

Health Communication In Southern Africa ~ Using Pictograms In A Patient Information Leaflet To Communicate Antiretroviral Medicines Information To HIV/AIDS Patients In Rural South Africa



Part 3: Patient Information

Abstract

The objectives were to design a simple, illustrated patient information leaflet for the antiretroviral regimen of stavudine, lamivudine and efavirenz and to evaluate its readability and acceptability in the local Xhosa population. In order to achieve this, a further objective was to design and evaluate illustrations to include in the patient information leaflet which were culturally acceptable and well interpreted. Illustrations or pictograms were designed to illustrate selected instructions appearing in the patient information leaflet and were individually tested in 30 Xhosa participants who had a maximum of 8 years of formal schooling. Results were used to improve the pictograms for inclusion in the patient information leaflet. The patient information leaflet was designed and tested in sixty Xhosa

participants with varied levels of education who had stated they could read. Demographic data were collected and they were then asked to read the patient information leaflet, available in both English and isiXhosa, and a series of questions was asked to assess its comprehension and acceptability. The overall average rate of understanding was 95. Six of the 20 questions were located and understood by all participants, and only two questions resulted in less than an 85 correct response. Physical appearance and quantity of information were highly rated and all participants were enthusiastic about the inclusion of pictograms.

Introduction

The communication of health-related information in Africa has involved various media including theatre (Mbizvo, 2006), video (Mathews, 2002), television and radio (Health Communication Partnership, 2008) and folk media which includes poems, dance drama, story-telling, rhymes and sayings (Gokah, 2007). However, the most commonly employed method has been the use of print media (Peltzer, 2002). Low literacy rates coupled with inadequate infrastructure and poor technological development in African countries have favoured the use of posters, billboards and pamphlets for health promotion and patient education.

Medicine-taking behaviour is complex, multi-factorial, and depends on a dynamic interaction of several factors, including cognitive, behavioural, social, environmental and physiologic factors (WHO, 2003). A minimum requirement for using medicines safely and effectively is a basic understanding of the medicine instructions and the ability to recall this information. However, the communication of this information to the average patient in southern Africa presents a complex challenge to health professionals as poorly resourced health care systems result in minimal time spent with individual patients and the cultural, educational, socioeconomic and linguistic differences that often exist between health professionals and patients may further challenge successful communication. Limited reading skills, a poor knowledge of the body and its systems and inadequate insight into diseases and their treatment also disadvantage patients seeking to address their health problems.

Traditionally, much health and medicine-related information has been communicated verbally, which is congruent with the strong oral tradition in Africa, but this has its limitations as patients tend to forget half of what they hear from the doctor within five minutes of leaving the consultation room (Kitching, 1990). The use of written materials for informing and educating patients on

health issues and medicines has increased substantially over the years, albeit mainly in the developed world, with the patient information leaflet being the most widely used form (Kenny et al., 1998; Raynor et al., 2007).

Patient information leaflets communicate more information than can be achieved by counselling alone and have been shown to be beneficial in improving patient understanding and knowledge of their medicines, enhancing recall of instructions, reducing medication errors along with patient anxiety about treatment, bridging the information gap between patients and healthcare providers and improving adherence to medicines (Johnson 2005; Kitching, 1990; Koo, Krass & Aslani, 2003; Mansoor & Dowse, 2006; Raynor, 1998). However, in order to fulfil its potential, the form and quality of written information must match the reading level of patients and should take into account their culture, beliefs, attitudes and expectations (Doak, Doak & Root, 1996; Schaafsma, Raynor & de Jong-van den Berg, 2003).

Irrespective of educational level, people generally prefer simple and easy-to-read materials and find it easier in the clinical situation to comprehend and act appropriately on short, simple messages than on more complex ones (Doak et al., 1996; National Work Group on Literacy and Health, 1998). Therefore, information intended for patients should be written in the simplest form possible for optimal acceptance and comprehension, particularly if a high proportion of the target population has limited literacy (Davis et al., 1994; Mansoor & Dowse, 2007).

For a number of decades, health education in Africa and other emerging countries has included the use of visual aids (Hugo & Skibbe, 1991; Kwansa, Cannon, Belcher, & Hosu-Porbley, 1972; Linney, 1995; Zimmerman, 1982). Visuals have been shown to enhance the understanding and recall of medicines information, particularly for patients with limited health literacy skills (Doak et al., 1996; Mansoor & Dowse, 2003; Dowse & Ehlers, 2005, Houts et al., 2006; Katz, Kripilani & Weiss, 2006; Ngoh & Shepherd, 1997). A common assumption often reported in popular literature is that visuals constitute a universal language which can be easily understood by all, regardless of culture, language, beliefs, or education. However, cross-cultural testing of visuals has clearly shown that pictures do not necessarily communicate the same concepts to all groups, even when the pictured objects are easily recognizable (Dowse & Ehlers, 2001; Doak et al., 1996; Tripp-Reimer & Afifi, 1989). Visual materials for health education are

often designed by health professionals and graphic design specialists who may lack adequate insight into the culture and the visual literacy skills of the target group and adopt a top-down approach of “we know best” in the design process. On the contrary, the optimal approach in designing culturally sensitive, content-applicable visuals is to involve the target group in all stages of the design process, and to test the final image rigorously in the target population before it is included in any type of patient information materials (Dowse & Ehlers, 2001).

The high incidence of HIV/AIDS in South Africa is well documented, with an estimated 18.8 of the adult population being affected (UNAIDS, 2007). AIDS is a chronic condition with no cure, but it can be managed with combination therapy using a minimum of three antiretroviral drugs concurrently. This chronic, complex therapy demands extremely high adherence levels of more than 95, as poor adherence has been associated with the development of resistance and ultimate therapy failure (Gardner et al., 2008). Patients initiated on antiretrovirals receive an enormous amount of information at a time when they are physically and emotionally vulnerable, and they are expected to adhere to a complex medication regimen which often results in distressing side effects. Written patient information materials may be of particular value for these patients when a large volume of information is communicated verbally, as it serves to reinforce the verbal information and act as a permanent source of reference and as aid to the recall of information.

Over the past two decades, growing evidence has revealed the magnitude and consequences of limited literacy on the health and health care of many at-risk patients. Literacy has been reported as a stronger predictor of health than level of education, being linked to delays in accessing and using preventive services, adherence to medical instructions, compromised self-care skills and poorer health outcomes (Davis & Wolf, 2004). The most recent census conducted in South Africa in 2001 reports that 22.8 of the adult population have no schooling, and a further 19.8 have only “some” primary school education (Statistics South Africa, 2001).

From these figures, approximately 43 of the population may have compromised literacy skills, with this same proportion therefore likely to encounter some difficulty in reading and comprehending written health information. The problem is exacerbated by this information often using language at a higher level than the average reading level of the patient (Doak et al. 1996;

Kenny et al. 1998).

In South Africa, the provision of patient information leaflets with all medicines was mandated by Regulation 10 of the Medicines and Related Substances Control Act, Act 101, as amended, from May 2003 (Government Notice, Department of Health, 2003). This regulation requires the pharmaceutical industry to develop and distribute patient information leaflets with all their manufactured medicines. Although antiretrovirals supposedly received high priority in this initiative, to date there is little evidence that these patient information leaflets are being distributed from public sector hospitals to patients receiving antiretrovirals. This project attempts to address the lack of written information available to patients receiving antiretrovirals.

Research objectives

The objectives of this research were to design a simple, easily readable, illustrated patient information leaflet for a commonly used antiretroviral regimen, and to evaluate its readability and acceptability in the local Xhosa population. In order to achieve this, a further objective was to design and evaluate illustrations to include in the patient information leaflet, which were culturally acceptable and well interpreted.

Method

Study site and study population

The two studies described in this chapter were both conducted in Grahamstown, a small town in the Eastern Cape province. This is one of nine provinces in South Africa and is largely rural, underdeveloped and economically poor, with a high unemployment rate. The majority of the local black population belongs to the Xhosa ethnic group, and it is from this group that the participants in this study were drawn.

Participants were recruited from a number of sites within Grahamstown; Settlers Day Hospital which is a primary health care clinic, a local community centre and the suburban areas adjacent to the community centre. Interpreters, who were used for all interviews and group discussions, received individual training and were subsequently evaluated during practice interviews. All participants received an honorarium in acknowledgement of their time. Approval for the study was obtained from the Rhodes University Ethical Standards

Committee.

Development of pictograms

Seven pictograms to be included in the patient information leaflet were identified. Five of the pictograms had been developed and tested by the author and co-workers (Dowse & Ehlers, 2001). For the design of two new pictograms, a workshop was conducted with the second year undergraduate Pharmacy class at Rhodes University. Students in this class represented 15 African countries, including the study target population. Background information on the design and use of pictograms as well as the problems associated with their interpretation were presented. Students were then split into groups of between 5 and 8 and were presented with two instructions to illustrate: "Keep medicines out of the reach of children" and "Store medicines in a cool, safe, dry place away from heat and direct sunlight".

The visual concepts and rough sketches generated from this workshop were discussed with a graphics designer who produced initial versions suitable for testing. A group discussion with five Xhosa participants guided the modification of both the initial images of the two new pictograms as well as the existing pictograms. Of the seven pictograms which were to be included in the patient information leaflet, three of these were direct instructions to take the medicine either once or twice daily. Only the "twice daily" pictogram was tested. Ten pictograms in total were tested, five of which were to be included in the patient information leaflet. The remaining five had been tested in previous studies (Dowse & Ehlers, 2001) and were included to contribute to the internal validity of the study, as results could be compared with existing data collected from a similar population. Only results for the five pictograms included in the patient information leaflet will be presented and discussed (see Appendix).

Testing of pictograms

For inclusion in the study, participants had to be 18 years or older, and have a maximum of 8 years of formal schooling. Thirty Xhosa participants were recruited with the help of an interpreter, who provided a brief, scripted explanation about the application of the pictograms followed by a discussion of two examples of pictograms to familiarise participants with the concept.

In individual interviews, demographic data were collected (sex, age education) and the ability to tell the time either from a clock face or a digital

display was recorded. The pictograms were then displayed in random order, one at a time, and participants were asked to offer their interpretation. Responses were recorded as correct or incorrect and all comments were noted. Participants were thanked and were given a small monetary donation in acknowledgement of their time and input. Interviews took between 15 and 30 minutes. The criterion used for acceptance of the pictograms was the American National Standard's Institute ANSI Z535.3 which advises that, in a comprehension test, pictorial symbols must reach at least a criterion of 85 correct (ANSI, 1991).

Development of the patient information leaflet

Information on the antiretrovirals constituting Regimen 1a (stavudine, lamivudine, efavirenz) used in the South African public health sector was collected and consolidated into one written leaflet. The patient information leaflet was designed to comply with most of the local legal requirements stated in Regulation 10 (Government Notice, Department of Health, 2003).

The design of the patient information leaflet was informed by published guidelines on patient information design (Koo, Krass & Aslani, 2003; Sless & Wiseman, 1997) with particular attention to designing for readers with limited reading skills (Doak et al., 1996, PATH, 2002). All information was carefully considered for its relevance, and concerted attempts were made to minimise medical jargon and avoid the use of complex, multi-syllable words rather including simple, easily understood words.

A three-column format was adopted and an easy to read font in an appropriately large font size (Arial 10 point) was used for the text. Large, dense blocks of text which are intimidating to poor readers were avoided by breaking the text into short blocks, and frequent use was made of bullet points to simplify and emphasise multiple points of information. Sentences were kept short and active voice was used throughout. Navigation through the leaflet was facilitated by using headings which were emphasised using a bold, larger font size and were bordered with a line above and below the text. The inclusion of adequate white space to enhance reader appeal was considered. The pictograms were included to illustrate selected information presented in the text and to promote the understanding of these points. The resulting two-page A4 size patient information leaflet was subjected to Fry's readability test (Doak et al., 1996) which allows a quick estimation of readability levels, and was found to be suitable for Grade 7 learners.

A pilot study using 20 Xhosa participants was conducted to test the first version of the patient information leaflet in English and to refine the questionnaire. Minor modifications were made to the content and layout of the patient information leaflet and certain questions were simplified for easier translation. The final version of the patient information leaflet (Mwingira & Dowse, 2007) was then translated into isiXhosa using a multistage approach of translation by a professional translator, followed by professional proofreading and subsequent back translation.

Testing of the patient information leaflet

Inclusion criteria for participants included a stated ability to read (at even a very basic level) in either isiXhosa or English, to be 18 years or older and to have attended a local clinic and received medication for any condition. Participants were not HIV/AIDS patients receiving antiretrovirals. A standard approach was used for all the interviews in which potential participants were first asked if they could read. If the reply was positive, they were invited to participate and were told that the study aimed to assess the quality and usefulness of the patient information leaflets, rather than to test their reading skills.

Selected demographic data were collected (gender, age, home language, educational level). Participants were then handed the patient information leaflet, with a choice of reading either the English or isiXhosa version, and were asked to read through it at their own pace. The time taken to read the patient information leaflet was discreetly recorded using a stopwatch.

In the first stage of the testing process, understanding of the pictograms was assessed. Participants were asked to study each pictogram included in the patient information leaflet and offer their interpretation of each one. Responses were recorded as correct or incorrect and all comments were noted.

The second stage involved evaluating understanding of the text-based information and was based on that pioneered by the Communication Research Institute of Australia (Dickinson, Raynor & Duman, 2001, Sless & Wiseman, 1997), whereby participants were asked a series of 20 questions. Each question was simply worded, related directly to information presented in the patient information leaflet and required no inferences or application of prior knowledge. Questions were asked in two parts; firstly, participants were required to locate the appropriate information in the patient information leaflet pertaining to the

question asked and to point this out to the interviewer, or to acknowledge that they were unable to do so. Secondly, they were asked to explain that information in their own words so as to evaluate comprehension as the ability to read the text does not necessarily ensure good understanding of the meaning. Participants had unlimited time to access and read the information before answering. Answers were recorded in two categories of “located” and “understood”. Understanding of the information was calculated according to the number of answers correctly located and explained.

Acceptability and participant opinion of the patient information leaflet were then investigated by asking a number of set questions as well as encouraging open-ended feedback. At the conclusion of the interview, participants were thanked and were offered a small honorarium in acknowledgement of their time and contribution to the study.

Data analysis

The percentage correct interpretation for each pictogram was calculated. An understanding score for the patient information leaflet was calculated based on the number of questions answered correctly. Understandability was assessed using the European Commission (EC) guideline (Dickinson et al., 2001) which sets a target that at least 80 of the participants correctly answer each question, in that they should both locate the appropriate information and be able to explain it in their own words.

