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Investigating community ownership of a text message programme to improve adherence to antiretroviral therapy and provider-client communication: a mixed methods research protocol

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ABSTRACT

Introduction: Mobile phone ownership and use are growing fastest in sub-Saharan Africa, and there is evidence that mobile phone text messages can be used successfully to significantly improve adherence to antiretroviral therapy and reduce treatment interruptions. However, the effects of many mobile health interventions are often reduced by human resource shortages within health facilities. Also, research projects generating evidence for health interventions in developing countries are most often conducted using external funding sources, with limited sustainability and adoption by local governments following completion of the projects. Strong community participation driven by active outreach programmes and mobilisation of community resources are the key to successful adoption and long-term sustainability of effective interventions. Our aim was to develop a framework for community ownership of a text messaging programme to improve adherence to antiretroviral therapy; improve communication between patients and doctors and act as a reminder for appointments.

Methods and analysis: We will use the exploratory sequential mixed methods approach. The first qualitative phase will entail focus group discussions with people living with HIV at the Yaoundé Central Hospital in Yaoundé, Cameroon (6–10 participants/group). The second quantitative phase will involve a cross-sectional survey (n=402). In this study, binary logistic regression techniques will be used to determine the factors associated with community readiness and acceptability of ownership. Data from both phases will be merged.

Ethics and dissemination: This study has been approved by the Yaoundé Central Hospital Institutional Review Board. The results of this paper will be disseminated as peer-reviewed publications at conferences and as part of a doctoral thesis.

ARTICLE SUMMARY

Article focus

- Text messaging to improve adherence to antiretroviral therapy and communication between patients and providers.
- Community ownership of supportive programmes.

Key messages

- Benefits and strengths of community ownership of programmes.
- Community readiness to own supportive programmes.

Strengths and limitations of this study

- Robust study design based on mixed methods.
- Components of research unfold during the study and may affect initial planning.

INTRODUCTION

At the end of 2010, approximately 34 million people were living with HIV. Close to 70% of them live in sub-Saharan Africa, even though this region represents only 12% of the world's population.[1] However, there has been a steady decrease in AIDS-related deaths as free antiretroviral therapy (ART) has become more easily available in recent years.[1] While governments and health systems in sub-Saharan Africa continue to invest in providing free access to ART, their efforts are hampered by health system weaknesses that prevent a continuous supply of ART and suboptimal levels of adherence.[2] Relatively high levels of adherence are necessary to achieve the goals of ART such as viral suppression and immune reconstitution.[3] High levels of adherence will therefore lead to reduced morbidity and mortality in people living with HIV (PLHIV), as well as minimal development of resistant strains.[3–6]

In recent years, WHO has endorsed the use of cheap and effective technologies to improve health outcomes in low resource settings,[7] and there is emerging evidence on the

role that a mobile phone text message—short message service (SMS)—can play in the management of HIV. Text messages (sending brief electronic messages to a mobile phone) can improve adherence to ART, reduce treatment interruptions and reduce viral load.[8 9] They are useful as appointment reminders and can improve communication between health personnel and patients.[10] Patients who receive them also report high levels of satisfaction.[8 11] These advantages, coupled with the rapid growth of mobile phone ownership and use in Africa,[12] make SMS an important tool to improve care in PLHIV. The research on mobile phone text messaging is somewhat nuanced by the complexity of the intervention. It is unclear how factors such as community phone ownership, content of the message, timing of the message, nature of the message (two way or one way) or source of the message (peers or hospital based) can influence the efficacy of mobile phone text messaging.[13] There is a need for further research which responds to many of these unanswered questions.[14]

Cameroon has the highest rate of HIV in West and Central Africa, with a 5.3% prevalence in the adult population,[1] poor adherence rates and serious health system weaknesses that pose a threat to the management of HIV.[15] Recent reports suggest that PLHIV would like to receive text messages.[16] The communication channels opened by text messaging also serve as a platform to identify key individual and health system weaknesses that diminish the quality of care and reduce the overall effects of text messaging. For example, human resource shortages and medication stock-outs can limit the potential of adherence-enhancing mHealth interventions.[17] Cameroon also has a high mobile phone penetration rate, with 52 mobile cellular subscriptions per 100 people in 2012.[18] Mobile text messaging and phone calls are mostly affordable, and can be as little as 25FRS CFA ($0.05) per message and 75 FRS CFA ($0.15) per min, respectively.

