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"When I receive the message, it is a sign of love": symbolic connotations of SMS messages for people living with HIV in Burkina Faso

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ABSTRACT

Mobile health (mHealth) has gained considerable interest recently due to its potential to improve health outcomes in developing countries with high outreach yet low costs. Several studies have explored the use of short message service (SMS) reminders to improve antiretroviral (ARV) retention and adherence, with mixed results. The majority of these studies has a quantitative nature and employs randomized designs, which do not provide further qualitative insights about other possible impacts of the messages. Based on the qualitative assessment of an SMS intervention in Burkina Faso, which complemented a (quantitative) Randomized Controlled Trial (RCT), we show that beyond the functional role of improving ARV retention and adherence, SMS messages can also play important symbolic roles in offering psychosocial support to people living with HIV (PLHIV) and improving their perception of life. Concomitantly, we show that sufficient (ICT) literacy skills cannot be taken for granted in resource-poor settings. Yet, regardless of (ICT) literacy skills, the symbolism of care was perceived. Furthermore, we highlight the importance of complementing quantitative evidence of mHealth interventions with qualitative assessments.

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1. Introduction

In recent years, mHealth has gained considerable attention due to its potential to improve health outcomes in developing countries with high outreach, yet low costs (Free et al., 2013; Kahn et al., 2010). While there is no standardized definition of mHealth, we understand mHealth "as medical and public health practice supported by mobile devices, such as mobile phones" (World Health Organization, 2011).

Uptake of mobile phones across the developing world has been rapid in the last decade, but it is unclear how they can be most effectively used to facilitate health service delivery. Strong evidence of a positive impact on health outcomes remains scarce and the potential for scalability questionable (Chib et al., 2015; Demena et al., 2020). Moreover, although adoption of SMS reminders seems a dated topic from a developed country perspective, basic mobile phones are still the most common appliances in poorer countries although internet-enabled phones have been on the rise. Therefore, SMS still remains the most preferred, low-cost Information and Communication Technology (ICT) to reach the masses (Mukund Bahadur & Murray, 2010). Common one-way SMS-based interventions within healthcare settings are patient reminders and information distribution (Déglise et al., 2012).

A large number of SMS-based interventions are particularly focused on HIV/AIDS (Lippman et al., 2016; Mbuagbaw et al., 2012; Ronen et al., 2017). In the care for PLHIV, the most common and widespread SMS interventions make use of appointment reminders, individual follow-up, prompts about ARV medication schedules, and/or informing about viral loads. This has led to a myriad of studies around the effectiveness of SMS messages for PLHIV in both developed and developing countries (Shet et al., 2013; Smillie et al., 2014). Some studies demonstrate a positive impact on ARV adherence (Lester et al., 2010; Maduka & Tobin-West, 2013; Pop-Eleches et al., 2011; Rana et al., 2015), whereas other studies have not found any impact (da Costa et al., 2012; Reid et al., 2014). In addition, there are numerous protocols for and systematic reviews about interventions to improve ARV adherence (Ma et al., 2016; Mbuagbaw et al., 2013; Mills et al., 2014; Yasmin et al., 2016). Overall, these reviews conclude that studies with longer duration and larger samples are needed to

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get a better understanding of the impacts and limitations of mHealth on ARV adherence (Hardy et al., 2011).

Good practice in public health trials entails integral process evaluations that draw on complementary quantitative and qualitative data, i.e., involving qualitative assessments of the mechanisms and context-specific aspects (Bonell et al., 2012). However, in the mHealth domain this is still not common practice and such an integral approach is yet to be embraced widely. Nevertheless, some scholars have already highlighted the need for further qualitative research to evaluate SMS interventions (Campbell et al., 2017; Ma et al., 2016). To date, there tends to be an (exclusive) focus on the predominantly functional and instrumental use of ICTs, as a mechanical input-output relation between a person and an ICT. Yet, besides their instrumental functionality, ICTs can also serve other more symbolic roles that are equally important (Geldof, 2010). The few existing studies paying attention to the impact of SMS messages beyond adherence demonstrate that they make people feel seen and cared for and that the messages have an inherent meaning for their receivers (Fairbanks et al., 2018; Haberer et al., 2016; Ware et al., 2016).

In light of the limited existing evidence about the inherent meaning of SMS messages for their receivers, our project complemented a RCT about the impact of SMS messages on ARV adherence with a qualitative exploration of the mechanisms underlying the intervention. In this article we demonstrate that beyond functional use of SMS messages as medication reminders, there is also great potential for the symbolic role of SMS messages as means to provide psychosocial support to PLHIV by making them feel cared for and thus improving their subjective wellbeing.

