

Using a Formative Research Rapid Assessment Method to Support the Development of a HIV/AIDS Antiretroviral Therapy Communication Campaign in Kenya

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Introduction

HIV antiretroviral therapy (ART) is a combination of drugs used in the management of HIV disease. The drugs are not a cure for HIV, but can help in managing the disease and slowing its progression, thus dramatically improving the quality of life of the patient [1]. In 2003, the WHO identified that around 6 million people were in immediate need of life-sustaining ART in the developing world.

Researchers have suggested that it is those groups of individuals who lack the knowledge, skills and resources to protect themselves and their partners from HIV infection, which are most vulnerable to the disease [2]. Many of these most at-risk population groups have been found to: (i) have poor access to information and services; (ii) be more likely to engage in activities that place them at risk of HIV infection; and (iii) have fewer resources to manage the impact of HIV/AIDS in their lives. This stresses the importance of effective communication, including informed decisions on appropriate messages and communication channels, in supporting protective behavioural responses to HIV/AIDS.

However, before designing and implementing health communication campaigns, public health authorities need to have a deep understanding of their priority audience(s). In a marketing context, this is achieved through market segmentation and audience profiling, as a fundamental precursor to communication campaign development. In this public health context, there is a parallel and exigent need to identify the needs and wants of patient population audience segments that are aware of and may be in need of ART, in order to support urgent treatment and care initiatives.

Behavior Change Communication to support ART

A number of agencies and individuals have noted the need for expanded communication programs to support the roll-out of ART [3,4]. The WHO also identified the need for an effective behaviour change communication strategy for ART in order to: provide information and support to different target groups; answer queries; prevent misinformation regarding antiretroviral therapy; provide information on the location of services and emphasise preventive measures [4].

The potential for social marketing to provide a means of addressing the HIV/AIDS epidemic has been widely acknowledged [5,6]. Also noted is the greater utilisation of broad-based 'population health approaches' to counter the increasing number of epidemics facing developing countries. This has endangered the need for new technological developments in the formative stages of program planning [7], and raising questions on the notion of 'one-shoe-fits-all' mass communication, messaging approaches [8]. This may be particularly true with clinically based programs involving life-saving drugs, with the critical need for more culturally nuanced HIV/AIDS communication programs which address needs and wants of specific target audiences. Against this backdrop, audience segmentation principles can be employed to assist in the development of tailored messages and selection of appropriate communication channels, to reach high-risk groups suffering with HIV or AIDS related illnesses.

The aim of this study was to identify specific target audiences for an

ART communication campaign and gauge the attitudes and opinions of this audience segment in relation to ART. The context for the study was Kenya, as a result of the proposed roll-out of the ART program in the country due to Kenya's priority status. The Kenyan government and donor community supported the need to conduct a national ART communication strategy as part of the clinical program roll-out. The study approach was endorsed by the members of the Kenya National ARV Taskforce in August 2004, with the Monash University Standing Committee on Ethics in Research involving Humans (SCERH), approving the study design in September 2004–Project Number–2004/982.

Methods

The formative research stage comprised of an HIV/AIDS rapid assessment methodology involving consultations with stakeholders and discussions with program beneficiaries in Kenya. The strengths of utilising qualitative approaches are that they can generate a richness of data, where the study participants' perspectives and experiences are the goals [9]. Qualitative methods, including: observational research, case study approaches, semi-structured and in-depth interviews, narratives and personal diaries, are generally seen as being underutilised in ART research [10]. However, these methodological approaches to data collection can act as powerful tools for understanding culturally-specific influences. Without these activities, the imposition of treatment models on their own which are inconsistent with local values and practices is likely to produce irrelevant or ineffective interventions [11].

Researchers have utilised qualitative research techniques to explore patient social, economic and structural barriers to seeking and adhering to highly active antiretroviral therapy in sub-Saharan Africa [10]. This has been done to assist in the development of more effective interventions to ensure patient adherence to the therapy [10,11]. One specific approach growing in popularity in low-and middle-income countries is 'rapid assessment and response (RAR)'. The approach is seen as a cost-effective, pragmatic method of public health research, used primarily in the resource-constrained settings of developing and transitional countries [12,13].

The formative research involved discussions with 72 participants. This included 23 key informants—doctors, ARV Taskforce and Ministry

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of Health representatives and staff from non-governmental organisations (NGOs) community based organisations (CBOs) and faith based organisations (FBOs). Program beneficiaries comprised of a convenience sample, 49 participants from patient populations comprising—people living with HIV/AIDS (PLWHA) and their family members.