Results

Pictogram study

Table 1. Demographic characteristics, n (%)

Demographic characteristic	Pictogram Study (n = 30)		Patient Information Leaflet Study (n = 60)	
	N		N	
Gender				
Male	10	33.3	30	50.0
Female	20	66.7	30	50.0
Age (yr)				
< 21	0	0.0	3	5.0
21 – 40	11	36.7	48	80.0
41 – 65	16	53.3	9	15.0
> 65	3	10.0	0	0.0
Years of schooling				
0	6	20.0	5	8.3
1 – 4	8	26.7	27	45.0
> 5	16	53.3	28	46.7

Table 1. Demographic characteristics, n (%)

Demographic results are presented in Table 1. Of the 30 participants interviewed, 20 (66.7) were female and 10 (33.3) were male, and all had isiXhosa as their first language. A majority (53.3) were between 40 and 65 years of age. Six (20) of the participants had not received any formal education and 16 (53.3) had between five and 10 years of formal education. Twenty-eight of the 30 participants could tell the time from a clock face.

The Appendix shows various stages in the progression of pictogram development. The USP pictograms, which are designed mainly for use in the United States (USP, 2000) were the original starting images for all our pictogram development work. The “Local version” pictograms are the images we developed by modifying the USP pictograms, with their development, testing, interpretation and misinterpretation having been previously reported (Dowse & Ehlers, 2001; Dowse & Ehlers, 2004).

Results from these two stages (USP and Local versions) have been included as they informed the current development process reported in this study. Examples of misinterpretation of each pictogram found in this study are displayed in the Appendix. The “Take medicine four times a day” pictogram was well interpreted but narrowly failed to meet the 85 ANSI criterion. The ideas from this pictogram as well as from a pictogram showing a “take at night” instruction (Dowse & Ehlers, 2001) formed the basis of the “Take medicine twice daily” pictogram included in the patient information leaflet. A dark background was used to convey the concept of night time, with a sleeping person on a bed and a moon included to reinforce the time of day. The times to take the medicine would be filled in by the health professional on the clock face. Only two of 60 participants failed to correctly interpret the version of the patient information leaflet.

Although the pilot study pictogram “Take medicine with a glass of water” complied with the ANSI 85 criterion, participants found the insert with the profile confusing and it was deemed to be superfluous. They also commented negatively on the lines depicting movement in a liquid, which were subsequently removed. The capsules and tablets were modified to more closely resemble those used in practice. The final version of the patient information leaflet was understood by all participants.

Certain images in the “Do not drink alcohol while taking these

medicines” pictogram were considered to be outdated, as containers such as the carton, which was previously widely used for beer, are no longer available. The carton image was replaced by a larger, popular beer bottle. The short, stout bottle was taken to resemble a milk bottle, which resulted in it being modified to a more slender, longer bottle. The lack of text on the labels elicited comments that the bottles could contain any liquid, so the word “Beer” was included on the label. The shape of the mug was modified and increased in size. Finally, the bottles were repositioned to increase their visibility below the cross, which was drawn as a solid cross extending to all four corners of the image box. From a very poor interpretation of 40, the final version of the patient information leaflet resulted in 100 understanding.

The pictogram describing storage conditions was totally redesigned as the USP and the Local versions only illustrated the instruction “Do not store near heat or in sunlight” and the interpretation of both versions was particularly poor. For storage of antiretrovirals, patients were encouraged to not only avoid any sources of heat, but also to store their medicines in a cool, dark place which was illustrated as a shaded cupboard interior. Various versions of the sun and the fire were informally tested on 5 local Xhosa people. The pilot study version was adequately interpreted, but failed by a fairly large margin to reach the ANSI 85 criterion. The image of the sun was variously described to look like the moon, a clock face, a broken tablet, whereas others failed completely to recognise it. Comments on the fire included “looks like a tree with leaves” and “a lit cigarette ready to be smoked”. The pictogram was modified to centre the sun in the circle, remove the smoke from the fire, include a solid black cross, and the shape of the cupboard was altered to one that looks more like a cabinet, with the size of the medicine packet being increased and the bottle image removed.

The final pictogram “Keep all medicines out of the reach of children” used the USP version as a starting point, with the initial image from the graphics designer shown under “Local version”. This was never tested and was designed for the current study. Following comments from the group discussion, it was modified to include an adult and a small child, and a cupboard similar to that used in the storage pictogram was added. This achieved a 90 correct interpretation and was subsequently modified only to change the look of the cabinet to ensure a degree of uniformity with the storage pictogram. Interpretation of all five pictograms improved following modification, when they were included in the

patient information leaflet and tested during the final study.

The study of the patient information leaflet

Males and females were evenly distributed for this study (Table 1), and the average age ranged between 21 and 40 years (80). Five participants (18) had less than five years of formal education. Just under half (47) had attended school for more than 10 years, with many of these having also achieved some form of tertiary education.

Participants took an average of nine minutes to read the patient information leaflet, with only three participants reading it in under 5 minutes. Most of the information in the patient information leaflet was well located and understood (Table 2) which is reflected in an average overall rate of understanding of 95. The answers to six of the 20 questions were located and understood by all 60 participants. The target set by the EC guideline that at least 80 of participants should answer each question correctly was achieved for 18 of the 20 questions. The most challenging question (Question 3) related to the possibility of developing resistance if medicines were not taken as instructed as only 40 of the participants were able to correctly explain the meaning of the text. A high degree of adherence to antiretrovirals is the cornerstone of managing HIV/AIDS and insight into the potential negative outcomes of poor adherence is crucial. The patient information leaflet therefore requires further modification to make this information more conspicuous and understandable.

Table 2: Percentages of participants' correct answers in locating and understanding patient information in leaflet (n = 60)

Questions	Located	Understood
1. Using the leaflet, can you tell me the name of these medicines and describe them?	100.0	-
2. Can one still spread HIV/AIDS while taking these medicines?	98.3	86.7
3. If you do not take your medicines as instructed, what may happen?	98.3	40.0 ¹
4. According to the leaflet, how many times a day must you take stavudine (d4T) capsules?	100.0	100.0
5. Looking at the leaflet, does it tell you what to do if you miss a dose of your medicines?	96.7	96.7
6. Like any other medicines, these medicines have both good and bad effects. Does the leaflet tell you what the bad effects are and what you should do if you experience any of them?	100.0	100.0
7. What do these medicines do to the viral load?	96.7	91.7
8. What does the leaflet tell you to do if you take too much of these medicines by mistake?	93.3	93.3
9. Do these medicines cure HIV/AIDS?	100.0	98.3
10. According to the leaflet, if you are taking any other medicines, what should you do before taking these medicines?	98.3	98.3
11. How long do you have to take these medicines for?	98.3	98.3
12. According to the leaflet, if you have any allergies, what should you do before taking these medicines?	98.3	68.3 ¹
13. Does the leaflet tell you how many of efavirenz (EFV) capsules you should take each time?	100.0	98.3
14. Suppose you have been feeling better for the past month, can you stop taking your medicines?	96.7	98.3
15. What should you do with left over medicines?	96.7	98.3
16. Some medicines can be taken with alcohol. Can you take alcohol while taking these medicines?	100.0	100.0
17. Does the leaflet tell you how to store these medicines?	100.0	100.0
18. Is there any advice in this leaflet about sharing your medicines with someone else who has HIV/AIDS?	98.3	98.3
19. Does it matter if you take these medicines at different times every day?	93.3	85.0
20. If you want more information about your treatment and medicines you are taking, who should you talk to?	100.0	100.0

¹ Questions that failed to reach the EC target of 80.

Table 2: Percentages of participants' correct answers in locating and

understanding patient information in
leaflet (n = 60)

The other question that failed to meet the EC target dealt with allergies and taking antiretrovirals (Question 12). As with Question 3, this is a complex, two-part question, firstly requiring the participant to identify with a condition i.e. experiencing an allergy, and thereafter requiring an understanding of the consequences of not obeying an instruction. In both cases, location of the information was excellent, but participants were unable to understand and use the located information to inform their own medicine-related behaviour.

Acceptability of the patient information leaflet

Interestingly, 18 of the 60 Xhosa participants chose to read the English version of the patient information leaflet, even though they were literate in isiXhosa, as they were more comfortable reading English and considered the English words to be easier to understand and simpler than the isiXhosa translations.

Most participants (62) found the patient information leaflet to be of average difficulty, whereas only three of the 60 found it difficult to read, with the remaining third considering it to be easy to read. All considered the font size to be sufficiently large (100), and almost all thought the length of the sentences to be reasonable (95), and the space between the lines of text adequate (97).

The amount of information included in the patient information leaflet was considered by 88 to be sufficient to inform the appropriate use of the medicines. The presence of pictures appealed to all 60 participants who felt that the pictures would contribute to understanding and recalling the information. The level of difficulty of the words generally appeared to be appropriate as most participants (90) said that there were only a few words that they were unable to understand e.g. 83 of participants reported being unable to understand “viral load”, 85 had difficulty with “CD4 count” and 87 reported difficulties with understanding “antiretroviral therapy”. Other words included “resistance” (12 misunderstood), “pharmacist” (10 misunderstood) and “capsules” (5 misunderstood). Participants appreciated having a choice of language in which to read the patient information leaflet. Forty-four of the 60 (73.3) stated that they would prefer to receive patient information leaflets in their home language of isiXhosa.

The product description section at the end of the patient information leaflet elicited many negative comments and was not understood or liked by the majority of participants. In their opinion, it did not constitute important or relevant patient centred information, was too technical and was of no value in informing medicine taking behaviour.

Discussion

The design and development of the pictograms and the patient information leaflet were iterative, multi-stage processes informed by established design guidelines and involved members of the target population at all stages of development and testing, thus ensuring cultural acceptability and an appropriate level of complexity. The high levels of understanding for both the images and the written text, as well as the positive opinions of the patient information leaflet reported in this study provide evidence of the success of this strategy, supporting previous research using this approach (Doak et al., 1996; Mansoor & Dowse, 2003).

The benefit of improved comprehension and high acceptability when incorporating visuals into written medicines information intended for a low-literate South African population has been shown by Mansoor & Dowse (2003), and is supported by the findings in the current study. The pictograms all illustrated concrete concepts and direct instructions which are easier to both represent and to understand than abstract concepts and feelings. The images were drawn as simply as possible, with clean lines, avoiding all unnecessary extraneous details. This strategy attracts the eye of the viewer directly to the core, central concept of the image rather than have the viewer randomly focus on distracting detail and reduces the cognitive load on the viewer, particularly relevant in those with poor visual literacy skills (Carstens et al., 2006). The majority of the images contained analogical objects i.e. familiar objects such as a glass, a cupboard, a bed, a fire, and the illustrated instructions were all familiar activities, both of which contributed to the high levels of interpretation.

Attempts were made to avoid the use of graphical conventions and symbols e.g. arrows, which require higher order symbolic interpretation strategies (Maes et al., 2008). An arrow had originally been included in the circular insert of the Pictogram Study version of "take medicine with a glass of water" and was intended to show the action of moving the glass towards the mouth, but was completely overlooked by many participants. Following testing, the insert was

identified as an unnecessary source of confusion and was therefore removed in the study of the final version of the patient information leaflet.

The importance of including representatives of the target culture in all stages of testing was clearly apparent with the “Avoid alcohol” pictogram. Early work on the USP version (Dowse & Ehlers, 2001) clearly showed that representing different types of alcoholic beverages by showing various shapes of glasses was meaningless in this population. An added problem was the use of the single slash, a graphical convention used widely in road signs, to denote a “do not” instruction, which was then changed to a negation cross. The many subtle changes made to the bottles and the mug which resulted in a successful final version were only possible as a result of insight offered from participants of the same culture.

The improved interpretation of the pictograms when presented in a combination text-image format (version used in the study of the patient information leaflet) possibly resulted from viewers being better able to contextualise the image within a body of information which provides an automatic prompt to the viewer in creating meaning from the image. Another reason is the generally higher level of education of participants in the study of the patient information leaflet, as all participants were required to possess literacy skills, unlike many of the targeted low literacy participants in the Pictogram Study.

Information leaflets should stimulate the interest of the consumer, and should be user-friendly, attractive, informative and easily readable. Consumer testing, in which consumer preferences are evaluated via open-ended questions, is the best way to assess this and forms an important part of the design process of patient information leaflets (Dickinson et al. 2001). This study employed a combination of open-ended and closed questions to ascertain opinion and preference, a process which was invaluable in informing the modification of the document and optimising its physical appearance and readability.

The lack of understanding of the words “antiretrovirals”, “CD4 count” and “viral load” may seem surprising, given the prevalence of HIV/AIDS in this country. However, this study was conducted at a time when the availability of antiretrovirals to patients in the public health sector was still severely limited. In addition, participants in the study were not taking antiretrovirals and were unfamiliar with the disease. It is anticipated that almost all patients on antiretrovirals would now be familiar with these words.

South Africa has 11 official languages, which complicates the distribution of “one-size-fits-all” information written in only one language. In accordance with previous findings (Mwingira & Dowse, 2007; Schaafsma et al. 2003), participants in this study strongly supported patient information leaflets being available in the patient’s language of choice, sending a clear message that such materials must be prepared in a variety of languages to satisfy the linguistically diverse South African population. African languages have a strong oral tradition and many modern medical terms have not been directly translated. This creates problems in preparing a written translation of these leaflets as a single English medical term may need to be described using a number of less specific, descriptive African words. This may partially account for almost a third of the participants choosing to read the English version. However, these participants were generally better educated and would therefore have had more experience with reading English texts.

Most industry-generated patient information leaflets are written according to a closely controlled format legislated by national guidelines with minimal deviation being allowed. Although considerable effort is involved in developing such materials, their design mostly reflects a top-down health professional and/or manufacturer perspective rather than a patient-focused approach, and may not adequately cater for patient-related factors such as health literacy level, culture, health beliefs, needs and opinions. In a recent systematic review, Grime, Blenkinsopp, Raynor, Pollock and Knapp (2007) noted that patient experiences were seldom incorporated in written medicines information. Patients queried the independence of information produced by the pharmaceutical industry with their vested interests, feeling that the content of the leaflets was dictated more by medicolegal issues than the needs of the patient.

In May 2004, the South African Medicines Control Council (MCC) published the first version of a document entitled “Guideline on the Requirements for Patient Information Leaflets” (Medicines Control Council, 2004). The guidelines require the inclusion of information such as the proprietary name, the composition of the medicine, interactions, presentation and description of packaging material, description of physical appearance of the table, registration number of the medicine and the verbatim inclusion of certain statements pertaining to areas such as pregnancy and side effects amongst others. One of the requirements was a product description section, which appears at the end of the

experimental patient information leaflet. In accordance with the findings of Grime et al. (2007), this section elicited a general consensus of being too technical and of little value to patients. In fact it was considered to be an important negative factor in that it adversely increased the overall length of the patient information leaflet and created unnecessary anxiety as readers were unable to relate this information to their own medicine-taking experiences.

The patient information leaflet in this study did not include all the legal requirements, although this was the original intention, as it would have resulted in an unacceptably long document. When designing materials such as these, user opinion and user reading ability should be taken into account by regulatory bodies when deciding on essential drug-related information. This is particularly relevant for important and potentially dangerous products such as medicines. Despite attempts to simplify and shorten the patient information leaflet, we were constrained by trying to satisfy many of the local legal requirements.