Most successful healthcare programmes are characterised by strong community participation.[19] Community participation has played a major role in the control of the HIV epidemic.[20] It should be encouraged because the programmes will have a better outreach; community contributions (money, manpower and material) can be mobilised and, more importantly, communities have a right to take part in the decisions that affect their lives.[21] Community participation (in HIV programmes) has often been limited to the less technical aspects. Apart from providing an organised front to defend the interests of PLHIV, they also take part in providing care, research, peer education and role modelling.[19] For newer interventions such as text messaging, which is more structured and technologically oriented, the potential of community ownership needs to be explored.

We expect to observe an overall acceptability and readiness to own a text messaging programme but a lack of skills in how to manage one. Our findings will be used to inform initiatives aimed at upscaling the use of mobile phone technology to improve adherence to ART and other chronic diseases in resource-limited settings and how best community members can be involved in the process. At the end of the project, we will develop a framework for transferring technology into the hands of the community and initiating a sustainable community-led project. We will build upon previous research using weekly motivational two-way text messaging to improve adherence to ART.[16 17 22] The following groups of people will benefit from this project: PLHIV in resource-limited areas; people living with other chronic diseases who can benefit from enhanced communication with the health system and health workers and community health workers who provide care for PLHIV.

The objective of this project was to determine how to set up a community-owned text messaging programme by determining the readiness and acceptability of ownership among PLHIV at the Yaoundé Central Hospital in Cameroon. We will proceed by collecting, analysing and comparing qualitative and quantitative data. The findings from this mixed methods study will be used to establish a framework for community ownership.

For the purposes of this paper, we define community ownership as a process in which the community members design, manage and reap benefits from a project. We also acknowledge that, in the course of our research, our definition may change. All references to 'community' are made in regard to PLHIV in Yaoundé, Cameroon.

The following research questions will guide the conduct of this study:

Qualitative research questions

- Will PLHIV in Yaoundé, Cameroon accept community ownership of a text messaging programme?
- How ready is the community of PLHIV in Yaoundé, Cameroon to take ownership of a text messaging programme?

Quantitative research questions

- What factors are associated with acceptability and readiness of community ownership of a text messaging programme among PLHIV in Yaoundé, Cameroon?
- What proportions of PLHIV will accept and be ready to run a community owned text messaging programme?

Mixed methods research questions

- Are the themes related to the opportunities and challenges involved in the community ownership of a text message project among PLHIV in Yaoundé, Cameroon generalisable to a larger sample of PLHIV in Yaoundé?
- In what ways do the qualitative and quantitative strands converge?

METHODS AND ANALYSIS

Study design

We will use an exploratory sequential design.[23] The exploratory sequential design is a two-phase design that starts with an initial qualitative phase, followed by a quantitative phase. In the qualitative phase, we will

identify individuals with experience in community ownership for in-depth interviews. The members of the associations of PLHIV and others with community level experience will be selected from the Yaoundé Central Hospital. This relatively small number of individuals will be interviewed to identify themes, ideas and concepts that will be used to guide the second quantitative phase. Data collected from the qualitative phase will be converted into variables that will be used on a much larger sample in order to generalise the findings to all the PLHIV in Yaoundé. This sample will be taken from the Yaoundé Central Hospital. See figure 1 for details on the procedures and products of the different strands of the study.

