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## **“I didn’t know that...” patient perceptions of print information, education, and communication related to HIV/AIDS treatment**

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### **Abstract**

Improving health literacy is a necessary intervention for people with chronic health conditions to ensure adherence with long or life therapies and increase participation in self-care. While adherence is a multifactorial process, increasing health literacy among HIV-infected patients at all stages of living with HIV has been shown to improve treatment outcomes. In the era of rapid scale up of HIV care and treatment, little has been done to evaluate the utility of IEC materials for increasing patient health literacy and how patients perceive such materials. Four patient-oriented print IEC brochures in Swahili were designed to be read at the clinic waiting areas and also carried home by patients to supplement the knowledge received from routine counselling during clinic visits. Brochures detail antiretroviral therapy and address common myths, side effects, types and management of opportunistic infections, and prevention of mother to child transmission of HIV. We conducted focus group discussions with HIV-infected patients to explore patient perceptions of IEC materials in the urban congested HIV care setting of Dar es Salaam, Tanzania. Groups of participants were recruited from eight public PEPFAR-supported HIV care and treatment centres in the city (N=50). In this paper we present the results of those focus group discussions and introduce the print IEC materials as a pilot intervention in a Swahili-speaking setting where a need for additional health literacy exists. Further evaluation of these materials will follow as the data becomes available.

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#### **Conflicts of interest**

None.

## Keywords

HIV; health literacy; health education; health behaviour; Tanzania

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## Introduction

Despite its severity, it is now possible to manage HIV infection as a chronic disease using antiretroviral therapy. Health literacy, defined as the degree to which individuals have the capacity to obtain, process and understand basic health information needed to make appropriate health decisions (U.S. Department of Health and Human Services, 2000), is necessary for patients with chronic health conditions to understand and adhere to their health care (Gazmararian *et al*, 2003; Bakken *et al*, 2000). Low health literacy in people with chronic health conditions leads to more ignorance about their disease conditions compared to those with higher health literacy (Baker *et al*, 2002; Lindau *et al*, 2002), more misconceptions about the disease and its management (Van Servellen *et al*, 2003) and, in patients living with HIV/AIDS, a greater likelihood of experiencing emotional distress in response to changes in their health status (including greater symptoms of affective depression and maladaptive coping strategies) (Kalichman & Rompan, 2000a). Patients with chronic conditions require regular clinic appointment keeping, complex ongoing medication regimens, and adjustments in behaviour based on specific knowledge about their conditions. Low health literacy patients have been found to be less likely to participate in their healthcare provider's recommended self care for chronic conditions as diverse as cervical cancer, asthma, and HIV/AIDS (Lindau *et al*, 2002; Williams *et al*, 1998; Kalichman & Rompan, 2000b).

HIV-infected patients need maximum adherence to antiretroviral therapy for successful outcomes (Kleeberger *et al*, 2004; Kalichman *et al*, 1999; Drainoni *et al*, 2008). Providing education to patients has been shown to improve adherence to therapy and care (Murphy *et al*, 2002; Van Servellen *et al*, 2003), empower patients to participate in their own care (Van Servellen *et al*, 2005), and reduce transmission from mothers to their infants (Van Servellen *et al*, 2003). Tanzania is among countries where high HIV seroprevalence, estimated at 5.7% (THMIS, 2007–08), occurs within the context of rapid scale-up of access to ART services for people living with HIV /AIDS and generally low education levels (median years of schooling 6.5 and 6.6 years in urban women and men respectively (NBS/ Macro, 2005). In 2005, urban literacy rates were estimated at 92.1% and 84.9% from a national representative sample of adult (aged 15–49 years) men and women respectively (NBS/Macro, 2005). While the literacy rates among this population are high, basic literacy is only one component of the functional health literacy that enables patients to participate in decision-making for their care, adhere to medications, and navigate complicated medical systems (Kalichman *et al*, 2005; Keller *et al*, 2008).