The MCC guidelines inform the developers of patient information leaflets on their content, format and readability but there is no requirement for evaluation of the final product prior to distribution and it is uncertain whether patient information leaflets developed using these guidelines will appropriately cater for the enormous diversity of the South African population.

The industry generates individual patient information leaflets for each antiretroviral, meaning that patients would receive three different leaflets for their triple therapy antiretroviral regimen, a volume of information likely to challenge even the most accomplished reader. A much more sensible approach is to produce a leaflet for each official three-drug regimen used in the public sector. Currently in South Africa, patient information leaflets do not appear to be included in the commercial medicine container for all antiretrovirals. When it is included, it is usually attached to the “package insert” which is information intended for health professionals, and is meant to be torn off and distributed to patients. This is a timeconsuming, unwieldy process and there are problems with this information, including the thin quality of the paper, the small size of the font, the reading level of the text, and the layout, all of which are factors detracting from the usefulness and readability of such information in a population with limited reading skills.

Conclusion

Written medicines information is currently not being distributed to South African HIV/AIDS patients, despite regulations mandating this process. Given the need for optimal self-care and medicine-taking behaviour in these patients, an urgent need exists for written information that is comprehensive yet simple and readable, and it should be available at all health care sites. This study showed that medicines information designed and tested according to good practice guidelines, taking patient characteristics into account, was successful in communicating essential medicine-related information. Medicines information should be designed specifically to cater for our diverse local population and should take into account the widely varying reading skills and cultures of the South African population, it should be available in the first language of the patient and should include visuals to enhance the appeal and user-friendliness of the material. All information intended for patients should be tested in the target group before distribution. The approach to designing and developing the visuals and the patient information leaflet used in this study forms a sound basis for extending the work to additional drug groups and to other African populations.

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Appendix

Pictograms in medicines information

Appendix

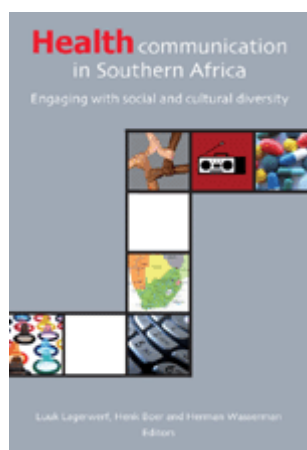
The development of the pictograms is schematized below. The intended meaning is listed in the left-most column, followed by the communication adjustments with correctness percentages from left to right. In the right-most column, examples of misinterpretations of the third picture in each row are given.

Intention	USP version	Local version	Pictogram study version	Patient Information Leaflet study version	Misinterpretations from pictogram study
Take medicines three times a day					Take 3 tablets 3 times a day Take on the clock every minute Four medicines bottles and 4 checks Take tablets and check in the box
Take medicines with a glass of water					Patients coughing/coughing not body parts Shower or open and glass Take medicines with food Take medicines with a little water or you may cough-out pills
Do not drink alcohol while taking these medicines					Do not take with food/drink - swallow traditional medicines Do not drink these drinks or the same time with medicines, only later Drink these while taking the medicines Take medicines with milk, it is more water in a jug Do not take pills and medicines together

<p>Store medicines in a cool, dry place away from heat and sunlight</p> <p>61.7</p>	<p>80.4</p>	<p>88.7</p>	<p>94.7</p>	<p>Stop smoking and eat the medicines</p> <p>Keep safety use use medicines properly</p> <p>Keep medicines in cupboard that should be closed at all times</p> <p>Keep medicines in cupboard and the box with boxes it is possible to do</p> <p>Use medicines through a window</p>
<p>Keep all medicines out of the reach of children</p> <p>Unread</p>	<p>Unread</p>	<p>80.9</p>	<p>100.0</p>	<p>Keep medicines in a cupboard - the more will give them to the child</p> <p>Change keep medicines cupboard locked so that children do not reach</p> <p>Open cupboard to share medicines</p> <p>Medicines displayed are for the body</p>

Results from the Patient Information Study are reported in this chapter. Results for interpretation are reported for a subset of participants (n=7) from who they returned from. Source: A. S. Jones (2000). Discussion of misinterpretation of these pictograms appeared in Jones & Miller (2001, 2006).

Health Communication In Southern Africa ~ Edutainment Radio Programmes: The Importance Of Culturally Relevant Stories



Abstract

The ways in which journalists frame HIV stories can strongly contribute towards news consumers' perceptions of the epidemic. This paper discusses the news values of HIV radio programmes in Ethiopia, Kenya and South Africa. It argues that the culturally appropriate 'humanisation' of HIV stories and the proper use of conflict as adding news value are paramount to the impact of stories. The skillful application of news values can make almost any HIV-related story newsworthy and therefore part of mainstream news. Moreover, it is maintained that HIV advocacy environments contribute to the newsworthiness of HIV stories in the media. The AIDS advocacy milieus of South Africa and Kenya are compared and related to the type of HIV stories that are published and broadcast in the respective countries. Journalism training methods are critically discussed in the context of the above. It is argued, that, in developing countries, where journalists often lack basic journalism skills, it is not sufficient to provide reporters with HIV-related information; HIV information sharing should be combined with general journalism training and mentoring.

Introduction

In December 2007, an excited Bashir Osman - a Somaligna-speaking journalist from Dire Dawa in the east of Ethiopia - broadcast a live call-in show on breastfeeding and HIV to his Somali audience on Dire 106.1 FM. According to the most recent Ethiopian government figures, Dire Dawa has the second highest HIV prevalence rate in the country, and almost doubles the national average. Each year there are almost 1, 000 HIV positive pregnancies with at least 230 children born with the virus. Yet this was the first HIV programme that Bashir had ever

produced.

AIDS was so stigmatised in the region that Dire 106.1 FM hardly ever discussed it on air. And Osman had no problem following this route. A week before the broadcast, the journalist – like most of his listeners – refused to be in the same room as people with HIV because he “didn’t want to risk breathing the same air” (Osman cited in De Masi, 2008) as them. He would never consider sharing a plate, or hosting an HIV positive person in his home, and thought it a deep insult to be tested for the virus.

But then Osman accessed what turned out to be a precious piece of culturally relevant information: he learned that babies of HIV positive women can get infected with the virus through their mothers’ breast milk (personal communication, December 6, 2007). All mothers with babies in his community breastfed their infants ... including his very own wife. His own five-month old baby could be at risk, he perceived with shock, because neither he nor his wife knew their HIV status. The realisation changed Osman’s entire view on AIDS, and HIV was suddenly a virus that had the potential to directly impact his own life and those of everyone else he knew, in ways he had previously vehemently denied (personal communication, December 6, 2007). In short, this piece of information made AIDS newsworthy to Osman, his community and his editors. It became something that was crucial and worthwhile to talk about.

HIV and the News Media

Several communication experts, AIDS activists and journalists (Collins, 2005; Kinsella, 1989; Malan & Gold, 2006; Scalway, 2003; Shilts, 1987) have argued that the news media have the potential to be an immensely powerful tool in the response to HIV. According to the Joint United Nations Programme on HIV/AIDS Executive Director (UNAIDS), dr. Peter Piot, “journalists can save more lives than doctors in terms of HIV prevention because preventing HIV is about communication and changing norms” (Piot, 2006).

Proving statements like this, however, is very complex; studies have not been able to conclusively show that stories in the news media have resulted in change in HIV-related behaviour on a large scale. Research has, however, strongly suggested that news stories are capable of setting the framework in which citizens discuss public events. McCombs and Shaw (1972) demonstrated that there was a strong relation between the topics that the news media highlighted

during an American election campaign and the topics that news consumers identified as important. Another US study illustrated the power of broadcast news to set the policy agenda when it proved that evening news bulletins had the effect of defining the policy areas by which the president should be judged (Iyengar et al., 1984).

McCombs and Ghanem (2001) have argued that “the level degree of emphasis placed on issues in the mass media influences the priority accorded these issues by the public” (cited in Reese, Gandy & Grant, 2001, p. 67). Dearing and Rogers (1996) stated that this proposition had been supported by more than 200 studies.

But, I would argue that the regular publishing or airing of stories on a certain subject does not necessarily lead to the public taking note of that subject. If such stories do not directly relate to the lives of readers or broadcast audiences, or are not presented in captivating ways with strong news values, they are unlikely to influence news consumers’ opinions – whether negatively or positively. In the case of a highly stigmatised and sensitive subject such as HIV/AIDS, even more so. Osman broadcast an interview with an HIV positive woman in her mid-twenties. Her name was Meskerem. He met her at an HIV journalism training of the media organization, Internews Network, that he was attending. Meskerem was mother to a baby that was HIV negative because she had used freely available drugs that helped to prevent her baby from becoming infected. Doctors advised her not to breastfeed – unless she could do so exclusively (i.e. without feeding the baby anything other than breast milk for five months followed by a total halt to breastfeeding).

When my listeners heard the woman speak about breastfeeding and HIV, everyone started to send text messages from their cell phones”, Osman says. “Like me, they wanted to know that their babies wouldn’t get harmed by HIV” (personal communication, December 10, 2007).

The information was directly relevant to the lives of the people of Dire Dawa. Moreover, it was presented with a “human face”, and told by an HIV positive

Ethiopian mother herself. And, on top of that, a strikingly attractive and presentable young woman that Osman acknowledged he initially could “not believe was infected with HIV because she looked so healthy and vibrant”

(personal communication, December 10, 2007). The interview was followed by a live call-in show with an instudio specialist HIV nurse who answered callers' questions or text messages. Most people who phoned or sent texts were desperate to know what they needed to do to protect their babies (Osman cited in De Masi, 2008; personal communication with De Masi, June 29, 2008). The nurse's most common answer was to tell mothers to get themselves and their babies tested for HIV.

Previously, Osman hardly got any strong audience responses. In many of his programmes - on other topics - he talked almost exclusively. But his HIV programme was different: it framed the AIDS pandemic in a human and culturally relevant way. The fact that it contained a local woman with HIV who was mother to an HIV negative baby, and that the dangers of breastfeeding were explained to a "breastfeeding society", is what made it of cultural relevance and ultimately newsworthy. Had Osman done his programme in the usual way, by inviting government spokespeople to rattle off statistics on health related subjects, his audience response is unlikely to have been the same. In his words:

They would have been their usual self, and not respond at all. I've realised those statistics alone don't move them. It's the human face and bringing out something that directly impacts them, that makes all the difference. Prior to this program, I didn't think it was possible to make HIV newsworthy. I thought people just didn't want to hear about it any longer (personal communication, December 10, 2007).

Influencing audiences

Bernard Cohen (1963, p. 13) has encapsulated the news media's agenda-setting function in a much quoted statement: "[The press] may not be successful much of the time in telling people what to think, but it is stunningly successful in telling its readers what to think about". By this, he meant that the news media can influence the topics news consumers talk and think about, but don't necessarily determine their opinions on those subjects.

However, some scholars find Cohen's statement misleading. Entman (2007) argued that it is impossible for the media to tell consumers what to think about without also exerting considerable influence over their opinions on the subjects they think about. Entman contended that "getting people to think (and behave) in a certain way requires selecting some things to tell them about and

efficiently cueing them on how these elements mesh with their own scheme systems" (Entman, 2007, p. 165). Moreover, Malan (2006) has asserted that the South African news media did in fact tell the public what to think with regards to AIDS policies (that they "lack comprehensiveness", p. 41) and antiretrovirals (that they "are effective and should be made available", p. 41) in the late nineties and early 2000s. In the case of Osman's radio program, the media or experts on his programme told listeners to "get tested for HIV" and "not breastfeed their babies for longer than six months if they test HIV positive".

Stories can obviously also negatively impact societies, sometimes resulting in media consumers thinking the "wrong" things. In March 2004 one of Kenya's major national dailies, The Standard, published a front page story on HIV tests arguing that the rapid tests used in VCT centers - which enable clients to receive their test results on the same day - were inaccurate. The news quickly spread when one of the most popular Nairobi based radio stations, Kiss FM, picked up on the story in its morning news bulletins. Most other radio stations followed suit. The story was covered by every major newspaper, radio and television network throughout the week, by using a strong news value: conflict.

It became an issue of extreme concern to AIDS organizations operating in Kenya. Although HIV testing experts were eventually quoted, and they explained why the stories were incorrect and that the tests were indeed accurate, the damage had been done. According to Emma Mwamburi, a USAID programme officer responsible for managing the US government's support to HIV testing in Kenya, several VCT centers all over Kenya reported a drastic decrease in their clientele for months after the publication and broadcast of the stories. Many Kenyans demanded to be tested with the expensive HIV kits that were used in hospitals at the time (ELISA tests). It took 3 days to get results from such tests, as analysis had to be completed in laboratories. This made the ELISA tests considerably more expensive to carry out than rapid tests; yet they were no more accurate.

Upon subsequent investigation, it was established that the source of the initial story that had painted the rapid tests as inaccurate was based at a company that had previously made large amounts of money from production of ELISA tests. When it was realised in Kenya that cheaper rapid tests were just as accurate as ELISA tests, this firm began losing its previous profits. Hence its spread of a false story, and one that did tremendous damage for a very significant

amount of time. It is therefore extremely important that journalists access accurate HIV information and are trained on how to use this information effectively. Inaccurate information presented with strong values and in captivating ways can potentially grasp the attention of news consumers in similar ways to accurate information.

Media and society

Researchers such as Garfinkel (1967), Goffman (1974) and Berger and Luckman (1967) have argued that news does not mirror society, but rather helps to shape it. These researchers have maintained that, when journalists describe events, they actively define those events by selectively attributing to them certain details or particulars. They have contended that news stories define what is “deviant” in society and what is “normative” and that news acts as a selective “window on the world” (Tuchman, 1978, p.1).

Osman’s report defined what was “normative” – namely breastfeeding – and what was “deviant” – namely talking about HIV and knowing your HIV status. Once the culturally-relevant information – that the breast milk of infected mothers can infect their babies – had been shared, knowing ones’ HIV status became “normative”; it became necessary to get tested for the virus as it could impact on ones’ babies’ health.

The culturally relevant framing of his programme encouraged Osman’s listeners to ask questions about HIV and think about the potential impact of the virus on their own lives. In the media analyst Robert Entman’s (2007) words, “it raised the salience or apparent importance of certain ideas”, in this case a virus that no one in the community dared to talk about and journalists at Osman’s radio station certainly did not address on radio. This is reflected in the number of call-ins/text messages his programme received: almost triple that of any of his previous radio programmes (that did not address HIV). The enhanced interest was an indication that the culturally-relevant way in which he framed HIV appealed to his listeners and significantly increased HIV-related discussion ... So much so that Bashir ended up doing two follow-up radio programmes on the issue and managed to sustain a high level of audience participation.