A sampling approach was developed following consultation with ARV Taskforce representatives. This included sampling of PLWHA patient populations in three geographic locations across Kenya where the ART program was being scaled up and HIV prevalence was high: Nairobi, Central Province and Nyanza Province. Given the high levels of potential stigma in selection of HIV positive respondents from the general population, HIV/AIDS support NGOs working with PLWHAs, were identified for recruitment of study participants. A screening instrument was provided to support this activity. The approach ensured that issues of participant vulnerable health conditions and the need to maintain patient confidentiality were considered by NGO support staff recruiting participants from health facilities located within their jurisdictions.

Final participants included male and female HIV seropositive; slum dwellers, commercial sex workers, transport workers and youth. Gender, age, socio-economic and health factors (T-cell counts) were identified during the initial screening. The approach provided a range of participants, family members and carers (where patient conditions, were a cause of concern) aged 16-44 years, of varying ethnicity, socio-economic status, occupational status and HIV/AIDS clinical diagnosis, from the three geographically dispersed Provinces located in the West, Central and Coast areas of Kenya.

Data collection

Consultations with key informants were conducted through semi-structured interviews (SSIs), as these are other commonly accepted qualitative research approaches [14]. This individualised approach was chosen due to the professional status and often busy schedules of a number of the clinical informants. SSI discussion agenda was developed, following a literature review and desk research. Questions included: clinical providers prescribing of ART, their perceptions of patient understanding on how to take ART, and how they could improve patient adherence to ARV treatment regimens, what they currently do to support and counsel PLWHAs who are taking ART, and three main barriers and potential benefits patients may perceive as important to ART adherence. Information was also elicited on anticipated target audiences for the communication campaign and specific ART communication support needs required by clinical providers. Preliminary data-analysis of SSIs provided important insights for tailoring of the focus group discussion agenda topics.

Formative research with program beneficiaries was conducted through focus group discussions (FGDs), as this approach has been found to encourage participation from people who may be reluctant to be interviewed on their own or who feel they have nothing to say [15]. FGDs have also been shown to have advantages for researchers in the field of health and medicine, as they do not discriminate against people who cannot read or write [15]. Due to the precarious health conditions of a number of participants and their need to access health services from the NGOs often on a daily basis, for ethical reasons, mixed groups were decided upon. To ensure free flow of information, NGO staff was trained as moderators, and also responsible for getting signed clearances from participants involved in the research.

Discussion agenda, emanating from the SSI findings with stakeholders, ensured a consistent line of investigation across all geographic groupings, as well as comprehensive exploration of key

themes. Questioning related to respondent knowledge, attitudes and beliefs toward HIV/AIDS and ART [16]. Given the literacy issues with patient populations, translation and back-translation of instruments was conducted by staff from NGOs to ensure semantic, conceptual and normative equivalence of concepts, items and scales [17]. Groups were moderated in a mix of English, Kiswahili and Luo languages, in keeping with the local vernaculars.

Each focus group comprised of 8-10 participants with 2 focus groups conducted in each of the 3 Provincial locations. Participants received a small gratuity (500-1500 Kenya Shillings) to cover personal travel expenses. To facilitate participant involvement and relaxed group dynamics, given the stigmatising nature of HIV infection, interviews were conducted within NGO offices, to which a number of program beneficiaries frequently visited.

The FGDs warm-up sessions were used to identify any stigmatising attitudes to HIV/AIDS patients, in line with other formative research study recommendations [18]. A number of communication needs were also investigated during the FGDs, such as participant trusted information sources, knowledge of treatment partner networks and community ART information needs. Other information elicited concerned program beneficiary knowledge, about ART, and their perceived attitudes and perceptions toward the therapy, and perceptions on the quality of care. As some patients had already embarked on the therapy, additional questioning related to ART uptake, treatment and adherence issues.

Group discussions lasted, on average, two hours. A supplementary questionnaire with 5 point Likert scales and 6 items related to ART was provided to participants following completion of the main discussion. This allowed participants to rate the importance of key issues related to the therapy. Moderators and other NGO staff provided support to participants with literacy difficulties, to complete the forms. The self-completion forms provided respondents with an added degree of confidentiality, given the potential predisposition toward a unified group view or the tendency to lead the group by more vocal and dominant participants [19].

As there were high levels of stigma identified toward PLWHAs, on-site summaries were seen as most effective in synthesising themes across all groups. Notes were compiled in Word format, directly onto laptops by note-takers working closely with interpreters during each session. Notes were compiled in a question-by-question format to capture what individuals had to say in regard to each topic theme. On-site summaries were supplemented through dialogue between the moderators and translators immediately, following discussion sessions. This assisted in clarifying any potentially ambiguous themes.