The exploratory sequential design is preferred for this study because of the following reasons. First, the separation of the qualitative and quantitative phases makes it easier for our multidisciplinary team to work together, and the separate methods and findings can be described easier. The anthropologists and sociologists will be responsible for data collection and analysis in the qualitative strand. The themes that emerge from their analysis will be converted into variables and built into a questionnaire by both groups. Second, the use of both qualitative and quantitative methods makes it more acceptable to researchers from both domains. Even though the overarching goal is to merge and compare qualitative and quantitative data, the findings from each domain still hold merit and can be interpreted separately. Third, it will be used to develop a measurement instrument. The data collection tool for the quantitative phase will be developed from the qualitative strand. Items to measure community readiness and acceptability of ownership will be framed based on the responses in the qualitative strand. Lastly, it is a good design for generalising qualitative research findings.[23]

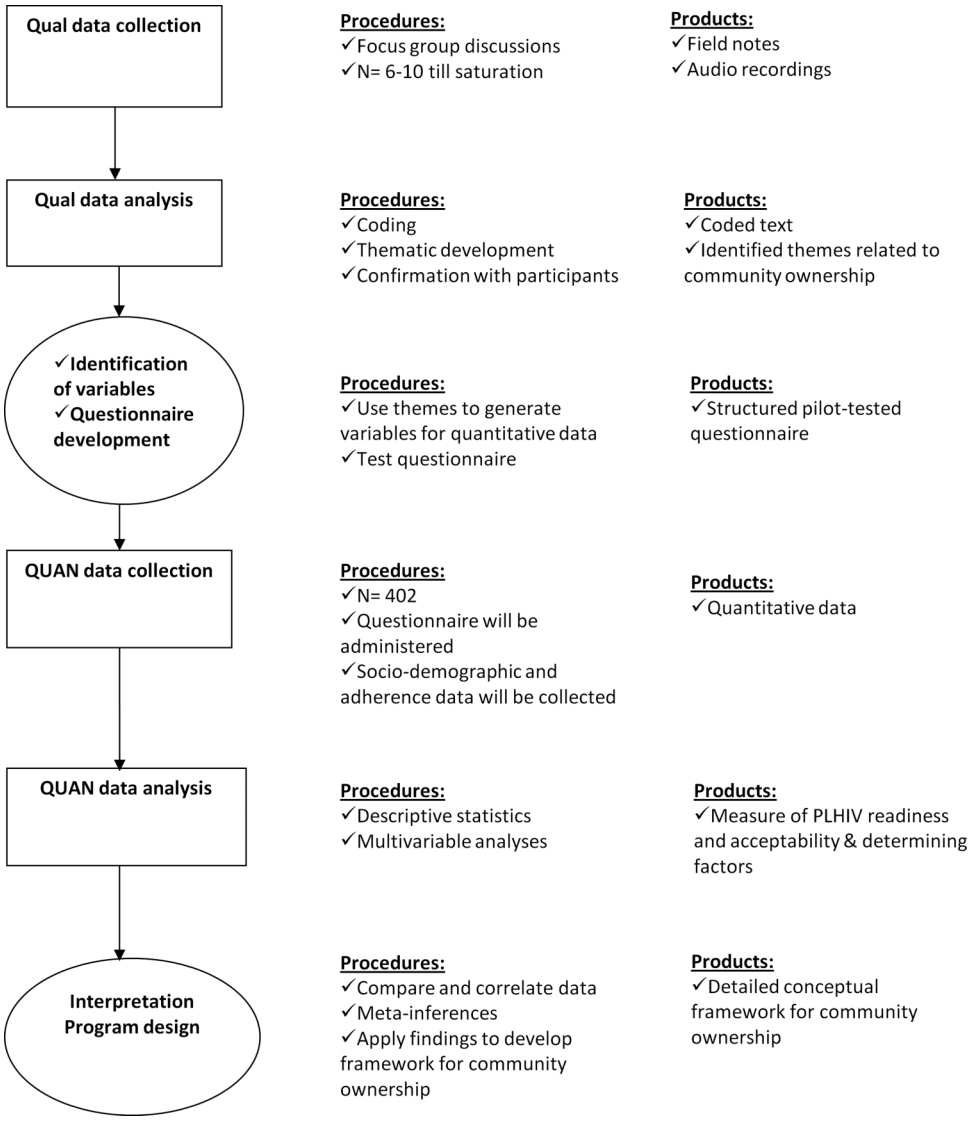

Figure 1 Overview of procedures and products of different strands.