2. Methods

The findings discussed here are part of a larger nationwide RCT employing SMS messages to increase retention and adherence to ARV therapy in Burkina Faso (Wagner et al., 2016). In addition to four rounds of quantitative data from an initial sample of over 3,800 individuals, a qualitative assessment of the intervention was undertaken. The assessment aimed to understand the beneficiaries' experiences with the SMS through an open-ended manner of data collection.

The two-year RCT started in 2015 aiming to evaluate the impact of four types of SMS messages (plus one control group) on PLHIV's retention and adherence to ARV treatment. The first group received one weekly text message, the second group two weekly text messages, the third group one text and one ASCII image message per week and the fourth group one weekly ASCII image. The sample comprised adult patients (>15 years) undergoing ARV therapy with access to mobile phone services, recruited at 80 healthcare facilities providing ARV therapy across Burkina Faso. Data collection was done at baseline and during three follow-up surveys at 6, 12 and 24 months after the intervention started. The surveys were administered by local self-help groups. The impact of the messages on the study population was analyzed through multivariate regression analysis (Wagner et al., 2019).

In addition to the quantitative surveys, two qualitative assessments were undertaken in 2016 and 2017 by means of semi-structured interviews and focus groups with beneficiaries and survey enumerators. We recruited participants from self-help groups involved in the intervention across ten locations in Burkina Faso. No particular requirements for selection of participants were imposed other than being involved in the study, since the RCT already had imposed eligibility criteria. The qualitative sample consisted of 75 study beneficiaries (53 female/22 male, representative for the gendered participation at the self-help groups) and 24 enumerators, who participated in 37 interviews and 13 focus groups.

The conversations were mostly semi or unstructured and particularly focused on experiences and perceptions of the SMS intervention and being surveyed. The interviews and focus groups lasted about one to one-and-a-half hours and were undertaken in different local languages with the help of translators (French, Mooré, Dioula). Interviews were all voice recorded with consent of the participants and extensive notes of the English translation were made during the interviews.

The wealth of data resulting from these interactions was systematically structured and analyzed. Firstly, it was digitized and transcribed on the basis of the recorded English translations and notes made during the encounters. Then, these transcriptions were coded in Microsoft Word and from there inductively organized into conceptual categories representing the identified themes emerging from the data. One category particularly standing out from the qualitative data was the perceived psychosocial support of the messages, which will be the focus of this article.

In what follows we present representative quotes indicating interview location, respondent gender and interview year. In order to protect participants, we kept all interactions completely anonymous since stigma and discrimination are considerable challenges for PLHIV in Burkina Faso.

3. Results

Neither the quantitative nor qualitative data showed clear evidence that the SMS reminders improved

retention and adherence to ARV therapy (Wagner et al., 2019). However, both did provide strong evidence that the messages were perceived as important psychosocial support improving the beneficiaries' subjective perception of life and wellbeing.

3.1. Impact of SMS reminders on ARV retention and adherence

The quantitative findings of the RCT showed no statistically significant impact of the SMS reminders on ARV retention and adherence at conventional significance levels of $\alpha \leq 10\%$. In both the intervention and control groups, 18% of the participants indicated at baseline that they occasionally forget to take their ARV medication; this figure fluctuates during the study (14% after 1 year, 16% after two years) but is similar for receivers and non-receivers of the SMS messages.[1] We measured retention as the number of health center appointments missed and loss to follow-up and found similarly no impact of the messages.

This does not imply that the SMS messages did not have any positive impact, the quantitative measures employed in the RCT might just not have captured it. Yet, the qualitative inquiry did not suggest a strong impact on retention and adherence, either. However, there is some evidence that the SMS reminders lead to better adherence when people are busy (Rodrigues et al., 2015) or traveling away from home:

> One Sunday when I was about to board a bus, the message came, so I went back home to get my medicine. (Banfora-F-2017)

There are many possible explanations why the RCT did not find any significant impact on ARV retention and adherence. First, according to the descriptive statistics the cohort participating in the trial already had high retention and adherence rates (Wagner et al., 2019). Moreover, those willing to voluntarily participate might already be more accepting of their HIV status and more committed to taking their medication than those who are in denial and refused to participate. Lastly, Burkina Faso has a fairly low HIV prevalence rate, 0,8% for adults (aged 15–49 years) in 2016 (UNAIDS, 2016). Therefore, our RCT cohort covers a fairly large proportion of HIV positive people who have been enrolled on ARVs for over 24 months.[2] The recognition that SMS messages might be most beneficial for newly enrolled ARV patients is an established finding (Rosen & Fox, 2011) and was explicitly shared in the interviews:

> Particularly for people who are new on medication, it is useful. (enumerator-Seguenega-M-2017)

3.2. Linguistic diversity and ICT literacy

The qualitative inquiry provided further insights that quantitative studies often overlook or not always consider, such as the role of limited language and/or literacy skills. RCTs assessing the impact of SMS messages on behavior tend to consider the client receiving an SMS as a black box with implicitly given characteristics such as the ability to read a text message and comprehend its meaning, and the ability to operate a phone and access the messages. Our qualitative inquiries demonstrate that in a resource-poor setting such as Burkina Faso these characteristics cannot be taken for granted and have a direct bearing on the outcomes of the broader study even if outcome measures are carefully chosen and randomization is perfectly applied.