There is a common perception that HIV has been over-reported and that audiences are “sick and tired” of it. But an audience perception study by the University of the Witwatersrand in South Africa seemed to dispel this myth, at

least as far as a Durban township is concerned. Kwazulu/Natal, the province in the east of the country, in which Durban is located, is often referred to as the “AIDS capital of the world”. AIDS is regularly covered in the city’s local news media. Surprisingly, Jooste (2004) found that respondents didn’t think AIDS was over-reported, but rather that they weren’t hearing or reading enough of the right type of stories.

Jooste analyzed the responses of 200 people in Cato Manor, an informal settlement in Durban. Ninety eight per cent of them said they wanted more reporting on HIV-related matters in print and broadcast media. When Jooste asked them what “kind” of reporting they wanted, 80 per cent indicated they were desirous of “more about people like us” or “more about people living with AIDS”. The researcher discovered that the stories respondents could recall most often were “peoplecentered” stories. A number mentioned the child activist, Nkosi Johnson – even though he had died about a year earlier – and Gugu Dlamini, a Durban woman who was killed two years earlier for revealing her HIV status. “Both old stories”, but they were “the ones best remembered”. In the case of Osman’s program, more than half of callers’ text messages and call-ins referred to “Meskerem’s story”. One read: “How did Meskerem know she was positive?” and another read “How did Meskerem know how to help her baby?”

These listener responses confirm Jooste’s findings: that media consumers remember “people-centered” stories and identify better with reports about “people like us”. The fact that an Ethiopian mother with HIV told her story herself helped listeners to identify with the issue and “defined a problem worthy of public attention” (Entman, 2007). In stark contrast to Osman’s HIV radio program, an AIDS programme on a major Ethiopian broadcaster seems to have had very little effect. It rarely receives any text messages or call-ins and according to producers, listeners seem to remember very little HIV-related information from it. While this programme is broadcast biweekly, thus regularly, the contents don’t seem to attract listeners – it consists of presenters reading HIV-related information and shocking statistics live on air and medical or government officers explaining strategic plans and scientific information. It rarely humanises the epidemic or makes it culturally relevant to listeners, and often relies on sponsorships, as it hardly ever attracts advertisements.

Lucy Macharia’s programme

A similar radio story of Kenyan journalist Lucy Macharia(i) in 2005 also illustrates

the news value of HIV programmes with a human face. Lucy attended a media workshop that focused on Voluntary Counseling and Testing (VCT). When she learned about the symptoms of HIV-related illnesses, she strongly suspected that her sickly sister was infected with the virus.

The radio programme that Macharia produced related her own experience of having visited a VCT centre to get tested for HIV. It was broadcast on the Catholic radio station, Radio Waumini, for which she worked at the time. She asked her sister to listen to the broadcast and also took it home on CD so that her sibling could listen to it repeatedly. Like Osman, Macharia's programme began with a human interest feature followed by live call-in show with an in-studio expert, in this case a VCT counselor, that addressed callers' questions. The human interest feature related Macharia's fears when she waited for her results. Part of the script read:

I don't need to tell you what I feel. My mind is drawing pictures of what the test kit looks like with my blood on it. Is there one or two lines? One red line means negative, two means I'm positive". But it also explained the help she received: "But Bancy, the counselor, speaks to me. She makes me feel safe. She tells me that it's important to know your HIV status. It helps you to protect yourself (Macharia, 2004).

Similar to Osman's story, Macharia's programme 'humanised' HIV for her listeners. It enlivened the issue, taking it away from the cold realms of words on paper, and far away from scientific lectures given by "dry" experts who were the usual participants in such shows and who never connected with radio listeners and hardly ever elicited great response. The fact that Macharia went for an HIV test herself and openly and humbly spoke about her fears when doing so and allowed listeners a "look" into an HIV testing room.

The human framing of the programme "defined a problem worthy of public ... attention" (Entman, 2007) and raised the importance of going for an HIV test. This is reflected in the kind of call-in questions the programme received - the three most common call-in questions were: "How did you feel when you went for the HIV test", "How do I get to go to the same HIV testing centre as you?" and "How did you know that the test was accurate?" (personal communication, April 30, 2004). Previously, said Macharia, her listeners had regarded the tests as "something out there that other people, but not me, do". After the programme it

changed to “something that Macharia has done” and listeners should therefore consider doing as well. After listening to Macharia’s program, her sister asked her to accompany her to get tested for HIV, at the same place as Macharia had undergone such a procedure. And, on the morning that they subsequently visited the specific VCT centre, Macharia’s sister did, indeed, test positive. According to Macharia, the “biggest factor” in convincing her sister to get tested for the virus was the fact that Macharia herself had been tested and that she had the opportunity to first hear “what happens in a counseling and testing room....having heard what a counselor says to you” and hearing the sound on the air of an actual testing kit being opened and used “is what made all the difference”. Macharia says it in fact gave her sister the “courage” to finally overcome her fear and face up to the reality that she was HIV positive (personal communication, May 5, 2004).

Two follow-up radio programmes on this issue proved that some of Macharia’s listeners seemed to have the same experience as her sister when listening to the programme. A week after the broadcast of the first programme – on a Sunday morning – four listeners called into Macharia’s next programme reporting that they had gone for HIV tests as a result of the first programme and requested to relate their experiences on air. Moreover, Macharia’s news editor was so convinced by the programme himself, that he allocated her airtime for a weekly HIV programme and had the entire staff meet with a VCT counselor who he invited to visit the radio station.

Prior to this program, Macharia had produced at least eight HIV programmes that had not resulted in a single call-in. Instead, she reported, it seemed as if her listeners wanted to “stay away” from the issue. She believes one of the main reasons for this is the fact that her programme didn’t make use of strong news values, and never humanised HIV:

I always presented HIV as something out there for other people...something that didn’t have a face and certainly didn’t impact on me. When I changed that, the response to my programme changed. I started getting listener reactions – often more reaction than to programmes I produced on other much more accessible subjects...I realised listeners aren’t tired of HIV, they’re just tired of the way in which we present it (personal communication, May 5, 2004).

‘A Stitch in Time’ (Kenyan Broadcasting Corporation) One more example of an

HIV programme that has used 'humanisation' as a news value is that of the radio presenter/producer team Ann Mikia and freelancer Sammy Muraya from the Kenyan Broadcasting Corporation's (KBC's) weekly HIV/AIDS programme "A Stitch in Time". In fact, it seems to have led to government action and strongly impacted on policy change. In August 2004 Mikia and Muraya decided to tackle a difficult topic which was not being addressed by the Kenyan government's AIDS programme. The radio team focused on matatu (minibus taxi) touts and drivers and the schoolgirls who were exchanging sex with the drivers and touts for free rides to school or money. Muraya took to the streets and recorded interviews with matatu drivers and touts, schoolgirls and also with officials from the Matatu Drivers Association (Muraya, 2004).

He produced a five- minute radio segment that was followed by a live call-in session between listeners and representatives from the National AIDS Control Council (NACC) and the Drivers Association (Malan, 2005). Muraya's humaninterest report raised and defined a problem "worthy of ...government attention". (Entman, 2007). In addition to this, the programme was framed in a culturally relevant way. The story raised many questions about the lack of government intervention with regards to transactional sex, a common occurrence in Kenya that most people know of. The representative from the Matatu Drivers Association followed up by asking the National AIDS Control Council (NACC) to commit to action on air. The NACC could not deny any of the problems that were raised in the programme as they were confirmed by the schoolgirls and matatu drivers themselves. One girl in the report admitted that "They [the matatu drivers] have sex [with us] and disappear just like that".

In December 2004 the team did a follow-programme about the issue, reminding the NACC that the problem had still not been addressed and asking them to explain on air why that was the case. Angry listeners called in to ask "Why is this happening?" and why nothing much was being done about it, while the girls and matatu drivers themselves were admitting to this happening. Then, in May 2005 - six months later - the government launched a matatu drivers HIV/AIDS programme for which they set up a special voluntary counselling and testing (VCT) centre for matatu drivers and provided HIV/AIDS counselling specifically targeted at them. The drivers were also provided with stickers with AIDS prevention messages to display in their taxis. According to NACC spokesman, Abel Nyagwa, the radio programme "A Stitch in Time" was a key

player in improving relations with the Matatu Drivers Association.

The radio team's culturally relevant and human interest framing of this story played a strong role in actively shaping the government's perception of the extent of the matatu crisis that eventually led to action and "activate[ed] schemas that encourage[d] target audiences to think, feel and decide in a particular way" (Entman, 2007). It also encouraged listeners to respond in ways that put pressure on the government to take action.

Journalism training and mentoring

Producing compelling HIV programmes is not something that comes without considerable journalistic skill. In this section the role of media training and

mentoring of journalists in developing countries are discussed in the context of the production of quality HIV radio programmes.

Challenges and limitations

Mikia, Osman and Muraya followed a well-tested method of radio production, albeit as yet uncommon in the developing world: to begin their radio programmes with focused, theme-based human interest radio features, followed by live call-in shows with in-studio experts. It is indeed a relatively straightforward radio production method ... But it is one that requires a considerable amount of journalistic skills and resources that these three journalists would not have mastered, nor had access to, without their having attended intensive media training workshops and receiving ongoing mentoring from highly experienced journalism trainers at an international media development organization.

But it is not only HIV-related knowledge that is required to tell such stories successfully. A significant amount of journalistic skill is needed in order to produce news media content that carefully interlaces aspects of the epidemic with "case studies" - people and communities which the virus has impacted - and to still be able to make it newsworthy. As a radio journalist you need to understand, and write well enough, to present "life with HIV" in a way that makes news consumers realise how it affects them as well.

In addition to this, radio producers and presenters need access to telephones and the internet for research, computers with digital sound editing programmes and recording equipment - facilities that are rarely available at under resourced

radio stations in poorer countries.

Training and access to resources

All three journalists received access to all of these facilities for the production of their programmes by each attending a weeklong HIV feature story production workshop at Internews Network's Local Voices programme. The programme follows a training method different from that of most other HIV media training programmes, with a 70 focus on the development of radio journalism skills and only 30 on HIV knowledge. Other HIV media trainings generally approach this very differently, mainly focusing on nurturing HIV knowledge and not journalism skills. At seven days duration, Local Voices workshops are also considerably longer than others, which are generally two to three days. It also trains no more than 10 journalists at a time. All trainees leave the workshops with a ready-to-air radio feature and outline with questions and research for the live call-in show that is to follow the broadcast of their human-interest stories.

During their respective workshops, the journalists learned how to write good scripts, to structure stories, to digitally edit sound and to use appropriate HIV

language. They met and interviewed people with HIV and visited pregnancy and HIV testing centres where they recorded natural sound and interviews with counsellors. During the production of their stories, they were carefully mentored by experienced radio journalists who specialised in HIV reporting to ensure quality. Each of them received access to recording equipment while on the training and received their own equipment after the production of five post workshop HIV stories. Mikia has also received several travel grants to produce HIV stories outside of her home city, Nairobi.

A combination of this training approach and access to facilities enabled them to produce HIV stories with human and culturally relevant frames. Without the training and relevant facilities doing this successfully would have proved unlikely, as they would not have had access to phones and research facilities to find the "human" faces of their stories and not have known how to effectively weave them into their programmes.

Advocacy environments

HIV advocacy environments can significantly contribute to the newsworthiness of HIV stories in the news media. The stories of Osman, Mikia and Muraya

were produced in an environment where many other inaccurate HIV stories, like the previously mentioned rapid test/VCT example, are being published simultaneously.

The rapid test story was for instance published a mere week ahead of Lucy Macharia's programme on HIV testing. This resulted in several conflicting messages competing with each other in the media.

Traditional approaches to analyzing news that argue that the news media reflect society without having much influence on shaping that information, hold some water, when one considers the influence of AIDS advocacy environments in the case of Kenya and South Africa. Although none of the abovementioned stories were aired or published in South Africa, the diverse civil societies of Kenya and South Africa are a good example to address "advocacy environments as a contributing factor to the framing of stories".

South Africa and Kenya have two very different civil societies. South Africa's AIDS activists are extremely vocal and proactive, holding regular protest marches and issuing almost daily press releases. In Kenya, advocacy groups are not nearly as visible and do not place as much emphasis on developing personal relationships with journalists. The ability of civil society organizations and advocacy groups to make their voices heard and present their views in a newsworthy manner, makes a vast difference to what ends up in the news media (Malan, 2005).

When the VCT story about rapid tests broke in Kenya, radio journalists had access to very few HIV testing experts they felt comfortable enough to phone at 6 am in the morning to get a comment on the newspaper article that had appeared that same morning. As a result, comments with accurate scientific information that could counter the information in The Standard's erroneous article was only obtained and reflected much later that day, and in some cases only later that week. So, for a significant amount of time, the Kenyan public only had access to harmful information regarding HIV testing.

In South Africa, on the other hand, the largest AIDS advocacy group, Treatment Action Campaign, in many cases dictates what appears in the news media. The group frames its opinions in newsworthy ways and TAC spokespeople are available to the media on short notice at almost any time of the day. As a

result, the movement's views are widely quoted in the local news media and scientifically inaccurate news reports and statements are instantly addressed. Several studies have indicated that the TAC is quoted more than any other source in the South African media - and that includes the government (Spur, 2005; Finlay 2004). The TAC uses newsworthy tactics such as protests, civil disobedience and public confrontation of government ministers to keep journalists interested in what they do.

An example of this would be the opening day of the fifteenth International Conference on HIV/AIDS in Bangkok, Thailand when South Africa's Health

Minister, Dr. Manto Tshabalala-Msimang, told journalists that the drug Nevirapine (a cost-effective drug used to prevent mother-to-child-transmission of HIV) was unsafe to use (Brummer, 2004). Two years prior to the conference, South Africa's highest court had ordered Dr. Tshabalala-Msimang to make the drug available, free of charge, to HIV positive pregnant women and their babies. The Minister had displayed resistance to the order ever since. Within a few hours after the Minister's statement, the TAC, AIDS Law Project (ALP), and Medecins Sans Frontieres (MSF) held an emergency mass meeting for South African AIDS activists, health workers, scientists, and journalists attending the conference. The story, along with reactions from local non-governmental organizations, that challenged the minister's statements, was headlined in almost every major newspaper and broadcast on regional and national radio and television stations throughout the country (Malan, 2005). Local NGOs and scientists were furious, insisting that statements such as Dr. Tshabalala-Msimang's undermined their efforts to educate South Africa's citizens about prevention against HIV infection. Ultimately, Zackie Achmat, who headed the TAC delegation to the conference, convinced the conference organizers to give the TAC an opportunity to speak at the Thursday morning plenary session, to plead for access to Nevirapine for HIV positive pregnant women in South Africa, and for scientists like Dr. Tshabalala-Msimang to distribute accurate information about the prevention of mother-to-child transmission. In the presence of thousands of participants, the TAC asked session Chairperson Graca Machel, the esteemed Nelson Mandela's wife, to speak to South Africa's Health Minister.