On the other hand, organising two separate strategies for data collection will be time-consuming. Separate sampling techniques have to be applied for both strands: the sample of PLHIV for the qualitative strand will be selected purposefully based on their experience with community activities, while the quantitative strand will be probabilistic. Details on the quantitative phase will not be available at the time of Institutional Review Board (IRB) approval.[23]

Rationale for design

Despite these characteristics, the exploratory sequential design is the method of choice when the variables that may come into play are unknown and there is no guiding framework.[23] This design has been used for complex research projects like mental-health assessment in older adults,[24] healthcare students' educational expectations,[25] health system research,[26] alcohol use among people with liver disease and tobacco use.[27 28] Text messaging interventions are relatively new and, to the best of our knowledge, community ownership has not been investigated for a text messaging programme.

In recent years, mixed methods research has emerged as a separate research paradigm—a seamless blend of both qualitative and quantitative research methods. Even though it was not initially used on the basis of its merits,[29] it is progressively gaining ground and acknowledgement in health research.[30] It offers a 'powerful third paradigm choice that often will provide the most informative, complete, balanced and useful research results'.[31] In order to explore how PLHIV perceive text messages and the eventuality of owning and managing a text message project, we are going to use mixed methods to identify the common themes that arise and to subsequently generalise these findings to a larger sample. The complex nature of the research question warrants the use of mixed methods to generate a rich and complementary body of evidence to initiate a community-owned programme. The methods used to initiate community ownership need to be well spelt out and should originate from a robust and expanded body of evidence, which cannot be achieved by only qualitative or quantitative designs. We therefore seek complementarity, initiation and expansion.[32] Figure 1 is a detailed flow diagram of the study procedures.

Study setting

Yaoundé is the capital city of Cameroon, a central African low-income country. The adult prevalence of HIV in Cameroon is 5.3%.[1] The Yaoundé Central hospital houses the largest HIV clinic in the country. It has a capacity of 381 beds and is staffed by 95 doctors and 270 nurses.[33] In the HIV clinics, there are 6500 regular clients and approximately 40 new cases every week. This hospital is one of the pioneer centres for HIV research in Cameroon, and offers a great potential for recruitment and data collection.

Sampling

The overall purpose of this sample is to address the research question in a generalisable way, using both purposeful and probabilistic techniques that ensure data collection in breadth and depth.[34] This is a useful combination of sampling strategies that helps to generate items and variables for questionnaires, as well as to generate hypotheses.[35]

Qualitative strand

A purposeful sampling strategy will be used to determine who will participate in the qualitative strand. PLHIV with relevant experience related to community activities shall be selected based on any of the following criteria:

- They should belong to an association of PLHIV (leaders or members)
- They are community health workers
- They are willing to participate in a community owned text messaging programme.

Focus groups of 6–10 participants will be constituted consecutively until no new ideas emerge. We will focus on depth of information and qualitative data obtained from the cases.[34] PLHIV will be recruited from the waiting rooms of the Yaoundé Central Hospital HIV clinic. They will be approached by the plain-clothed non-staff moderator to determine their interest in taking part in a group discussion and if they meet the prespecified criteria. This is typical case sampling, aimed at identifying representative cases.[34] Consenting participants will be shown to a quiet nearby room prepared for the focus groups. Notes will be taken in writing by a note-taker using an audio recorder. No financial incentives shall be offered, but the waiting times at the clinic will be reduced (in collaboration with the attending physician) after participation. The protocol will be presented to the hospital staff and the procedures for reducing waiting times will be discussed.