Existing ethnographic research provides evidence for the obstacles patients living with HIV/AIDS face in order to maintain high ART adherence rates. These challenges include socioeconomic barriers such as high out-of-pocket expenses (for laboratory tests, some medications, and transportation), long distances that must be travelled to attend clinic visits,

social stigma, as well as systemic barriers such as medication stock-outs and inadequate numbers of health care workers (NBC/Macro, 2005; Ware *et al*, 2009; Hardon *et al*; 2007). There is an indication that low health literacy may be an additional challenge (Kalichman *et al*, 2005). These challenges may be augmented in an urban, resource limited setting such as Dar es Salaam. Observations from patient exit interviews, conducted as part of quality management team activities within the MDH HIV and AIDS care and treatment sites (MDH CTCs) in Dar es Salaam in 2008 (M. Lo, unpubl), found that 83% of the patients had only primary education or less which could contribute to low health literacy. This further necessitates the development of education level appropriate IEC materials and the validation of such materials. An internal report from the same team that was evaluating the roll-out of provision of group-based ART counselling in groups at facilities in 2008 showed that only 36% of HIV-infected patients knew the common side effects of ART (D. Nambiar, unpubl). The evaluation also noted variations in levels of patient knowledge across the eight MDH CTCs. The overwhelming work load in congested HIV care clinics combined with the low numbers of health care providers in Tanzania (Mapunjo & Urassa, 2007) may not allow enough time for HIV infected patients to receive sufficient information. We conducted the present study to better understand patient perceptions of newly developed IEC materials and the utility of these materials in conveying new information and addressing patient misconceptions.

## Materials and Methods

### Study area and data collection

The Print IEC materials are a collection of four brochures adapted from English language brochures used by Family Health International in Kenya. They were designed to supplement clinical counselling in care and treatment centres (CTCs) in Dar Es Salaam, Tanzania. For our purposes they were redesigned with a Tanzanian audience in mind, using Kiswahili as the language of communication. We conducted eight focus group discussions (FGDs) to explore patients' perceptions about these materials among persons living with HIV residing predominantly in urban localities and recruited from support groups offered by CTCs. The CTCs are sponsored collaboratively by Muhimbili University of Health and Allied Sciences, Dar Es Salaam City Council and Harvard University School of Public Health (MDH). The eight CTCs represented in the current study include large (>1000 patients seen per month), medium (300–1000 patients seen per month), and small sites (<300 patients seen per month).

Patients over 15 years of age who were active, literate participants in support groups sponsored by their CTCs in Dar es Salaam in Tanzania were eligible to participate. They were verbally consented, after agreeing to participate. Patients were asked their opinions about the materials in general, with prompting to ascertain their opinions on font, pictures, colour choices, and size of the materials and their overall perception on the context clarity of the language terminologies used and the utility of the materials. They were then asked open-ended questions about each of the four brochures, which cover the topics of antiretroviral therapy (ART), ART side effects, opportunistic infections (OIs), and prevention of mother to child transmission of HIV (PMTCT). These questions were primarily focused on what the

patient perceived the materials to be about, and whether or not they thought that such a brochure would help someone like them know how to perform specific actions related to self care. They were asked whether there was information contained in the brochures that they had not encountered before or if they had encountered this information before, where they had seen it. The last major questions of interest were related to what value the patients attributed to the materials, whether they thought such brochures would help them live a healthier life, and how they now felt about their HIV status and treatment after having read them.

FGD sessions were conducted by local nurse counsellors working in teams of two who had been trained in facilitating and recording FGDs, and in conducting qualitative interviews. Participants were divided into four subgroups based on gender and whether or not they were monolingual in Kiswahili or bilingual in Kiswahili and English. Knowledge of English was used as a proxy for educational attainment since English is not used as a communicating language but is taught as a separate subject in primary schools in Tanzania and becomes a communicating language only in secondary schools. The four subgroups were therefore males and females of lower educational attainment, and males and females of higher educational attainment. Two focus groups were conducted per subgroup (total of eight focus groups), with 6–10 participants per group, who all consented to their responses being recorded for evaluation purposes. Sessions were tape recorded and written transcripts produced and translated to English by nurse counsellor interviewers. Translations were reviewed for accuracy by one of the researchers. The evaluation team then performed a thematic analysis of the data. Initial coding was performed by a collaborative team of two researchers and was based on a comprehensive list of key words and phrases which emerged through the focus group discussions. This list was used to define thematic content and understand the patients' perceptions of the materials and their answers to the questions asked (Krueger & Casey, 2008). The codes were then systematically applied to the transcripts in an indexing exercise. Comments were designated as positive or negative, and responses tabulated for each of the eight groups by a second researcher.

### **Ethical considerations**

Ethical clearance for this study was obtained through the Institutional Review Boards (IRB) of both the Muhimbili University of Health and Allied Sciences in Tanzania and the Harvard School of Public Health in the United States of America.