This incident, in which prejudicial and incorrect information was disseminated, and then refuted by activists, is a clear example of NGOs taking on

the responsibility of informing the media and the international community of the facts. The result was responsible media coverage which reflected the quality and efficacy of the activist environment of the country. As a result of this activism, policy or human rights issues relating to HIV appear far more often in the South African than in the Kenyan media (Malan, 2005). In this regard, NGOs, government spokespeople, academic researchers, doctors and AIDS advocates from countries that do not have adequate media liaison skills need as much training as the journalists themselves. They need to be taught how to relate to the media, how to assist reporters to access information, and sometimes they even need to be trained on how to make resources such as transport to some of their projects available to journalists. It is not just the responsibility of the media to tell the story of HIV; the people who produce the research on this epidemic have a responsibility to make it available to society through the news media.

The media training programme in which the journalists who produced the radio programmes discussed in this chapter participated, includes this aspect; at least 10 HIV spokespeople are trained in effective media relations for every 30 journalists trained in the countries where it operates (Kenya, Nigeria, India and Ethiopia). Media relations trainings are five days in duration, with trainees holding an actual media event attended by journalists on the final day. The reasoning behind this approach is that it doesn't make sense to train journalists on how to interview activists and local government spokespeople, NGOs and PLHIV networks if those people are not available to the media as a result of their lack of understanding of the sector.

Conclusion

A combination of strong journalism skills, HIV knowledge and an environment conducive to telling stories about AIDS are essential in empowering the media to assist in the response to HIV. Culturally relevant stories "with a human face" can be incredibly powerful, as shown by the case studies discussed in this chapter. In all of the three human-interest radio programmes that were discussed, the human and culturally relevant framing of the programmes resulted in listener responses that actively engaged with the subjects addressed, whether that was HIV testing, protecting your baby from HIV infection or transactional sex between taxi drivers and school girls.

In the context of HIV and of an increasingly competitive news world, it is no easy task to get airtime for an HIV story and to make an HIV-related human-

interest story newsworthy, accessible and accurate. At a media panel at the International AIDS Conference in Toronto in 2006, the Wall Street Journal Science reporter, Marilyn Chase – who had been reporting on HIV for twenty years – echoed this concern:

As the pace of the epidemic matures, our challenges as reporters get more complicated. Editors get choosier about stories. And that means many projects ... which are worthy ... may not be deemed newsworthy. That requires us, as reporters, to be smarter and more strategic in uncovering unique angles that make clear what really are the breaking, compelling news developments in the epidemic. (HIV science and responsible journalism media panel, 2006).

Reporting on subjects other than HIV/AIDS is often considerably simpler. There is more often than not less science to understand, issues are less sensitive and not as much work and skill is needed to produce good stories.

There are several HIV journalism trainings happening in Africa. But some training organizations ignore the importance of training reporters as much in journalism skills as HIV knowledge. Simply giving journalists access to a vast amount of AIDS-related information by slapping together one speaker after another rarely makes a difference to their reporting. Journalists need more than that – they need to improve their journalism skills, and they need time and money to travel to access the “human faces” or case studies, and research, that will help them to tell compelling HIV-related stories.

In this regard a recommendation is that more journalists are intensively trained in “humanizing” the HIV pandemic. Journalists from all mediums (print, television and radio) should be trained, but, as radio is the most accessible media form in most African countries, it should receive the most attention.

It is also important to provide journalists in Africa with access to facilities and mentors to produce quality HIV stories. Sending journalists back to under-resourced media houses where there are no facilities to create human-interest stories after a training workshop, is counterproductive. If there is no access to facilities, journalists will not be able to effectively apply the skills they were taught in the training. They also need to be mentored by a senior journalist with significant HIV reporting experience to further develop workshop skills. Moreover, it is the responsibility of the news media, training institutions,

activist communities, scientists and governments, amongst others, to cooperate to ensure that the information surrounding HIV given to the public through journalists' stories leads to the saving, and not the endangering, of lives.

The programme topics in Osman, Mikia and Muraya's HIV radio programmes were not addressed as a result of advocacy communities raising their importance; it was journalistic skill and research that motivated reporters to focus on these subjects. Other than in South Africa, reporters in Ethiopia and Kenya can rarely rely on AIDS advocates to identify relevant "news frames" for them.

As shown by the comparison between Kenya and South Africa, the advocacy environments in which reporters file their stories can significantly contribute to the accuracy and creativity - or the opposite - of journalists HIV stories. It is therefore equally important to also train communication teams from government, PLHIV networks and non-profit organizations in effective media relations. The more conducive HIV advocacy environments are to HIV reporting, the better the chances are that creative and accurate stories with "human and culturally appropriate faces" will appear in the media.

NOTE

i. Lucy Macharia is not the journalist's real name; her identity is being protected as her sister is not yet comfortable with being public about her HIV positive status.

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Health Communication In Southern Africa ~ The Employment Of HIV Positive

Young People For Health Promotion In Higher Education: A Case Study Of The DramAidE Health Promoters Project, South Africa



Abstract

This paper explores two essential questions related to health promotion and HIV/AIDS education.

1: Do HIV positive health promoters and peer educators have positive effects on students' health attitudes, behaviours and HIV stigma reduction?

2: Which programme characteristics have better effects on health education performance? The paper seeks to address these questions with relation to the DramAidE Health Promoters Project run at a number of Higher Education Institutions in South Africa. The project makes use of HIV positive young people to live openly as role models with HIV on campus, to break stigma around the disease, increase prevention efforts, and encourage testing for HIV and positive living with HIV. A project evaluation conducted in 2007 included interviewing students, staff and the HIV positive health promoters working at nine campuses across South Africa, and forms the basis for this study.

Introduction

This chapter introduces the DramAidE Health Promoters Project and gives some background on its history and the rationale for its inception, with an overview of the current situation and response to HIV/AIDS at Higher Education Institutions in South Africa. The Health Promoter Project is rooted in the fields of

peer education and entertainment education, and this chapter explores some of the theories that inform those practices, as well as an overview of some of the literature on similar projects that employ HIV positive people.

The chapter then explores two areas of study, namely the effect that HIV positive peer educators have on other students, and the programme characteristics that have better effects on health education performance; in an attempt to highlight good practice in the field of health promotion and HIV prevention efforts in South Africa. Some of the data relevant to the DramAidE Health Promoters Project are presented and discussed, with conclusions regarding the successes, challenges and potential of this strategy.

The DramAidE Health Promoters Project

The social impact of the HIV/AIDS epidemic in South Africa highlights the need to ensure that communities band together to deal with all aspects of the disease. Social behaviour change theories suggest that it is most effective to educate, sensitise and mobilise individuals by addressing the community in which these individuals find themselves, and to make HIV/AIDS a community concern (UNAIDS, 1999b). A number of commentators on HIV/AIDS behaviour change interventions agree that behaviour change can only happen in a supportive context where individuals are empowered to act within the group (Tomaselli, 1997; Airhihenbuwa & Obregon, 2000; Papa et al, 2000; Kelly, Parker & Lewis, 2001; Tufte, 2002).

The Health Promoters Project is a project running in Higher Education Institutions across South Africa, where these institutions are seen as able to respond to HIV/AIDS in a strategic and focused manner, as communities that find themselves within other broader communities. It is understood that the Higher Education sub-sector in South Africa may be disproportionately more affected by HIV/AIDS than other sectors, as the majority of students found on campuses across the country are in the in the age group with the highest prevalence of HIV infection (SAUVCA, 2006). According to a 2000 study conducted by the research organisation Abt Associates, the rate of HIV infection at a university undergraduate level was estimated to be roughly 22. This was expected to rise to 33 by 2005 (Thom & Cullinan, 2003).

Higher Education Institutions are often places where young people first explore serious relationships, and may form opinions and develop behaviour patterns in

relation to sexual behaviour. They are also the training grounds for the leaders and trend-setters of the future. Training these young people to develop a positive attitude towards managing the HIV/AIDS epidemic could ensure that they respond accordingly when they take on positions of power in society. Furthermore, Higher Education Institutions are often well-resourced and well placed to share information and expertise with surrounding communities that may have access to fewer resources. This means that the influence of campus based programmes may spill over into surrounding communities.

The project was developed by DramAidE, a South African based NGO working in educational institutions, and the Johns Hopkins Bloomberg School of Public Health Centre for Communication Programmes (now known in South Africa as Johns Hopkins Health and Education South Africa, JHHESA). It was initially established on nine historically disadvantaged campuses. It involved recruiting young people living openly with HIV to live and work on the campus and to provide information and support to students, as well as to provide a public “face” of the epidemic.

From its inception, the project has grown and gathered popularity. From the initial nine campuses in 2002, DramAidE has been approached over the years by a number of institutions wishing to implement the programme on their campuses. In 2006/7 the project was implemented on 23 campuses and reached an estimated 762.000 students (DramAidE Annual Report, 2007).

The Health Promoters Project aims to personalise the risk of HIV infection and to demystify HIV and AIDS and reduce the stigma attached to living with HIV and AIDS. Through providing health information and support, promoting campus-wide voluntary counselling, testing and treatment and the concept of Positive Living amongst the student population, the project hopes to reduce the number of HIV infections on campus. The health promoter is tasked with spear-heading and facilitating a number of initiatives on campus. These include providing basic HIV/AIDS information to students and staff through workshops and entertainment education based events, providing individual support to students and staff both affected and infected with HIV/AIDS, providing information to students as well as access to appropriate referral services, and providing assistance and leadership with HIV/AIDS programmes on campus and for community outreach programmes.

In practice, the health promoters work in orientation programmes for new students, provide workshops for peer educators, and develop support groups for students who are HIV positive. Peer education models provide the framework for this project by supporting HIV awareness events such as Candlelight Memorial Services, concerts and events that emphasise Voluntary Counselling and Testing (VCT) and ABC ('Abstain, Be faithful, use Condoms') prevention techniques.

Literature review

HIV Positive health promotion

Using specifically chosen individuals as peer educators and role models in health education is a common practice. The practice of using HIV positive people in HIV prevention campaigns has become more common-place in the past decade, as people living with HIV speak out more openly about the disease and have become involved in structured programmes.

Although there is little published South African literature on the issue of the impact of communication campaigns including people living with HIV and AIDS, there are studies from other countries. Studies from both Australia and the United States (Markham et al., 2000; Paxton, 2002) found that HIV positive speakers were highly popular with students and teachers, and had a positive short-term impact on students' attitudes. Both studies found that meeting HIV positive people decreased stigma, fear and prejudice, increased audience awareness about prevention messages and made young people more aware of their own vulnerability to HIV infection. These changed attitudes were still significantly different up to three months after an intervention. The studies found similar reports from Zimbabwe, North America and Thailand.

An early evaluation of the DramAidE programme (Frizelle, 2002) involved a case study of two campuses where HIV positive people were employed on campus in HIV prevention efforts. The evaluation found that the programme had played a valuable role in developing dialogue on stigma and discrimination both on and off campus. The HIV positive young people who were employed were seen as rolemodels by other students, who were assisted to develop their own confidence in their ability to make better lifestyle choices and build healthy relationships. A follow-up evaluation (Mukoma, 2003) found that peer educators working with these HIV positive people had developed a more in-depth understanding of HIV/AIDS, the social issues that place people at risk, gender issues, and VCT through the project. In its conclusions, the research found that the strategy of

using an HIV positive health promoter was effective for impacting on students' knowledge, attitudes and behaviours. All of these studies suggest that health education on HIV that involves people who are themselves HIV positive assists in combating stigma and in allowing people to recognise and assess their own risk behaviours.

Peer education

Peer education typically involves members of a particular group working to educate and develop other members of the same group in order to effect change. Peer education is generally used as a method to influence and change knowledge, attitudes, and behaviours at the individual level. It is also used, however, to effect change more broadly at the community and societal level. Educating a group of individuals can mean that group norms are modified, and that individuals are encouraged to work together to effect changes in their environment (UNAIDS, 1999a).

Peer education has been used globally with groups of all sorts, in schools, factories, religious groups and prisons, in an attempt to share information about HIV/AIDS and to encourage healthy behaviour change. A UNAIDS global study of 30 peer education programmes found that peer educators are seen as “credible teachers and facilitators who possess critical and unique access to their intended audiences” (UNAIDS, 1999a, p. 21). A 1998 study conducted in the United States compared a peer-driven HIV intervention, using intravenous drug users as peer educators with a traditional outreach intervention using professional outreach workers (Broadhead et al, 1998). The study found that utilising active drug users in the intervention allowed access to larger and more diverse networks of the target audience, and that the programme was more cost-effective and more effective in reducing risk behaviour among the target group. The programme used drug users to recruit their peers into an education and counselling programme, based on an incentive system. Results showed that those recruited into the programme by other drug users used their social influence to recruit others to both be educated and to become peer educators. Through peer education these individuals stake their reputation on the sincerity and content of what they convey, and are therefore more likely to practice what they promote, namely safe needle use and safe sex to prevent HIV transmission. This points to the potential of genuine behaviour change through peer education programmes.

Study 1 below seeks to ask whether the DramAidE HIV positive health promoters

and peer educators have had positive effects on students' health behaviours and attitudes, and in HIV stigma reduction.

Programme characteristics and effect on health education

Health communication has come along way from the Shannon and Weaver model of "sender, signal, receiver" (1949), and more importance has been placed on the role of receiver as an active participant in the communication process, encoding and decoding information in an attempt to fully understand and engage with the content of the message. Kincaid's convergence model, redefines communication as "a process in which the participants share information with one another in order to meet a mutual understanding" (Kincaid, 1979). The model suggests that "effective communication begins with the audience, the client, or the consumer and continues over time as a process of mutual adjustment and convergence" (Piotrow et al, 1997, p. 18). One of the key components to the success of any communication intervention is an understanding of the knowledge and attitudes held by the prospective audiences.

Singhal and Rogers (1999) outline a number of factors that influence the effectiveness communication strategies for health promotion (particularly in the field of entertainment education, on which DramAidE bases many of its programmes, including the Health Promoters Project). These six factors include audience characteristics; organisational factors; the media environment in which the programme finds itself; audience research; programme specific factors; and infrastructural factors such as access to support services.

Singhal and Rogers' research suggest that audience members actively negotiate meaning when processing health education messages, and that this meaning can be intended or oppositional. Audience research and the pre-testing of messages can facilitate a dominant intended reading of these messages. They also suggest that audiences interpret messages selectively. The second determinant, organisational factors, includes the presence of champions and strong leadership, access resources such as time and funding, the collaboration of relevant stakeholders and the presence of technical experts including project managers. The third determinant, the media environment, suggest that the degree of media saturation, media credibility, the appropriate channel and the penetration of the target audience through integrated campaigns all influence the success of the programme. Fourthly, Singhal and Rogers (1999) suggest that the quality of

audience research, both formative and summative, can determine a programme's success. The fifth component includes programmespecific factors specific to such interventions, including the use of colloquial language, the employment of both celebrities and real-life characters, programme scheduling and repetition. They suggest that for success, these programmes must be theory based and must contain a balance of education and entertainment. The theories that provide the foundation for entertainment education communication programmes include marketing principles, persuasive communication theory; play theory and social learning theory. The sixth factor that Singhal and Rogers highlight is the need for strong infrastructure to support the programme, including service provision that allows the audience to enact intended behaviour change. Study 2 below refers to these success-determining characteristics identified by Singhal and Rogers (1999) and seeks to find which programme characteristics have better effects on health education performance in the Health Promoters Project.