Quantitative strand

All PLHIV attending the Yaoundé Central Hospital HIV clinic during the study period will be eligible for enrolment, provided they are aged 21 years or more and give consent. Sample size will be determined using the formula proposed by Cochran for surveys.[36] Assuming an α level of 0.05, a 5% margin of error (for categorical data), an SD of 0.5 (for a primary outcome—community readiness measured as a binary variable) in a population of 6500 PLHIV at the Yaoundé Central Hospital, we arrived at a sample of 402, taking into account a 'refusal to participate rate' of 10%—documented in another text messaging study among PLHIV in this clinic.[22] This sample is meant to be representative of the entire population of PLHIV attending the Yaoundé Central Hospital HIV clinic. We acknowledge considerable uncertainty in the variables that will be used in the quantitative phase of the study, but opt for a binary outcome in order to achieve a larger sample size.

Data collection

Prior to data collection, we will organise brief training sessions for the data collectors in the qualitative and quantitative strands. The purpose of this training will be to familiarise them with their working instruments and to standardise the procedure for participant invitation, obtaining consent and data collection.

Qualitative strand

Focus group discussions will be conducted using a pre-established interview guide (see box 1). It will contain basic sociodemographic information, a description of participant involvement in community activities (eligibility criteria fulfilled) and specific themes related to the phenomenon under study. An experienced moderator and note-taker will invite, request consent and enrol participants, in that order. For each session, the data collectors will be dressed in plain clothes and use a separate room free from distractions for the focus groups. The note-taker will be responsible for noting the non-verbal cues emanating from the participants and operating the audio recorder. The audio recorder will be tested in a mock session for clarity of recordings. Participants will be encouraged to speak in tones that can be recorded. The moderator will be responsible for keeping the discussions in line with the guide while exploring interesting dimensions that arise from the discussions. More importantly, the moderator will be responsible for gaining the trust of the participants and encouraging participation from all. The data collected from this strand will be used to formulate questions that best characterise acceptability and readiness.

Box 1: Focus group discussion guide

Focus Group Discussion Guide

Preparatory steps

- Does the participant meet the criteria?
- Have they given written/verbal consent?
- Collect sociodemographic data (age, gender); note time; number of participants

On existing community activities

- What community initiatives/activities/organisations exist for people living with HIV?
- What community activity do you participate in?
- How do you benefit from these activities?

On a text messaging project

- The purpose of this project is to improve adherence to HIV medication and to foster communication with health workers. What other goals do you think can be achieved through text messaging?
- Do you think you (as a community) are ready to run a text message project?
- Would you accept running or taking part in a text messaging project?
- What are the strengths of the community that can be used to run such a project?
- What are the weaknesses of the community that can hinder the project?
- What roles can the community play in such a project?

On feasibility

- How do you think the project should be financed?
- Are you willing to pay to receive a text message?
- Do you think the community is ready to run such a project?
- Would you like health workers to be involved in the management of such a project?

Are there any other issues that the participants would like to discuss?

Quantitative strand

In the quantitative strand, patients will be approached at the clinic in various locations: the outpatient department, the pharmacy and the laboratory. Four interviewers will concurrently conduct the survey to maximise recruitment. Recruitment and data collection will continue until the required sample is achieved. The trained interviewers will employ the pretested questionnaire developed from the qualitative strand and existing frameworks,[37] to collect data from all eligible participants. The data collection tool will be developed based on findings from the qualitative strand. It will contain basic sociodemographic data, adherence data, phone ownership and autonomy, information related to participation in community activities and other variables generated from the themes identified in the qualitative strand. The questions will be closed-ended with simple 'yes or no' responses. Complex items like readiness may be presented on a seven-point Likert scale.[38]

DATA ANALYSES

Qualitative data analysis

We will conduct a thematic analysis. Qualitative data will be analysed by transcribing into text. Codes will be generated by looking for repetitions in the text.[39] These repetitions (codes) will be grouped based on their similarity into categories and the overarching themes will be identified. We will use a number of preset categories to guide the process, but emergent categories will also be noted.[40] For example, preset categories like lack of familiarity with text messaging or lack of skills to run a text messaging project shall be identified. This coding will be performed by multiple researchers to determine if coders agree on the themes assigned to a segment of text. The themes will be displayed visually in a conceptual model, showing how the themes are linked to each other.[39]