### **Results**

The mean number of participants across the eight groups was between six and seven (range 6–8 individuals). Overall, the low educational status male subgroup had the highest number of participants (n=15) while the higher educational status male and female subgroups had less total participants per subgroup (n=12). The focus group discussions, which included time to read all the materials and then discuss them, took a mean time of 124 minutes from start to finish, with a range of 85 minutes to 210 minutes. Groups of male participants in general spent more time reading and discussing the materials.

During the sessions, broad themes of commonality and differences emerged across groups of differing gender and educational status. Men tended to discuss topical content, and shy away from opinions about format, colour and presentation, whereas female groups were more likely to spend equal time on both content and presentation. Male groups were also more likely to provide critical feedback or suggest changes to the information. More educated participants tended to discuss the topics in greater depth and to emphasize the value of concepts that they had not encountered in other settings, whereas less educated participants often reiterated that this was their first exposure to much of the information and that they had learned a lot of new things. Across the four subsets of participants, there was broad agreement that the topics being covered were important (all groups), that the materials would be useful to them or someone like them (7 out of 8 groups), and that they were pleased to have their feedback incorporated into future work with these materials (8 out of 8 groups).

### ART brochure

After reading the brochure, participants commonly reported that they better understood indications for taking ART medications and importance of taking their medications properly once they are initiated. Many patients reported feeling more confident that they understood the purpose of ART, namely that it will not cure HIV but will help their immune system to suppress viral replication. One female participant said, *“I like most the information on ART drugs, especially on what ART can and cannot do.”* This brochure was spoken of most highly by men and women of low educational status, and women of higher educational status. Both focus groups of men of higher educational status reported that they found the explanations a bit too simplistic and that they wanted more information on biochemical processes, such as how the drugs work, and more detailed explanations of factors that affect CD4+ T-cell counts. They were also more knowledgeable in general about the different drugs currently offered in Tanzania, and asked about drugs that were not discussed by the brochure. In contrast, a participant in one of the groups of men with lower educational status said, *“This information is very clear, I am sure that everyone who reads these brochures will be able to take their medicines as the nurses tell them.”* After saying this, everyone in his session nodded their heads in agreement.

### ART Side Effects Brochure

This brochure was received favourably by participants, but was also the most likely to generate heated discussion amongst them. Participants went back and forth on whether or not various pictures were appropriately concerning and realistic, or perhaps too scary or stigmatizing for patients. One picture that depicted a patient who had to run quickly to the latrine due to a diarrheal side effect was spoken of as demeaning by some, but defended as accurate by others who had experienced that particular side effect. Importantly, it was mentioned at least once in every group that they felt side effects had been clearly discussed and that they would feel more confident in knowing what to do and when to seek treatment. Participants of lower educational status reported more often that they had learned something new on how to self-manage minor side effects, such as *“I didn’t know that I could help a headache side effect by resting in a quiet, dark room.”* Participants of higher educational status listed additional side effects that they would like to see added to the list included in

the brochure, and men in particular often wanted to know more specifically which drugs caused which side effects.

### **Opportunistic Infections Brochure**

Participants liked this brochure, but some reported difficulty in reading it due to smaller font size, which is an important consideration in a country like Tanzania which may have a high level of undiagnosed and untreated visual impairments (Congdon *et al*, 2001; Njuguna *et al*, 2009). This one was mentioned favourably by those who liked the colours, as it is printed on bright blues, greens and yellows. Participants in six out of eight groups reported that they felt opportunistic infections were clearly discussed, and in seven out of eight groups that they would be more likely to know what to do if they suspected they had one or wanted to avoid getting one; such as; *‘Going to hospital when you feel sick even if it is not your appointment date will prevent infections to become chronic’*. Lower educational status participants often commented specifically on measures that they had learned to reduce OIs, mentioning body and oral hygiene and good food preparation. Participants also reported gaining the understanding that opportunistic infections occur in individuals with low immunity.