Analysis of the data was carried out in two iterative stages: individual responses (in the case of SSIs), and within-group (in the case of FGDs), in order to explore cross-case patterns based on grounded theory [20]. Grounded theory has been found to provide a systematic way of examining qualitative data from the perspective of those who are actually experiencing the phenomena [21]. The first stage of analysis focussed within-cases and involved writing up key issues emanating from stakeholders and beneficiary groups. Summary memos on each case's approach were compiled for both groups, following which, cross-case analysis took place. Cross-case analysis was the next stage of the analytical process. This involved the use of open, axial and selective coding to identify, categorise and describe phenomena from the transcripts. Axial and selective coding was designed to explore the inherent categories and properties (codes), in order to see how they related to each other. Selective coding was utilised by choosing one core category and relating all the other categories to that core category.

This provided for the identification and exploration of specific themes and core concepts. Triangulation of the data was conducted to yield patterns and common themes across stakeholder and beneficiary groups, as well as compare qualitative and quantitative (questionnaire responses) feedback and identify any gaps through the comparative categorical analysis [22]. The approach allowed for the extrapolation of core categories and a number of specific themes to illuminate the study [23].

Results

A number of key themes were identified from the analysis and expressed, in the context of a communication program, as core categories of a 'Barrier' or 'Benefit' to ART [23]. Barriers to ART subsumed eleven themes. Comments by respondents referring directly to each theme were quantified to provide frequencies based on participant's identification of these potential ART barriers. The predominant themes emanating from the barrier analysis, as well as indicative quotes from respondents related to the themes are provided in Table 1.

Cost was the most frequently cited perceived barrier to ART uptake and adherence (65%) identified by participants. Other perceived barriers to ART included: side effects (47%); adherence to the medication and pill burden (31%), and lack of information and knowledge about ARVs (29%). A number of other issues relating to: access to the drugs (18%), long term commitment to the program (18%), myths and misconceptions about ART (16%), food security (14%), quality of counselling (10%), stigma (8%), and denial (2%)—which leads to lack of patient disclosure to partner, family or other community members—were also identified as potential barriers to ART uptake.

The second category related to the benefits associated with ART.

A total of eight themes emerged under this category. Indicative quotes associated with each of these themes are outlined in Table 2. The most frequently cited perceived benefit of ART identified was: strength, better health and quality of life (42%). A number of other benefits also ranked highly with participants, including: reduction in opportunistic infections (37%); reduction in viral load (37%); and good counselling and advocacy (35%). A number of other benefits relating to access, availability and cost (24%), and quality of life issues, such as: being more productive (27%), improved appearance 16% (reduces stigma), as well as fixed dose treatments (6%), were also seen as important benefits of ART.

Following completion of the formative research study, the qualitative data results were amalgamated with the desk review on existing HIV/AIDS and ART knowledge, attitude and behaviour studies to provide important insights into message designs, communication channels and strategic approaches for an ART communication campaign and subsequent outcome evaluation.

Discussion

Given the critical nature of ART to improved health outcomes, the lack of consideration of formative research—including message pretesting—to inform the communication strategy design, can have dire implications for effective HIV prevention, treatment and care programs in developing country contexts. For these reasons, the greater utilisation of formative research approaches to support behavioural change for HIV/AIDS clinical services delivery is highly recommended.

Formative research, using qualitative approaches such as RAR can provide insights into specific barriers and benefits to patient adoption of services or adherence to life-prolonging medications. Additionally, the approaches provide opportunities for communications researchers to

Barriers to ART	Program beneficiaries/Stakeholder feedback
Cost 65%	"They are not affordable—Ksh8000 for all these tests, before you even get on ARVs—then Ksh6000 per month for the ARVs!" PLWHA—Central
Side effects 47%	"I tried them and then I left because of the side effects." PLWHA—Central "Toxicities of the drugs can be extreme – which requires proper follow-up and support." PLWHA Advocacy NGO stakeholder—Nairobi
Adherence/pill burden 31%	"The multiple drug therapies are a barrier as the pill burden is extreme." Women's NGO stakeholder-Central "The side effects mean you have to go and buy other drugs." PLWHA—Central
Lack of knowledge about ARVs 29%	"To those who don't know about them, they may not use them because they don't have information." PLWHA beneficiary—Nyanza
Access and availability to ARVs 18%	"If the clients are started on the regimens, then after some time the drugs are out of stock." FBO stakeholder-Maragwa "You can get free drugs from MSF but they are already too busy with other patients." NGO stakeholder—Central
Long-term commitment 18%	"It's sometimes stressing to include a handful of drugs on your menu for a lifetime." PLWHA beneficiary—Kisumu
Myths and misconceptions 16%	"When one starts, they say they die within 1st-3rd month of starting, which is not true." PLWHA beneficiary—Thika
Lack of food 14%	"You also need food and we can't afford it." PLWHA beneficiary—Central "Nutrition support is also a barrier especially during drought times as good nutrition is needed for the drugs to work." PLWHA Advocacy NGO stakeholder—Nairobi
Poor counselling or service delivery 10%	"The nurses are rude." PLWHA Women's NGO stakeholder-Central "There are negative attitudes of hospital staffs towards PLWHA." CBO stakeholder—Nyanza
Stigma 8%	"What kills us is the belief that when you are HIV+ you are dead." PLWHA NGO stakeholder—Central
Denial 2%	"Lack of disclosure is an issue." Clinician stakeholder—Nyanza