Quantitative analyses

Quantitative data will be analysed using using Statistical Package for Social Sciences (SPSS) V.20.0 (SPSS, Inc, 2009, Chicago, Illinois, USA). Statistical significance will be set at α=0.05. Adjusted OR, 95% CI and p values will be presented. We will explore community readiness for ownership of a text messaging project as the binary

dependent variable in a logistic regression analysis. Potential independent variables include: sociodemographics, mobile phone ownership, familiarity with text messaging, level of adherence to medication, need for additional support and level of comfort with community management.

Data integration

Owing to the sequential design of the study, the qualitative and quantitative components will be analysed separately in a sequential qualitative-quantitative analysis. This is the method of choice when the analysis of one strand is necessary to inform the conduct of the next.[41] Inferences will be drawn from both strands and across strands. These 'meta-inferences' will be used to draw conclusions.[41] The qualitative and quantitative strands will be merged in a matrix to display how they are related to each other. Table 1 is a sample of how both strands of data will be put together, linking themes to thematic variables and statistical analyses. This correlation matrix will help to identify relationships between themes and thematic variables (statistical triangulation) and strong thematic variables (variables that occur frequently). It will also show how the quantitative data expand on the qualitative findings. These techniques of data integration have been used previously and have been described in detail.[42]

In the event that the qualitative and quantitative strands do not converge, the data will be handled in one of four ways: first, the data may be reanalysed through the lens of a different theoretical framework (reconciliation); second, the divergence may introduce new perspectives that generate new research questions (initiation); third, irreconcilable differences may be viewed as best-case and worst-case scenarios (bracketing) and finally, a complete reappraisal of the body of evidence in terms of completeness and validity (exclusion).[43]

In the qualitative strand, data will be analysed, reduced, displayed and transformed into quantitative variables. In the quantitative strand, data will be analysed, reduced and displayed. At the final stage (data mixing), data will be displayed, correlated and integrated.[44] Figure 2 demonstrates the steps we will follow for analysis and integration of data.

Validation checks and dealing with sources of bias

We will draw from published criteria for acritical appraisal of mixed-methods studies to validate our research,[45] using items identified by as a cross-paradigm framework for trustworthiness and rigour.[46]

Internal validity

In the qualitative strand, internal validation (credibility) will be performed by using an audio recording device to ensure accuracy; member-checking of collected data for general accuracy and accuracy of quotes and comparing codes among several coders.[23 47] In the quantitative strand, we will limit information bias by pilot testing the questionnaire for clarity (participants understand the questions as they were meant to be understood) and using non-staff interviewers. We will also adjust for potential confounding during analysis. For example, participants who already participate in some community activities may be more likely to report readiness to participate in a text message programme. We will try to capture this in our analyses.

Data will be collected from PLHIV at the Yaoundé Central Hospital, the population to whom we want to generalise our findings, so selection bias is unlikely to be significant. However, we will collect sociodemographic data from the participants who refuse to participate to see if they differ significantly from those who do. Selection bias can be avoided at the design and analytical stages of a project.[48] Data from the qualitative phase may help to identify variables that are associated with willingness to participate in the survey. These variables can be used to restrict participation or be measured accurately and used for adjusted analyses.[48]

External validity

The extent to which our findings can be generalised to the rest of the population of PLHIV at the Yaoundé Central hospital will be verified by using a large (predetermined) sample, comparing the sociodemographics of our sample to that of the parent population and by investigating any refusals to participate. In this way, we will be able to make statistical (external) generalisations.[49] We also state the purpose of our study, the setting, the data collection procedures and the outcomes we are measuring: community readiness and acceptability of ownership of a text messaging programme among PLHIV at the Yaoundé Central Hospital.