### **Prevention of Mother to Child Transmission (PMTCT) Brochure**

*“I now know after reading these materials that a mother who is infected with HIV can have a child who is not.”* This particular comment was raised by all subgroups of respondents, gender and levels of educational status notwithstanding. Of the four that were shown to them, this brochure was received the most favourably by participants, especially for its depiction of the importance of the father’s presence and participation in antenatal care. Both genders reported that this was a very important point to make, and highlighted photos showing the presence of the male partner in the room during checkups. While male groups often reported that they were already performing such actions, female groups often laughingly joked about how they wished their partners would escort them to the clinic, saying *“Women are not escorted to clinics in Africa.”* Patients often spoke of how little information there was available to them on PMTCT, and how much they had learned from this particular brochure, even though they sometimes had lingering questions on the details of viral transmission. They were relieved to learn that PMTCT services are available in Tanzania, and they reported that they would now know what to do if they or their partner became pregnant. One major misconception was cleared up for a female patient of lower educational status, who reported, *“I now know that nevirapine is not given to cause infertility, unlike what the rumours say.”*

### **Overall Participant Perceived Utility of the IEC Materials**

Overall, participants gave favourable reviews to the print IEC brochures and reported learning new things. In six out of eight groups, participants reported learning at least one new thing from each of the four topical areas. These groups were more likely to report less previous exposure to information on the topics in general, and those who made the most positive comments regarding the utility of the brochures, males of low educational status, often reported previous exposure only in the clinical setting or in free patient seminars.



Two of the groups reported limited knowledge gain from the brochures. One of the focus groups reported that they felt they had been previously exposed to all of the material covered in the brochures, while the second group mentioned having previously learned material from at least one brochure, but not every brochure. Both groups included individuals of a higher educational status and the one focus group with participants who did not report learning anything new had male participants. The degree of detail in the responses of the latter group indicated a high level of independent learning on how to live successfully with HIV, and in some cases may have even reflected a background in health care.

### Post Exposure Reported Attitudes and Closing Comments

Patients of lower educational status, both male and female, reported feeling more confident after reading these materials, as well as less afraid of being HIV positive. They reported that such materials would have encouraged them or someone like them to get tested for HIV, and that it would help those who were currently living with HIV to live more positively and healthfully. Participants reported that they would feel more confident and more likely to discuss additional questions or concerns with their physicians, and that they had learned things that would protect them from bad outcomes. Most of the groups also reported that the brochures were an important reminder to continue condom use and take ART medications properly, and that they felt more likely to do so after reading the brochures. However, those of higher educational status and males were less likely to report attitude changes after viewing the IEC materials. Still, when asked how the brochures had made them feel about their HIV status and living a healthy life, one male participant commented “*Living a positive life is individualized, but if you take these materials and live by them individually, you can live much better than before.*” Additionally, many participants reported that being included in a quality improvement activity such as the focus group discussions had made them feel more positive about their treatment and care. They also reported that they appreciated the respect that it showed to them and to their opinions.

When asked if they had any additional comments to make before the close of the focus group session, many groups reported that they enjoyed the materials, and wanted to see them become widely distributed. Some also reported that they would like to see similar information in an audiovisual format. Additional concerns unrelated to the materials that came up were the need for more ART adherence support groups in the city, more support targeted to elderly individuals living with HIV/AIDS, and a desire on the part of women living with HIV for counselling targeting their partners.

### Discussion

Patient interest in learning about ART indications, ART side effects, OIs, and PMTCT is high, and their enthusiasm about interventions of all types came out during the focus groups. In addition, focus group testing itself revealed areas where our population’s health literacy was initially deficient and subsequently improved through exposure to the materials, evidenced by patients saying “I didn’t know that...” Furthermore, while the brochures proved a good method for imparting new information, it is also important to note that the brochures also served to clear up misconceptions and rumours. For example, the woman

who noted that she had previously believed that nevirapine caused infertility, a misconception that was clarified after exposure to the IEC materials.

It has been shown that patient health literacy about HIV influences many major decisions along the course of their disease such as seeking voluntary counselling and testing and engaging in high risk behaviours (multiple partners, no condom use) (Peltzer *et al*, 2009). Patients' educational status, which is associated with the ability to independently interpret health information, has also shown correlations with better clinical outcomes like appointment adherence, adherence to treatment, and even improved CD4+ T-cell counts (Collazos *et al*, 2009). By seeking to increase the overall health literacy of patients in our setting, we hope to see increases in knowledge, improvements in attitudes, and gains in self efficacy that correlate with better health outcomes and a decrease in high risk behaviours.