Study 1: HIV positive health promoters and peer educators' effects on students' health attitudes, behaviours and HIV stigma reduction.

Method

The data for this paper were collected at 9 Higher Education sites across South Africa. This selection crossed a range of provinces in both semi-rural and urban areas. Selected campuses reflect both previously disadvantaged campuses, as well as the previously advantaged campuses, and the student population across campuses covers a variety of race groups, both genders, and a range of students enrolled in both technical and theoretical academic courses. Annual reports are prepared by Health promoters and their campus supervisors and submitted to DramAidE. A collection of reports from 2004-2007 informed this study.

A fieldworker familiar with each site was appointed and briefed about the purpose and methods of the evaluation research project. Instruction was given about fieldwork procedures and data collection methods. As the project unfolds differently across campuses, set questions were not drawn up for these researchers, so as to allow them to develop their own picture of the project on each campus. Evaluation reports are cited and added to the References.

Focus group discussions and interviews. Open ended interviews and focus group discussions were held with all respondents. These were recorded on tape, and notes taken during the sessions. Transcriptions of these interviews and focus

group discussions were analyzed and form the basis of this evaluation.

Health promoters. The health promoters at each campus were individually interviewed by the researcher in person. Some follow-up questions were addressed by telephone or via email. A total of nine health promoters were interviewed.

Health promoter Supervisors. Nine health promoter supervisors were interviewed individually by the researchers and notes taken during these interviews. These supervisors generally hold positions within the HIV/AIDS units of health clinics at each institution.

Peer educators. Peer educators or other students who had attended DramAidE workshops and involved in peer education programmes on the campuses were interviewed, either individually or in focus group discussions. A total of 71 peer educators were interviewed. The sample included a balanced mix of male and female students.

Students. Fifty-two students were randomly selected; exposed and not exposed to the programme they completed questionnaires at two of the campuses.

Reliability. A guideline was drawn up for researchers but no formal protocol or list of questions was specified for the research. This has resulted in different questions being asked and answered at different sites, and the content of the data varies accordingly. The quality of the data at the different sites also varies, as some of the regional researchers were closer to the programme and therefore more able to ask probing questions with an informed understanding of the project.

Results

The key difference between the Health Promoters Project and many other HIV/AIDS initiatives is the employment of HIV positive individuals to fulfill the role of health promoters. According to the DramAidE programme plans, the health promoter must be a person who is living openly and positively with HIV. The benefits of using people who are HIV positive are highlighted in the interviews with students and staff.

It has made a huge difference. I was diagnosed this year in June and I couldn't cope. I was frustrated and lonely because I haven't told my family yet. But talking

to the Health promoter really helped. She made me realise that I have more to live for and that this is just another challenge I need to face positively (HIV positive student).

Peer educators at most campuses reported that knowing the health promoter personally makes the workshops that they run easier, as they can refer to a close and relevant example of living with HIV.

She's like a living example, which makes your message stronger. You can say to people, 'I know a person like this, she's with us. She's healthy and strong. If someone gets HIV, they can live beyond that (Peer Educator, Cape Peninsula University of Technology).

On some campuses, the health promoter is linked with the clinic and a great deal of their time is spent counselling students for VCT. The benefits to the health clinic of having an HIV positive person on the team are noted from staff at these clinics on many campuses. VCT Campaigns conducted as part of the project are reported as having been successful at most campuses, and result in an increased uptake of campus VCT services. The health promoters are seen as good role models for those who are thinking about testing.

Students find it easier to go for a test because they see someone else who is living openly with HIV (Supervisor, Cape Peninsula University of Technology).

The continued visibility of students living positively with HIV on the campuses helps to counter stigma. Living openly with HIV means being a positive example to students, and the health promoter has taken on the mantle of support at most campuses.

He acts as the pillar of our care and support towards HIV positive students... The emotional and social support he gives students is incredible (Programme supervisor, University of the Western Cape).

The research across campuses suggests that the health promoters offer support to those both affected by and infected with HIV, as well as to other students and staff who have family members who are affected.

When the time came I was ready, I had accepted my father's status and I could help my mother accept it too. Even afterwards at the church, my mother and I

could be there for others who came to us to help them... (the health promoter) helped me a lot (Student, Durban University of Technology).

Peer educators and others who attend the health promoters' workshops report a change in attitude and a move towards safer sex behaviours, which are part of the prevention efforts of the project. Both peer educators and clinic staff across campuses suggest that the health promoter has a great effect on attitudes and moving people to take responsibility for their lives.

He came to residence and spoke and he was so strong, if he can stand up, encouraging me to be strong, so I went the next day. It was not about the result, but only but that I could stand up and choose for myself and show that strength in myself (Student).

The health promoters' presence on campus normalises HIV and allows students the opportunity to reassess their prejudices.

At first I knew the virus was there, but when I saw the living proof in (her), it changed everything. I thought maybe someone who was positive would be different from us. But it's not written on their face, you can't see it. Seeing her over and over, it's like normal now (Peer Educator, Cape Peninsula University of Technology).

Students comment that they find it difficult to think of the health promoter as 'different' from themselves. This reduces 'othering' and stigma on campus.

We forget his status; we admire him so much as a person. He does not preach but practices strength and positive living. He is a leader and I have taken this into my life (Peer Educator).

Students report on the empowering experiences of workshops that they have attended, and reflect on how they now practice reformed behaviours and attitudes. These differ from the patriarchal and often stereotypical learnt behaviours that are sometimes experienced in more familiar environments. On most campuses, peer educators are directly affected by the health promoter, and research at one campus noted that they agreed unanimously that the health promoter was having an impact on other students (Burman, 2007). Students confirm that the role of the health promoter is a powerful force in their lives. They say that the programme works as both a stimulus and inspiration. The research

findings suggest that the HIV positive health promoters, together with the peer educators challenge students' attitudes towards those who are HIV positive, as well as their attitude towards their own personal HIV vulnerability and their ability to cope with a positive diagnosis.

Campuses report a direct correlation between the involvement of the health promoters in VCT campaigns and the number of students reporting for testing, suggesting that student health behaviour is also influenced by the health promoter. The research undertaken at the selected sites also suggests that stigma levels have decreased since health promoters started working on campuses. This may be attributed to a multitude of factors outside the project such as increased portrayals of HIV positive characters on television, national media campaigns and increases in disclosure by celebrities. The health promoter, however, is a personal role model to whom the campus has access to.

Study 2: Programme characteristics' effects on health education performance

The 2007 project evaluation uncovered a wealth of information on the varying efficacy of the project on each of the campuses in which it runs. For the purposes of this study, I have arranged the data collected on the programme according to the six factors affecting programme efficacy as determined by Singhal and Rogers (1999).

Method

The data for this study were collected at the same 9 campus sites across the country, in a series of focus group discussions and interviews.

Health promoter Supervisors. Nine health promoter supervisors were interviewed individually by the researchers and notes were taken during these interviews. These supervisors generally hold positions within the HIV/AIDS units of health clinics at each institution.

Senior management. The Vice-Chancellor, Rector, Student Affairs manager or other senior management member knowledgeable about the programme and its relationship to other HIV or health programmes and policies in the Higher Education Institution was interviewed at seven of the nine campuses.

Institution staff. Health clinic staff was interviewed on each campus. HIV/AIDS programme managers or clinic managers were targeted for these

interviews, and at some campuses additional interviews were conducted with clinic nurses and doctors. Six random lecturers from two campuses were interviewed for their views on the programme. In addition to these meetings, the individuals involved in the DramAidE programme management were interviewed with a view to understanding the dynamics and challenges of managing the programme. Specifically, DramAidE Manager Mkhonzeni Gumede was interviewed in June 2008; and researcher and consultant Laura Myers in July, 2008.

Results

Audience characteristics

The target audience for the project is students living and studying at the institutions, as well as institution staff and members of the surrounding community. The fulltime presence of a Health promoter on site allows for a continuous negotiated meaning of the health promotion messages between the audience and the health promoter.

She's always here 24/7. If someone has a crisis, someone will know that there's this health promoter on campus that you can go to (Peer Educator, Cape Peninsula University of Technology).

Audiences are exposed to messages continually, and this increases their message retention.

Organisational factors

The presence of champions and persons of influence involved in the project continues to strengthen it. Where the Vice Chancellor or other upper management is aware of the programme, they comment favourably on it:

I think institutions of higher learning are environments where this kind of intervention should be promoted. [When] a person is affected, it makes more sense for them to talk to someone who has personal experience. It has more impact in that way than other projects. For that, I would urge institutions to promote this.... These kinds of positions need to be established as mainstreamed positions (Vice Chancellor, Cape Peninsula University of Technology).

Not all campuses enjoy the same level of support though, and this affects the manner in which the Health Promoter Project is viewed by the entire staff:

I feel like we are doing this work alone. It would make such a difference to know the management was giving us support ... Staff members do not know about me. I try to make myself visible, but it's not happening [that I am] received as someone who's making a difference in this institution. Some faculties don't even want to offer me a slot. That's the kind of attitude I get from most lecturers (Health Promoter).

It is clear that the institutions seem more committed to the programme if they pay the health promoters salary.

The importance of becoming institutionalised is very important as it helps to make you feel welcome and a part of the institution. If not, you don't have as much influence and reach people higher up. I can now participate in a more meaningful way. You have to be recognized as a part of the structure. It has an impact on how I run programmes (Health promoter).

This formalisation of the health promoters' role in the institution may ensure that the programme is more sustained, with longer-term funding and programmes guaranteed, as well as an improvement in the care and support that can be offered to health promoters themselves as permanent employees of the institution. This has also been raised as an issue by project managers, DramAidE. As the health promoters are not employed by DramAidE itself, the organisation cannot provide benefits or care. Since the inception of the project, a number of health promoters have become ill and four have died. This is a situation which demands attention from the institutions where they are working.

Employing the health promoter means that most campuses have had to ensure that there is a flexible and workable HIV policy for the institution, affecting both staff and students. A number of programme managers and supervisors interviewed for this study reported that this was a challenge for the institution.

On paper, we want HIV to be something manageable, that we can control, but there is much more to learn about having a colleague with HIV We wouldn't have learned that in other ways. It challenges us every time in terms of our own workplace policies (Programme manager, Stellenbosch).

At one campus, the peer education programme manager comments that in terms of total funding for HIV/AIDS interventions on campus, the cost of hosting the health promoter is their smallest cost. In terms of costs and outputs, the project is

seen as bringing the greatest value to the campus prevention projects.

The environment in which the programme finds itself

While students often claim “AIDS fatigue” (HIVAN, 2008), the Health Promoter Project seems to be seen in a different light to other AIDS education campaigns, because of its highly personalised message, thereby avoiding media saturation. Because the health promoters themselves are HIV positive, they give the health messages a certain amount of credibility as part of a more integrated campaign on each campus.

I'm now well-known on campus. They refer to me as the HIV lady... I get stopped in corridors here by people asking questions about HIV... If they know of anyone who is HIV positive, they know who to come to. I'm here for them... (Health Promoter, Cape Peninsula University of Technology).

Health promoters fit into programmes run by campus health clinics as well as other bodies on campus. One of the most widely reported relationships is that that the health promoter has with the peer education programmes on campus. In some cases the health promoter runs the peer education programme, in others he or she is an advisor to the peer educators and a resource for them. Many health promoters fit into campus orientation programmes for new students entering the institution. A number of students recall that their first meeting with the health promoter was during Orientation Week. The health promoter is often responsible for all health calendar events on the campus and in many cases has ensured that HIV/AIDS issues are on the agenda of recognised student bodies. Some health promoters assist lecturers in presenting some HIV/AIDS related content for the curricula, often presenting guest lectures to students, or assisting students with HIV/AIDS related academic projects.

Student services and clinics report that the health promoter has offered them additional impetus and legitimacy, as well as offering additional capacity in order for them to deliver more effective services, particularly with regard to VCT and support. Many health promoters are also involved with housekeeping and maintenance staff on campuses, and keep them informed of activities as well as running awareness workshops for these groups.

Audience research

DramAidE conducted two evaluations of early phases of the project in an attempt

to find what would work best for students at these institutions. This gave rise to a number of suggestions for improvements to the project, and the 2007 evaluation further highlighted areas for attention. This practice has meant that the programme is constantly evolving. The research conducted for this study shows that the primary target audience (students) respond particularly well to the health promoters, in contrast to health professionals on campus. This suggests that the dual factors of youth and HIV positive status of the health promoter are key to the project's success.

Programme specific factors

Across campuses, programme managers and others report that the project has added value to already existing campus programmes, as well as bringing new programmes to the attention of students. The health promoters use participatory methodologies such as workshops and entertainment education as a way to reach and move students.

Workshops and drama are very important in so far as everything you do has meaning. I use them to create empathy, and develop a spirit of sharing so that we can learn together. People also see the need to respect each other and see each other challenges, as well as finding ways to deal with these challenges. We work through fear through games, and learn to participate which helps us to face up to issues (Health Promoter).

It is reported by peer educators that workshop methodologies that are drama based are most often appreciated and successful. The workshops seem to be effective in the development of responsible and empowered young people who have HIV/AIDS agency skills. It is suggested that this kind of small scale strategy and peer education will add to the mobilisation of a social movement that will have far reaching effects in society more broadly.

We see the students willingly engaging in this project in high numbers. This in turn will reduce the spread of this disease which is in our midst (Campus Nurse, University of Venda).

Infrastructural factors

All of the campuses involved in the study link the Health Promoter Project with VCT services, which are offered on campus. This means that there are direct links between the messages of positive living and the services provided. Health

promoters also distribute condoms on campus.

Six of the campuses included in the study make specific reference to the fact that the health promoter offers a referral system for students to doctors and hospitals, and advises on where the best and most affordable care can be found. It is unclear as to how many of the campuses are registered as anti-retroviral distribution sites, but would seem that many health promoters refer students to services off-campus. Almost all campuses report that most of the students who test HIV positive seek out the health promoter, whose influence and support for these students is evident. A number of campuses report that before the Health Promoter Project was initiated, their own HIV/AIDS campaigns and services were sporadic and not sustainable. In many cases, students regarded the clinic staff running such programmes as unfriendly and unhelpful. Campuses report increased use of these services since the health promoter came on board. The findings of this research suggest that the factors influencing the programme has been maximised to meet the potential for success as defined by Singhal and Rogers.

General discussion

Campuses report that the sphere of influence of most of the health promoters is significant and includes students, community members, and, on some campuses, staff. Health promoters are seen across campuses as visible HIV positive activists advocating acceptance, and challenging discrimination against students or employees who are living with AIDS. They serve as valuable resources to the university community, in providing information about HIV that supports prevention efforts, serving as an example of how to live openly and positively, and in being an instrumental part of the institution's effort to care and support staff and students who are HIV positive.

