with spouses receiving ART at UCH discussed that they reduced family expenses on transportation to and from the clinic by performing one refill visit for self and spouse. Other participants reported helping as ARV refill collectors when a friend could not obtain permission to be excused from work. Members of the youth group reported using ART adherence counsellors as refill intermediaries during school examination periods. Participants distinguished between ARV refill intermediaries (perceived as occasional errand persons for refill and delivery only) and treatment supporters (perceived as HIV care confidants).

### **Suggestions for preventing abuse of ARV drug refill through intermediaries**

Though keen to protect ARV refill through intermediaries from abuse, participants did not endorse a discussant's suggestion that the maximum number of refills per year by a helper should be predetermined, or that ARV refill intermediaries should present a letter of authorization from the patient. A similar suggestion for refill intermediaries to present the patient's clinic appointment card (as proof of authorization) was viewed more favourably. Overall, participants decided that ARV refill intermediaries should make a call to the patient in the presence of a health worker who can endorse a refill and also update the patient's phone number (if necessary) in the clinic's database.

## **Discussion**

This study highlights how patients in a low-resource setting are evolving a social option for ARV refill at a busy outpatient clinic despite perceived constraints. The assumption by participants that defaulter tracking was the primary purpose for seeking their mobile phone numbers underscores the responsibility of ART providers to minimize patients' suspicions of undue surveillance, while projecting the benefits of client–provider phone communication from the patient's perspective

(Deribe, Hailekiros, Biadgilign, Amberbir, & Beyene, 2008). Instead of recurrently scrutinizing phone details, participants suggested that ART providers should induce patients to actively maintain client–provider connection by rewarding an accessible mobile phone line with care-related privileges (such as convenient ARV refill through intermediaries).

Even though not all participants had utilized intermediaries for ARV refill, the popularity of this strategy across all five focus groups was apparent, possibly because this coping strategy originated from patients themselves. In mobile phone-using ARV refill intermediaries, providers have a window of opportunity to replace patients' doubts about the usefulness of client–provider phone connection with a sense of strategic relevance. Only the participants in the youth group were explicit about using clinic personnel as ARV refill intermediaries. We opine that a clinic policy which rewards staff for assisting with patients' ARV refills may encourage clinic personnel to demonstrate better support. The predominance of family members over friends as ARV refill intermediaries in our study corroborates reports about the supportive role of the African family in times of crisis (Inem et al., 2004). Among a Ugandan cohort, “medicine companions” (treatment supporters who remind ART patients to take their medications on schedule) were predominantly family members of patients (Foster et al., 2010). Our study participants differentiated treatment supporters from ARV refill intermediaries, and delineated ARV refill intermediaries as collection agents only on an as-needed basis. This stance may be instructive for ART providers because well-intentioned attempts to foist additional roles (such as feedback about treatment issues) on ARV refill intermediaries may be resented by patients. As with all studies, there are limitations; participants' expressions may have been influenced by social desirability bias, pressure from group dynamics, and even performance anxiety over the opportunity to recommend a preferred ARV refill strategy. Participants expressed that the use of familiar clinic staff as FGD moderators enhanced discussion dynamics, but this could also have inhibited participants from giving full expression to their views about lapses in the clinic's ARV refill practices.

Based on the perspectives of our study participants, we conclude that there are modifiable lapses in the use of mobile phones in ARV refill operations locally. At the heart of these lapses seems to be patient scepticism about the value of formal client–provider connection by mobile phone. This perception can be positively influenced if providers consistently invest in patient education to mollify stigma-related anxieties, and also organize patients and ARV refill intermediaries to utilize

voice calls for confirmation of refill intentions with designated clinic personnel. We conclude that ARV refill through mobile phone-using intermediaries drawn from patients' social pool holds promise for meeting the yearnings of both ART patients and providers in this HIV treatment clinic.

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