Important differences were seen among FGD participants based on gender and educational status. Individuals with a lower educational status reported greater utility of the brochures and were more likely to report no previous exposure to the content. A higher educational status was also linked with a greater ability to critically engage with the content of the IEC brochures and a desire for more detailed information than that provided. However, individuals with higher educational status were less likely to report attitude changes. Previous studies have documented a correlation between low educational attainment and poorer health outcomes. Researchers have suggested that such an association may exist because a higher level of education increases agency and gives individuals a greater sense of control in their lives (Ross & Wu, 1995; Mirowsky & Ross, 2003). Additionally, individuals with higher educational attainment may have greater access to new health information (Link & Phelan, 1995) and may be in a better position to more critically evaluate such information. Similar differences were seen based on gender. Male FGD participants tended to be more critical of the materials and less likely to report attitude changes after exposure to the IEC materials. These differences in health literacy and health outcomes based on gender and educational attainment need to be further studied in resource limited countries.

Our study has a number of limitations. The FGDs were conducted in an urban setting, with participants recruited from support groups for HIV/AIDS patients at eight CTCs. Individuals in an urban setting such as Dar es Salaam may generally have greater access to health information than individuals living in rural settings. We hope to address this in the future by developing materials more appropriate to rural settings in Tanzania and that could potentially be used elsewhere. Another limitation to the generalizability of our study is that participants from eight CTCs throughout Dar es Salaam were represented, yet it is unclear whether these CTCs are representative of the patient population in the city as a whole, or of other resource limited settings. Additionally, participants were recruited from support groups, therefore potentially representing a self-selected and more highly motivated and informed subpopulation of HIV-positive patients. However, most groups reported learning from the IEC materials, suggesting that the brochures may have even greater utility among individuals with less exposure to HIV health information. The fact that low education males and females appeared to gain more from the brochures than their higher education counterparts, supports this premise.



Another limitation of this study is the use of English as a proxy for educational attainment. Kiswahili is the national language in Tanzania; a knowledge of English therefore generally implies higher educational attainment, as English is a communicating language from secondary school and thereafter. While this is a crude proxy measure of educational attainment for participants, experience with the patient population at the public CTCs suggests this is a measure that accurately approximates educational attainment. Unfortunately, other educational measures were not recorded for participants. Despite this, we do not feel this severely limits the interpretations of the FGDs, as the main purpose was to evaluate the IEC materials and identify next steps.

The FGDs served not only to evaluate content but to identify areas for improvement and targeted interventions. The IEC brochures were adapted to incorporate FGD participant feedback. For example, some of the pictures that were identified as exaggerated or demeaning to patients were changed and terminology that was deemed confusing was clarified. An audiovisual component, which could be screened in patient waiting rooms, was planned and developed after this was indicated by participants as a useful addition. These are examples of ways that FGDs can be used to strengthen and validate prevention and educational materials geared to an HIV positive population. The participants of the FGDs also raised additional concerns, such as implementing ART adherence support groups in Dar es Salaam and further engaging male partners in PMTCT. The utility of the materials in encouraging individuals to know their HIV status was indicated, further suggesting their use may be expanded beyond HIV positive patients to a wider audience and thus serve as a prevention tool.

This is one of the first Kiswahili language brochure interventions to target knowledge, attitudes, self efficacy and behaviours that relate to better health outcomes for persons living with HIV. Adherence to treatment and self care for persons living with HIV is complex and multifactorial issue; of which health literacy is only one component. In Tanzania, many factors affect ART adherence, including resource and income constraints, family support, adoption of specific techniques at the individual level, and clinician-patient relationships (Roura *et al*, 2009; Watt *et al*, 2009). Linked to these limitations are the level of knowledge patients have about their own ART medications (Ezekiel *et al*, 2009), which could facilitate family support, the development of individual adherence strategies, and doctor-patient communication. Our focus in this paper on patient educational materials addresses only one aspect of patient adherence, yet we feel that it will contribute to the growing literature on adherence to ART in Tanzania. We are currently conducting a cohort study to further evaluate these materials and assess pre- and post-exposure knowledge, attitudes, self efficacy, and behaviours regarding these HIV health topics. This paper thus serves as an introduction for those future results.

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**Table 1**

## Characteristics of focus groups

	<b>Number of focus groups performed</b>	<b>Average number of participants per group (Total participants)</b>	<b>Average time of focus group discussion in minutes</b>
Females, Lower Educational Status *	2	6.5 (13)	105
Females, Higher Educational Status *	2	6 (12)	115
Males, Lower Educational Status *	2	7.5 (15)	120
Males, Higher Educational Status *	2	6 (12)	150

\* Educational status was divided between primary and secondary education levels, and knowledge of English was used as a proxy for this measure. All participants were from CTCs in Dar es Salaam, TZ and were literate