The health promoters challenge HIV related stigma and discrimination by encouraging students to examine their stereotypes and preconceptions of what it means to be HIV positive. Where health promoters are living in the campus residences, their impact is noted, as they are always available and visible to other students. Peer educators and other students report that meeting the health promoters brings HIV closer to home and has affected their views on people living with HIV. It is apparent through the research across the campuses, that the health promoters have added value to campus campaigns and HIV/AIDS initiatives. Health promoters also believe that the programme is vital and that

without it, there would be a negative impact on students.

I know more people would be positive. So many people still get infected and it is because there are not enough people like us openly talking about our status. If we weren't around, more people would be infected (Health promoter, 2007).

Health promoters add to the peer education programmes on campus by encouraging them to use new participatory methodologies in workshops, and assisting in developing other skills, including facilitation, organisation and advocacy skills. They also offer new and engaging methodologies for campus campaigns, including using popular media that engage campus communities in an exciting way. Some health promoters offer activity based programmes and support that contribute to a supportive environment for marginalised students who may have experienced stigma and discrimination. They have also initiated and strengthened off-campus programmes and allowed the institutions to develop new links with the surrounding communities.

On some campuses, health promoters have directly contributed to the development of the institutional policy on HIV/AIDS. Having HIV positive, and sometimes sick employees, has challenged the institutions to be able to effectively manage HIV positive employees and put their policies into practice.

Health promoters help students to personalise the risk of infection and in most instances, the health promoters are good role models for students who are thinking about testing, and as examples of positive living. Students who test HIV positive report that having a health promoter on campus has helped them to come to terms with their own diagnoses. Students who are infected relate to the health promoter on a personal level and feel an affinity with them. The support offered by the health promoters is invaluable, and they assist peer educators, students and staff to accept HIV as normal.

Although all of the evidence points to overwhelming benefits to employing HIV positive people for such a programme, there are a number of challenges to doing so. These include issues such as employment policy, illness and fatigue on the part of the health promoter, and in extreme cases death. Health promoters also report difficulty in separating their private lives from their public appearances, and without ongoing counselling and support are prone to burn-out. For the successful implementation of the project, these are issues that must be addressed.

The programme is afforded varying degrees of recognition on different campuses, depending on its level of institutionalisation. It is noted that staff support for the programme is vital for its survival on campus. Where the health promoter is recognised by staff, it seems that there is greater access to students and more visibility on campus. Access to funding and campus resources affects the success of the programme, and is another issue that needs to be negotiated for the successful continuation of the project.

While there are ongoing administrative issues that threaten the success of the project at many of the institutions, a number of campuses report that the Health Promoter Project has become the flagship HIV/AIDS project that contributes towards creating a supportive healthy environment amongst both staff and students on campus.

The DramAidE Health Promoter Project meets a number of key success criteria, including the involvement of HIV positive people in interventions, costeffectiveness, relevance, replicability, innovativeness, and sustainability, and should be seen as an example of best practice with regards to HIV prevention projects.

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Health Communication In Southern Africa ~ Cell Phones For Health In South Africa



Abstract

There is widespread global use of technology in medicine and health communication, leading to terms such as telemedicine, telehealth and e-health. A wide range of information and communication technologies (ICTs) is used both in the provision of services, as well as for messaging and communication campaigns. In South Africa, limited Internet penetration has led to increased experimentation with cell phones as a tool for social change. This paper provides a discussion of three of such projects: The Teen SMS Helpline of the South African Depression and Anxiety Group (SADAG); SIMPill which assists patients with compliance to their tuberculosis medication; and CellLife's Cell phones for HIV programme. The projects are described, and the paper reflects on the general possibilities for using cell phones in healthcare, weighing advantages and disadvantages, particularly in the local South African context.

Introduction

The global trend of using new technologies in healthcare and health communication has made its way to Africa. A range of healthcare initiatives makes use of palm devices, the Internet, and other information and

communication technologies, giving rise to the terms e-health, tele-health, and telemedicine (see Oh, Rizo, Enkin & Jada, 2005, for a literature review on the topic).

While the growing body of literature on this subject explores both the Internet and cell phones as 'new' media in the use of health promotion efforts, it is cell phones that are emerging as most popular, and possibly most effective, in health communication on the continent. Internet penetration in South Africa is increasing steadily, but the numbers of people with access to high-speed Internet connectivity here and elsewhere across Africa are probably still too low to allow the widespread success of Internet based applications, outside of telecentres set up specifically for this purpose. Recent statistics indicate that only one in 700 Africans has access to the Internet, versus one in four Europeans (Chakraborty, 2008).

On the other hand, the number of mobile subscribers in Africa has increased dramatically over the last few years. In 2007 Africa added over 60 million new

mobile subscribers and mobile phones represented 90 percent of all telephone subscribers (African Telecommunication/ICT Indicators, 2008). Indeed, cellphone penetration in Africa has increased rapidly since the privatisation of telephone monopolies in the mid-1990s (LaFraniere, 2005). Between 2000 and 2006, the total number of subscribers to cellphone services increased from 10 million to 110 million, in the 24 countries of sub-Saharan Africa, and South Africa had more subscribers to cell phones than fixed lines (Buys, Dasgupta, Thomas & Wheeler, 2008). Similarly, an earlier study revealed that the number of mobile subscribers in 30 Sub-Saharan countries rose from zero in 1994 to more than 82 million in late 2004 and the rate of growth for the entire continent has been more than 58 per year (Mbarika & Mbarika, 2006). Clearly, Sub-Saharan Africa is the world's fastestgrowing wireless market and the rate of growth for the entire continent has been more than 58 per year (Mbarika & Mbarika, 2006). In South Africa, cellphone use is widespread, particular with the introduction of pre-paid services; and there are over 30 million users (Shackleton, 2007).

Drawing on Kaplan's (2006) definition of 'intervention' to mean the intentional use of cell phones to achieve a specific health-related outcome, this paper surveys past and present cellphone 'interventions' in South Africa, drawing on an extensive literature search and qualitative interviews with project leaders.

There is an extensive array of literature on a range of projects using cell phones in health communication (see McBride & Rimer, 1999, who provide a literature review), but there is little literature documenting such projects in Africa. Furthermore, in South Africa, the idea of cell phones for development (including health) is not new, but while there are some disparate articles on specific projects, there is little scholarly work on the subject.

This chapter thus provides an overview of the area of cell phones for health in South Africa, with brief discussions of three of the largest and/or longest running projects: The Teen SMS Line of the South African Depression and Anxiety Group (SADAG); The Cell phones for HIV project run by CellLife; and SIMPill, previously known as the TB Compliance Project.

Background: Cell phones in Africa

Before discussing these three projects, first a brief look at how cell phones are currently used in the region, to provide some context to the situation in South Africa.

As a result of widespread penetration, cell phones have been widely used across Africa for a number of applications. In various countries including Kenya, Senegal (Mbarika & Mbarika, 2006) and Sierre Leone (The Economist, 2008), they've been used for political activism, where citizens can report ballot fraud via SMS. Cell phones have also proven useful for isolated communities to participate in the global economy e.g. farmers in Uganda have used cell phones to find out about the latest crop prices (Gray, 2006).

In South Africa, cell phones are already used quite prolifically for a number of applications. Students in their final year of school can access their final school year results by SMS as part of a service offered by the Department of Education. A project called the Mobile Dictionary (MobiDic) allows users to access dictionary entries via their phones, sending definitions of words by return SMS; the Department of Home Affairs department is piloting a system which allows citizens to receive SMS notifications on their cell phones regarding the status of their applications for passports and other documents. The organization Abahlali baseMjondolo has used mobile phones extensively as a way for people in settlements across the city to stay in touch to arrange meetings, share information and mobilise citizens for what they call 'cell phone toyi-toyi', where members SMS an official to request a meeting (Shackleton, 2007). Similarly, the

UmNyango Project, in KwaZulu Natal, set up an SMS gateway to distribute messages to rural women and also allowed them to send messages to paralegals if they needed help with incidences of violence or threats to their access to land (Manji, 2008). With widespread access to cell phones and the introduction of more affordable payment options, South Africans already use cell phones widely for a range of applications, from cellphone based online banking, to online chat systems such as Mxit (see Bosch, 2008).

The progression to using cell phones for health-related services seems natural given the high saturation of the technology; and the use of cell phones for healthcare applications in the rest of the continent is already widespread. In Rwanda, the Manyange project uses cell phones for health workers to call up the records of pregnant women from an online database and then tell caregivers what to do in an emergency. Each phone has a training manual on maternal and childcare with pictures and audio instructions that can be sent to families. Around 143 private and public health centres in Rwanda use Tracnet, a system that uses cell phones to collect information on patients' infections, and to keep track of which medicines are available in each health centre, making shortages of antiretroviral medicines less common (Kimani, 2008; Chakraborty, 2008).

Information about a polio outbreak in Kenya became available because health workers were using hand-held devices to collect survey data (The Economist, 2008). Further, a recent edition of The Soul Beat (2008), a newsletter distributed by the Communication Initiative, profiled several initiatives currently underway in Africa. These include MyQuestion and MyAnswer, a Nigerian project which allows young people to request information on reproductive health and HIV/AIDS via SMS; a cellphone project in the Democratic Republic of Congo (DRC), set up to monitor and report on child rights violations; and the edutainment Freedom HIV/AIDS Game based in India and six African countries, among others.

Most of these applications make use of text messaging or SMS, although, as discussed below, there are other ways to use cell phones in the field of health communication. While text messaging has been slow to rise in some markets (e.g. the United States), Goggin (2006) documents its widespread popularity in Japan and the Nordic countries. Text messaging is similarly popular in South Africa, particularly as it is much cheaper than voice calls. SMS thus has obvious advantages, most importantly its relatively low cost. Moreover, SMS messages

can be sent even when a user's cellphone is turned off (and they can then retrieve the message later), SMS messages are private; and sending SMSes is already a widely diffused technology, meaning that there's no need to train participants to use the technology. But there are also some limitations: SMS messages are limited in the number of characters (160), illiterate participants cannot use them, and they do not promote the interactivity or complexity of interpersonal feedback.

Cell phones for health in South Africa

Several projects in South Africa have used various aspects of mobile telephony for health communication. Following international trends, most of these began with using cell phones to help patients with adherence to drug routines. The Perinatal HIV Research Unit (PHRU) in Soweto conducted a pilot project with DocVia.com to provide drug and appointment reminders. Similarly, the Dokoza Project was piloted for six weeks over November and December 2004 at the HIV/AIDS Adult Clinic at the Helen Joseph Hospital and the Paediatric Clinic at Johannesburg General Hospital in Gauteng.

The aim of the piloted system was to fast-track the roll-out of anti-retroviral treatment (ART) in resource poor settings, with its capacity to collect and disseminate real time data (e.g. patient registration, obtaining patient medication history etc) and transaction information for patients receiving ART and TB treatments (White & Patel, 2005); as well as offering hospitals a common interface to the National Laboratory System to allow fast access to blood test results (Spur, 2005). This system was designed to allow for a range of real time updates, and it was anticipated that applications would extend to allow hospitals to use cell phones for national searches to track where patients are registered and when the latest medication was dispensed, or to provide instant feedback about possible duplication of services (White & Patel, 2005).

Similarly, a second pilot project, at Brits Hospital in the North West Province, was set up to manage patient numbers, as a result of the common phenomenon where patients, many of whom travel long distances, are often turned away because there is no mechanism to anticipate demand (White & Patel, 2005). A company called Mohwiti Technologies set up AccessHealth, for the Department of Health, which involves using cell phones to improve patient referrals between local clinics and district hospitals. Similarly, the UWC Project, is an ongoing pilot in the rural Eastern Cape involving the remote Canzibe Hospital and Lwandile Clinic in Libode District. It uses a long-range WiFi network, and WiFi enabled

smartphones in addition to mobile applications such as Mxit, Skype and Fring, to cheaply allow communication between rural hospital doctors and clinic sisters – e.g. test results can be photographed and sent via the wireless network from the satellite clinics for instant analysis (Shackleton, 2007).

South Africa presents an interesting case study with its simultaneous high levels of diseases like HIV and TB together with high cellphone penetration. And as such, there seem to be some obvious possibilities for drawing links between these two trends. As the project manager of the NGO CellLife, says:

For the first time that I'm aware of, there's now an interactive digital technology, literally in the hands of the majority. So now most people in a township or remote rural area literally have one, which means you're close to 90 of people who have access to one through a family member neighbour etc and I doubt that's ever been the case before (Benjamin, interview, 14/6/08).

The following projects will be described in further detail below: The SADAG Teen SMS Helpline, SIMPill and CellLife. These cases were selected as they are the oldest and/ or longest running projects using cell phones in the country; and because of their perceived high levels of sustainability i.e. all the other projects found were short-term pilot projects, with limited utility beyond their test period.

SADAG Teen SMS Helpline

The South African Depression and Anxiety Group (SADAG) launched an SMS project in 2000, to provide psychosocial support to distressed teenagers in an

attempt to reduce the high teen suicide statistics. This is a good example of a project that provides a counselling service via cellphone technology. Teenagers send an SMS to the number 31393, and a counsellor replies to the message. According to the project director, Janine Shamos, the centre receives between 30 and 50 SMSes per day, and more during peak periods e.g. during stressful exam periods; and the content ranges quite widely, from teenagers or their parents seeking basic information, to counselling requests for very specific problems.

They ranged from things like "I think my daughter needs help" to "I've tried to kill myself 5 times, I hate my life. I want to die tonight, Please help me". In that kind of a case obviously we would actually phone the person back. But we do get a wide range of different things coming on SMS. But the first point of contact

from us would be to say thank you for contacting the centre, we got your message, please give us a call we can help you so much more if you phone us. Very often we'll get someone SMS'ing back and saying I don't have a landline or its too expensive and then we'd say to them would you like us to call you back and we will then, because if someone SMSes and says "Hi I'm looking for the nearest branch of alcoholics anonymous in my area", fine we'll send that to them on SMS, not a problem. But if someone calls and says "I want to kill my 3 children" we're not going to risk it over SMS, we need that proper, face-to-face contact, we need that voice-to-voice contact (interview, Shamos, 23/6/08).

In this instance, the SMS line is used mainly as the first point of contact, and not for actual counselling. SADAG explained how the idea arose after a school programme they ran called Suicide Shouldn't be a Secret, where informational talks in schools in the Gauteng region were introduced as a response to the rise in teen suicide in South Africa. While teens posed lots of questions to the visiting counsellors after each talk, they seemed hesitant to call the centre's toll-free line afterwards. As a result, the centre then decided to introduce an SMS line, as a potentially easier way to encourage young people to initiate contact.