Table 1: Perceived barriers to ART identified by program beneficiaries and stakeholders.

Benefits to ART	Program beneficiaries/Stakeholder feedback
Strength, better health, quality of life 42%	"The PLWHAs will live as normal as before." PLWHA beneficiary–Nyanza "The PLWHAs life is prolonged with the use of ARVs–life has to go on" PLWHA beneficiary–Central
Reduction in opportunistic infections 37%	"They don't fall sick often, making PLWHAs active with their daily chores." PLWHA beneficiary–Central
Reduction in viral load 37%	"ARV adherence can mean fewer hospitalisations and reduced burden of costs to the family." CDC stakeholder "If the CD4 count is up you get less opportunistic infections." PLWHA beneficiary–Nairobi
Good counselling and advocacy 35%	"If they are counselled on how to prolong life or decrease other infectious diseases." PLWHA beneficiary–Central
Being more productive 27%	"Promote the improvement in people's quality of life, their ability to feel well enough go back to work, be productive and support their families." International NGO stakeholder "I would like to go back to working my garden so I can bring food home for my family." PLWHA beneficiary–Kisumu
Access, availability, cost 24%	"It can be cheaper to get ARVs than to treat frequent illnesses." Clinician–Nyanza
Improved appearance– 16%	"The body physique improves" PLWHA beneficiary–Nairobi
Fixed dose treatments 6%	"One pill three times a day is what they take." PLWHA beneficiary–Central

Table 2: Perceived benefits of ART identified by program beneficiaries and stakeholders.

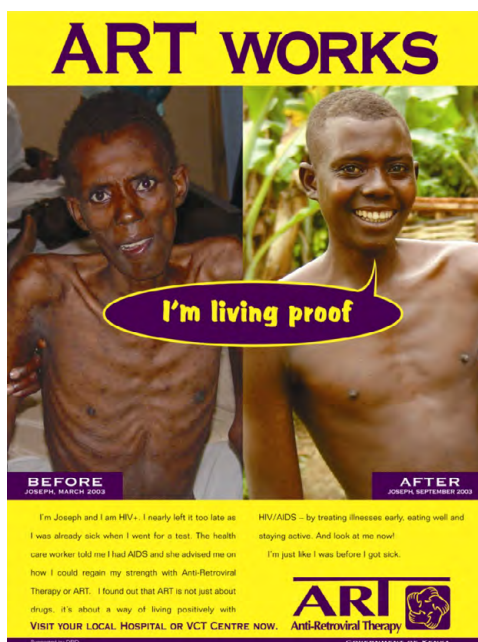


Figure 1: CART communication campaign poster using transformational messaging emanating from study findings.

accurately identify key themes, messages and communication channels to support protective behavioural change with specific audience segments in most need.

The qualitative study findings identified a number of gaps in knowledge, poor attitudes and perceptions among HIV positive participants and supporting family members, which could undermine the successful roll-out of ART in Kenya. These included a lack of perceived community awareness and accurate knowledge about ART treatment options, coupled with a number of myths and misconceptions, and poor attitudes and perceptions to ART. Patient perceptions of the quality of service from providers were also poor. This contrasted sharply to stakeholder perceptions of their own high quality of service. Any of

these 'barriers to behaviour change' could significantly impact on ART health seeking behaviour or treatment adherence.

The themes identified in the formative research study and secondary data analysis greatly assisted in the development of the communication strategy, creative approaches, and more specifically, the tailoring of messages. This included the use of 'transformational appeals' in TV, radio spots and print materials, demonstrating how patient body morphology could return to a previous, 'healthy state', (Figure 1), including the ability to once more become productive within a family and community setting.

Other important creative approaches emanating from the findings included the modelling of more empowering, doctor/patient relationships

using social learning theory [24] approaches, by depicting more desirable scenarios in communication materials of how health providers should relate to patients. A useful adjunct to the RAR approach was that important themes gleaned from the study led to the development of key behavioural indicators for the post-intervention study instrument design [25].

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