With 71 different languages being used across the country (Simons & Fennig, 2018), the linguistic diversity in Burkina Faso made it difficult to design an SMS intervention that targeted all clients in a language in which they were competent reading (Kaplan, 2006). Many languages prevalent in the country are mainly used orally. Consequently, even if literate beneficiaries receive a message in their literary language, this does not necessarily imply that they are conversant in reading and understanding the message:

> Language is a problem. Some people know how to read French, but not their local language. (enumerator-Tenkodogo-F-2016).

Another limiting factor for SMS interventions to reach their full potential is that most beneficiaries completely lack the literacy skills to read a message in any language (Kaplan, 2006). One enumerator estimated that:

> [a]lmost 80–85% of the patients in the survey can't read. (enumerator-Pama-M-2017)

Those who lack literacy skills rely on others to read messages for them, but given the sensitive nature of the messages and stigma around HIV, this can be problematic (Georgette et al., 2016).

One way of overcoming the challenges of linguistic diversity, lack of literacy skills and sensitivity of the messages is by using pictorial messages (Sidney et al., 2012). We explicitly included pictorial messages employing basic ASCII codes. Yet, these messages had their own limitations. They were distorted on some phones and therefore incomprehensible despite extensive pre-testing on different types of phones. Interestingly, even distorted images seemed to still have the intended impact of reminding clients of their medication:

> When I receive a message, I know it is to remind me of taking the drugs, but I don't know the meaning of the picture. (Ouagadougou-F-2016)

Apart from the ability to comprehend a message, one of the biggest challenges that transpired was a lack of ICT literacy skills and inability of many beneficiaries to even access their inbox to open a SMS message:

> Most beneficiaries can't operate their phone and access the inbox, but many of them can read. (enumerator-Seguenega-M-2017)

3.3. Psychosocial impact of the SMS messages

Despite the challenges with language and ICT literacy, our qualitative study shows that the SMS messages did have a positive impact on beneficiaries. The following statement from one of them nicely summarizes the main areas of impact, namely as a timely reminder to take medication (functional), but also as an encouraging support (symbolic):

> We are happy when we receive the messages; it comes in time to remember us about our medication and it also encourages us. (Tenkodogo-F-2017)

The first qualitative inquiry in 2016 revealed that the SMS messages were perceived as important psychosocial support, even more than a medication reminder. We have strong evidence that the messages make people feel they are not alone and there is someone who cares about them. As a result of these findings, additional questions about the subjective perception that respondents had about their lives were included in follow-up quantitative survey rounds. The quantitative findings show that for beneficiaries receiving SMS messages the perception of wellbeing has become more positive compared to those in the control group. We used nine Likert-type measures of psychosocial wellbeing.[3] All except one measure show a positive effect (Table 1). The effect on self-assessed health is moderate (4.4% of a standard deviation). Yet, the effects associated with happiness are more than one tenth of a standard deviation. Faith in life is most positively affected. The average effect across outcomes is 7% reinforcing that the SMS positively affected psychosocial wellbeing (Wagner et al., 2019).[4]

Table 1. Average treatment effect for psychosocial outcomes.

Subjective health status	Self-assessed health status since last survey	Statement: Life is beautiful	Currently happy	Expects to be happy in future
−0.002	0.044**	0.047	0.130***	0.132***
(0.017)	(0.021)	(0.040)	(0.043)	(0.043)
Has faith in life	Not worried about the risk of falling ill	Does not feel alone	Considers forgiveness as important	**Average effect**
0.127*	0.075	0.031	0.014	**0.070*** **
(0.071)	(0.049)	(0.032)	(0.017)	**(0.026)**

Note: A seemingly unrelated regression is employed. The specification contains the following control variables: Health center fixed effects, time effects, gender (an individual being female is coded as 1, zero otherwise), age, dummy variable for being single, dummy variable for being married, dummy variable for being a member of the largest ethnicity (Mossi), dummy variable for being the household head, dummy variable for completed primary education, dummy variable for completed education at the level of secondary 1, dummy variable for completed education at the level of secondary 2, dummy variable for higher education, household size, dummy variable for living in an urban area, number of HIV group meetings attended. Coefficients associated with the control variables are not shown for the sake of brevity. Standard errors of the average effect account for correlation in the error term across outcome variables. ***/**/* indicates statistical significance at the 1/5/10% level.