Consistency

We will apply standardised qualitative (focus groups) and quantitative (survey) techniques (described above)

Table 1 Mixed methods data matrix

Strand					
Qualitative		**Quantitative**			
Themes identified	Number of times mentioned n (%)	Thematic variable	Representativeness N (%)	Influence on community readiness	
				Univariate (OR, 95% CI; p)	Multivariable (aOR, 95% CI; p)

aOR, adjusted OR.

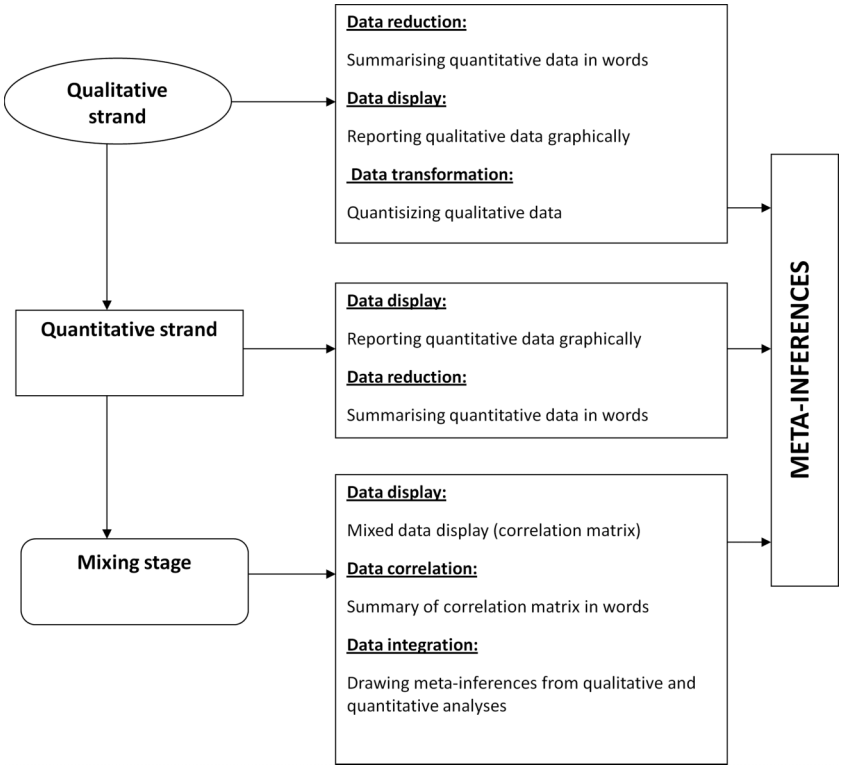

Figure 2 Steps in data analysis and integration.

to ensure consistent results. A journal of study activities will be kept so that the study procedures can be followed and replicated. Our data collection tools and techniques will be externally audited by the Cameroon National Ethics Committee.[50]

Feasibility

This study will benefit from a number of characteristics that make it feasible. First, the study is situated in a very active HIV centre with a large potential for recruitment in both strands of the study. Second, we have a pre-existing multidisciplinary team with collective experience in other qualitative and quantitative research projects. This team is made up of public-health physicians, clinicians, sociologists, anthropologists, health economists and public-health administrators. Third, surveys in this setting are relatively inexpensive to conduct.[51] Finally, our host centre, the Centre for the Development of Best Practices in Health, has the infrastructure and experience for a research project of this scale and can provide administrative, logistic and communication support.

ETHICS AND DISSEMINATION

Ethics

Ethics approval has been obtained from the IRB of the Yaoundé Central Hospital (N°288L/MINSANTE/SG/DHCY/Stages on the 16 May 2013).

Dissemination plan for results

We plan to disseminate our results at public presentations to stakeholders in Cameroon (Ministry of Health Staff, journalists, PLHIV, clinicians, community-health workers, social workers, mobile communication operators); to publish the manuscript; and publicly present and defend our findings as part of a doctoral thesis. As part of the ethics approval agreement, a copy of this thesis will be submitted to the Yaoundé Central Hospital IRB.

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Competing interests None.

Ethics approval Yaoundé Central Hospital Institutional Review Board.

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