The qualitative inquiry further reinforced this quantitative finding by highlighting that the SMS messages were perceived as an important psychological support, making people feel their lives matter. These findings should be understood within the context of Burkina Faso, where awareness and acceptance of HIV is relatively low and consequently stigmatization of PLHIV high, with many suffering in silence and feeling unsupported by their environment.

Expressions of respondents about the psychosocial support they experience from the SMS messages are manifold, here are just two exemplary ones:

> When I receive the message, it is a sign of love. (Fada-M-2017)

> The SMS have helped us a lot because you know you are not alone in this fight. I know there are some people caring about us. (Bobo-Dioulassou-F-2017)

Words that are clearly prominent in the expressions are "alone" and "love" pointing to how the messages make people feel less alone and more appreciated.

Although studies of SMS interventions have primarily focused on their impact on ARV retention and adherence, there are a few exceptions that have also covered the psychosocial impacts of SMS messages (Fairbanks et al., 2018; van der Kop et al., 2012; Ware et al., 2016) and they came to similar conclusions.

Fairbanks et al. (2018) observed in Kenya that the sense of feeling cared for mostly came from the knowledge that the sender had invested time to send a message rather than the message content per se. Similarly, our study reinforced that regardless of whether beneficiaries were able to open a message or decipher its functional meaning, the perceived support and symbolism of care was relayed and appreciated. In other words, it was particularly the knowledge that someone made an effort to send the message that made the difference:

When the message comes it makes me happy, because it tells me that my life is important for somebody. (Tenkodogo-F-2016)

4. Discussion

Our qualitative inquiry highlighted the strong impediment of limited literacy and ICT literacy skills on SMS interventions. Neither the ability to read a text message in a particular language and comprehend its meaning, nor the ability to operate a phone and access SMS messages can be taken for granted in many contexts. Such uncovered hurdles to the success of SMS interventions have not received enough attention until now and are easily overlooked when exclusively analyzing quantitative impacts. We highlight the value added of qualitative observation and conversation to discover such challenges.

As already argued by Hatcher and Bonell (2016), mHealth interventions involving SMS messages and related evaluations should become more open to techniques from social and behavioral sciences. Qualitative explorations of the mechanisms through which mHealth interventions work can serve as important complements to the quantitative outcomes of RCTs. The findings of this study reinforce the importance of such qualitative research to evaluate mHealth interventions. Qualitative research can identify impacts that would otherwise go unnoticed and thus helps to arrive at more refined interventions and outcome measures (Campbell et al., 2017; Ma et al., 2016).

Traditionally most SMS interventions for PLHIV have a functional nature, such as reminding clients of appointments, taking medication or for communicating information. This study demonstrates that beyond their functional role, SMS messages can have a perhaps even more impactful symbolic role in offering psychosocial support, particularly in countries where PLHIV face stigmatization and isolation. While we might conclude from a purely functional and medical perspective that SMS messages are not working to improve the conditions of PLHIV in developing countries, integrating psychosocial aspects in the analysis forces us to revise that conclusion and to widen the set of outcomes analyzed in relation to mHealth interventions. Beyond functional aspects it is high time to acknowledge psychosocial necessities in resource-poor settings. This warrants more research about SMS interventions, their symbolic connotations, and the psychosocial support they can provide.

Like any study, ours also had its limitations: First, some of the original meaning has likely gotten lost in the translations. Second, it was not always straightforward to classify which intervention group the respondents belonged to and whether they were able to open a message on their phone and to understand its functional message.

5. Conclusion

In this article we argue that beyond the functional role of improving ARV retention and adherence, SMS messages can also play important symbolic roles in offering psychosocial support to PLHIV and improving their perception of life. Furthermore, we highlight the importance of complementing quantitative evidence of mHealth interventions with qualitative assessments.

Notes

1. We have similar findings for the actual number of pills missed during the last week. There is a sustained reduction of roughly 0.1 pills missed per week between baseline and the follow up rounds and this equally applies for all study participants.
2. The average duration under ARV in our sample is about 43 months at baseline. Short-term patients who have been under ARV for less than 24 months at baseline only constitute about one third of the sample although we are aware that about 22.5% of patients on ARV treatment discontinue within the first 10 months, and 56% are lost to follow-up or death within the first two years of therapy (Fox & Rosen 2010; Rosen & Fox 2011).
3. These include subjective health, perception of life, happiness, faith, forgiveness, fear of falling ill, and the feeling of loneliness.
4. A detailed presentation of the employed estimation techniques and discussion of the results is presented in Wagner et al. (2019).

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Registration

The project has been official registered as trial. The trial reference N° is ISRCTN16558614.

Ethical approval

All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Local, ethical clearance was obtained from the Burkinabe national ethics committee on December 3, 2014 (Deliberation N° 2014-12-141).

Informed consent

Informed consent was obtained from all individual participants included in the study.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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Data availability statement

All relevant qualitative data used and/or analyzed during the current study are within the manuscript.

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