A lot of people and particular kids - you know teens are so used to SMS'ing, it's so second nature to them they've forgotten how to speak to people - it's a lot easier to SMS a couple of times, get some feedback, get some reassurance that what they're doing is the right thing, and then they're happy to call us in. And we've found that definitely with the teen suicide programme (interview, Shamos, 23/6/08).

While originally started as a service to teens, the SMS line is now open to the general public. The centre drew on the popularity of texting to encourage people who need counselling to make the initial contact with the centre, in a way that is possibly less intimidating than a telephone call. The almost impersonal nature and relative anonymity of the text message could potentially relieve the stress and embarrassment of direct voice contact with a stranger regarding emotional and psychological problems.

Remembering a 5-digit number is very, very easy, and people SMS because it's second nature. You're sitting watching TV, you've got your phone in your hand, it's much quicker. And what people have said back to us is that they want to test the waters a bit and see that someone is really there, so that if they do phone the

phone is not going to just ring and ring, there is a human on the other end of the line who is waiting for their call and is going to take them seriously and once they know that that's there, then they're prepared to phone us back (interview, Shamos, 23/6/08).

The SMS line operates between normal toll-free line hours of 8am and 8pm, with counsellors on duty to respond immediately to messages or to call back in urgent cases, or when a potential patient does not have access to a landline. After hours, Shamos can access the SMS system from home via the Internet.

SADAG are also exploring using the South African based instant chat system Mxit, as well as online social networking software Facebook, in a similar way. But Shamos stresses that the function of the SMS is merely to initiate contact; and that similarly, Facebook would only be used to create an online group and to give people enough information about mental illness so that they either feel less isolated or seek help directly from SADAG (or any other similar service providers). As such, text messages are used mainly to make their services more accessible to people who might be afraid to call the centre directly. As Shamos explains,

Ethically we don't do counselling over SMS, it's just far too risky to all parties. But it is something that at least allows people first contact, and that's often the hardest part. Sometimes picking up a phone can be very, very scary for them. So SMS kind of neutralises that fear a little bit, so we're quite happy with how it's working (interview, Shamos, 23/6/08).

SIMPill: Monitoring drug adherence

This second case is a good example of a project that uses cellphone technology for drug adherence, helping or reminding patients to take their medication. Unlike some of the other projects, which are run by NGOs, SIMPill operates purely as a commercial enterprise. The project was set up in 2001 as The Compliance Service, providing support for patients taking TB Treatment through SMS. Based in the Western Cape, it was designed to increase patient compliance with TB drugs, as Cape Town has one of the highest TB infection rates in the world due to socioeconomic and climatic factors; and in addition, a high rate of non-compliance which increases the virus's resistance and renders expensive medicines useless. TB patients must strictly follow a complicated drug regime over an extended period of time, which they often neglect simply because they forget; and this non-compliance with the drug treatment has burdened local

health care services (Gray, 2006).

Project director and medical doctor, David Green, partnered with the City of Cape Town to run a pilot project, which tested the use of cell phones to remind patients to take their medication, and which had a very high success rate (only 1 treatment failure out of the 138 participants). He explained that there was such a great demand for the technical capabilities that the company then expanded from being just a compliance project to an larger company called On-Cue (of which the former was a part). Today they form part of an even larger company called Neil Harvey Associates. Green explains that the project arose out of the concern to avoid sending spam or unwanted messages to patients.

One of the things that we discovered in On Cue is that sending people a message at least once a day and in the case of HIV twice or three times a day, irritates people. The novelty very quickly wears off and they develop what I call message fatigue. That is they know what the message is and it irritates them more than is helpful. So then I set about trying to work out how we could send them messages only when they need it, and then I developed SIMPill (interview, David Green, 27/ 06/ 08).

SIMPill provides a special pill bottle that delivers an SMS to a central server when the bottle is opened, sends a message to a central server; and which can be programmed to send a message to the patient or to their support services e.g. family and friends, or community health workers (Verclas, 2007), if they don't open the pill bottle, based on the assumption that the patient has not taken their medication. The service is currently offered to a number of TB and HIV patients around the country, and the project partners with government and a medical scheme. In this case, the costs exceed the price of a simple SMS message.

It's fairly expensive, the SIMPill bottle itself has a full radio frequency module in it, if we put all the screens and buttons on it, it'd be a fully functional cellphone, and there's no other way of doing it. And then there's sending the messages from the bottle and so on (interview, David Green, 27/ 06/ 08).

SIMPill do not send unsolicited SMS messages, but Green says that they often 'flood' for a few days when a patient initiates therapy, as well as sending monthly messages, which include a call-centre number, to remind patients to pick up their medication refills.

If it's a newly diagnosed diabetic, for example, it might be information about why it's important to get eye care or look after your feet or take your medication. Once a week we send out humour, just a random joke, it's got nothing to do with anything, and then a reminder to take your medication; just to try and break the tedium and to try and get people to pick up their phone and look at it (interview, David Green, 27/ 06/ 08).

The messages sent are only in English, a decision made after feedback from focus groups with speakers of other languages, who indicated that they would prefer to receive messages in English. Green believes that the success of the project is directly linked to their expansion as a commercial entity.

I can only reflect on why we've been successful, and this is going to sound really harsh, but it's partly because we shelved the social entrepreneur concept quite early on, and that's almost directly opposite to how CellLife's gone about it. But we said we're going to have to make good amounts of money and employ the right people and for that we have to make sure we can sell our product. So we've pursued a commercial path quite aggressively and that's allowed us to continue doing what we're doing (interview, David Green, 27/ 06/ 08).

CellLife: Cell phones for HIV

The final case is an example of a multi-pronged project that uses cellphone technology to assist with the dispensing of AIDS drugs, to help healthcare workers in the field to gather patient data, and to provide individuals with pro-social messaging aimed at targeting behaviour change. While the commercial product SIMPill was found to be effective in assisting patients with their TB medication, assessment results were inconclusive in the utility of the system for HIV/AIDS projects. On the other hand, the NGO CellLife Project was set up specifically with HIV and AIDS in mind. Set up by researchers at the University of Cape Town, in conjunction with the Peninsula Technikon in 2000, the name comes from the idea that a cellphone or SMS could save your life. Specially tailored cell phones were programmed with a list of questions which counsellors posed to HIV positive patients during home visits. The answers would then be sent via text message to a central database monitored by doctors and health workers, who could respond to urgent requests (Harrison, 2005).

Currently, there are two main elements to the project: Firstly, a software system (called CellLife) is used to assist with the dispensing of anti-retroviral

drugs to people with AIDS. As general manager, Peter Benjamin, explains:

It's a software system basically to manage the pharmacists, patients and prescriptions and stock levels and reporting that assists, particularly under-resourced clinics, to be able to dispense the ARVs. And that's currently in about 20 clinics, about 25 000 people get the drugs every month. It's currently in 5 different provinces ... (interview, 14/6/08).

The organization, registered as a Section 21 non-profit company or NGO, still develops applications that use cellphone based software to replace paper questionnaires in the field. This is currently being used for an NGO called the Community Health Media Trust, whose trainers in the field use the system to return information about patients at their workshops.

The most interesting project that CellLife is currently embarking on is a 3-year pilot programme called Cell phones for HIV. The major premise behind this is quite revolutionary. Benjamin and his colleagues have been exploring ways to provide people with information at as low a cost as possible or free of charge, as well as to develop a system that will work on all handsets. Firstly, people will obviously have to opt-in to avoid sending spam SMS messages. Secondly, Benjamin's idea is that these people can send what's called a "Please Call Me", which is commonly used in South Africa and completely free. By sending a message, free of charge, to another user, the latter receives a text message which reads "Please Call Me". Instead of responding with the limited characters of an SMS, the response will be in the form of a public service announcement (PSA), which the user will retrieve from their voicemail box (retrieving voicemail is also free for South African subscribers).

What I was missing is something blindingly obvious- voicemail. Send it to their mailbox and the person does a normal check their voicemail. So how can you push the sound from here to here [from sender to user]. You can do a normal phone call but that's the normal cost of a phone call. WASP (wireless application service provider) 180 of them in the country - what these Wasps can do is to push via ftp a .wav file from the system to the voicemail and it's 45 cents for one minute. And I've done embarrassing things like stand in front of the bathroom mirror for 45 seconds to see how much you can say...You can get about ten times the amount of information than in a regular SMS. And also as you obviously know you can get so much feeling and information as a text is so boring. (Benjamin, interview,

14/6/08).

One aspect of this is a partnership with the entertainment-education radio and TV programme Soul City, which will allow listeners and viewers to send a 'Please Call Me' at the end of the programmes, to give producers immediate feedback. Moreover, sending a message to a specific number will allow audio to be sent back in the language of your choice. This is particularly useful given that information on prevention is often most effective when it forms part of a larger multimedia campaign (Shackleton, 2007). CellLife will also be using a similar system in another project which will be run in conjunction with the Treatment Action Campaign (TAC) to allow them to communicate more easily with their 18 000 members (of which 16 000 have a cellphone, while only 600 have an email address).

Despite the concerns raised by SADAG about 'online' counselling, CellLife also plans to tap into the existing and hugely popular South African based instant messaging system, MXit, to provide cellphone based counselling for people living with or affected by AIDS. This would be similar to the Dr Maths service already on MXit, where high school learners can send a MXit message to a maths tutor, and immediately receive feedback for help with their homework. In fact, researchers found that teens using this service often attempted to develop a social relationship with the anonymous Dr Maths, often logging just to say hello, or asking for counselling, even though tutors were prohibited from asking or answering personal questions (Butgereit, 2007). An earlier study among adolescent girls (Bosch, 2008) has shown the prevalence of MXit and how youth use cell phones to navigate and make sense of various aspects of their lives, including peer and parental relations, self-representation and identity formation.

Discussion

What this exploratory discussion shows is that cell phones are on the rise in South Africa, and that they are already being used in interesting ways in the field of health.

While critiques of the so-called 'modernisation' paradigm are well documented, many international agencies (and sometimes local NGOs) continue to promote information and communication technologies (ICTs) in Africa, often seeing these as a solution to development problems. But many authors (see for example Alzouma, 2005) have argued that this techno-centrist approach ignores

local social conditions and incorrectly assumes that access to ICTs will leapfrog people into a technological world of economic opportunity.

However, cell phones are often perceived in a different light, and several argue that the increasing penetration of cell phones can promote development, particularly in their use to coordinate and mobilise demonstrations; or to provide information about health issues. As Benjamin argues,

Most of the discourse around these new technologies is assuming that they are almost obviously beneficial. And the whole dynamic is of the digital divide, that the only problem is that people don't enough cell phones or computers or websites and so the problem is to get websites and computers into rural villages. I don't agree with that at all. The majority of the products I've seen are quite naively just pushing the technology out there (Benjamin, interview, 14/6/08).

Benjamin argues for a different approach to Castell's network society, based on a Freirian approach, for which he has coined the phrase, 'informatics of the oppressed'.

If the overwhelming ideology is that you plug in and absorb other people's content, CNN, Hollywood, BBC ... then in exactly the same way that Freire said, the answer isn't rejecting information networking, but is to base it on knowledge, experience and values of the people. So what we're trying to do is seeing if we can get people using these systems to exactly the principles of conscientization, to reflect upon their experiences, reflect their views and link to people with similar views to together develop knowledge, rather than just knowledge absorbing what the latest Hollywood film is (Benjamin, interview, 14/6/08).

Certainly, the rise of cellphone activism in South Africa demonstrates the potential usefulness of the technology, as an expression of Benjamin's informatics of the oppressed. During the recent xenophobic attacks around the country, an SMS line was set up by a coalition of NGOs to allow South Africans to express opposition to the attacks, donate money or to report an attack. Community activist, Mark Weinberg who was involved in this project, explains, they were receiving a lot of SMS messages and calls from cell phones during this period, and the "Say no to xenophobia" SMS line was a natural extension of this cellphone communication.

Cell phones are an immensely popular medium of communication amongst the

working class and the poor. There are two contradictory tendencies. One is that it's by far the most democratic form of communication we've ever had - everyone owns and controls one [a cellphone] ... while at the same time we've got this crazy monopoly situation with 3 or 4 countries that control the infrastructure and make these outrageous prices. Cell phones at the moment are prohibitively expensive to make them your primary means of communicating and accessing information.

One might assume that the use of cell phones in health may become an extension of these kinds of mobile community activism, particularly as convergence allows for increasingly interesting and useful applications, which might include using cell phones to access radio signals or even the Internet. In addition, cell phones offer relative privacy within the context of high stigma associated with diseases such as HIV and AIDS, they have already diffused widely among the population; they are relatively cheap and accessible, and they are already being used informally for support and information sharing.

However, what is missing from the debate is the notion that the 'medium' might not be the 'message' (to paraphrase McLuhan's famous conjecture). The major challenges for health communication in Africa remain the same, which might be reduced to the so-called KAP gap, or the gap between knowledge, attitudes and behaviour. And as such, there appears to be little empirical evidence to demonstrate the utility of technology, cell phones included, in health communication. At a basic level, the main challenges in the field are increasing knowledge about a specific health issue, changing a target audience's attitude towards a positive orientation, and adopting a specific practice or changing behaviour and adopting the desired practice, which could be anything from using a condom to learning how to correctly treat water for drinking. While cell phones are certainly useful in providing information about health issues to populations who might not be reached through traditional means, the long-term challenge in the field is closing the gap between knowledge and attitude. Whatever the chosen medium, the communication challenges will remain the same. As Benjamin says,

Cell phones, in particular automated systems, SMS or others, are pathetic at behaviour change, they just can't do it. It's close to laughable to think that someone will choose not to have unprotected sex if they're slightly drunk or under pressure on a Friday night because they get a beep and see 160 characters, that just doesn't happen. Particularly the automated systems are useful if people already want the information. So if people are requesting the information for

example “I need a test, where do I go”, or “I’m worried about this symptom, could it be AIDS”. If people are requesting information, cell phones are great. If you’re talking about behaviour change, they’re pathetic (interview, 14/6/08).

Of course, these kinds of interventions are useful for providing information and increasing knowledge, a critical step in the behaviour change process. However, there are no clear indicators as to whether the delivery medium has any impact on health outcomes or audience responses. Kaplan (2006) has argued that the overall lack of well designed, randomised clinical trials with economic evaluation to confirm or refute clinical and economic benefits with mobile phone/healthcare interventions is an evidence gap that should be addressed in a systematic way. In other words, the message is still most important. Some research also seems to indicate that the mass media is not the primary factor in behaviour change, but that it is rather opinion leaders (who consume mass media messages), who are most instrumental in placing health issues on communities’ agendas and thus endorsing or promoting behaviour change. As Manji (2008) similarly argues, while cell phones offer many new opportunities and tools, people are the resource most central to development, and cell phones should thus be seen useful as only one part of a strategy in which people are prioritised, a sentiment echoed by Green.

It’s not about the technology ... it’s about the people sitting at our call centre, those DOTS [Directly Observed Treatment for TB] workers. If we send a text message from the SIMPill system to a DOTS worker, who’s a very poorly paid community worker; if they take the message and they delete it then we’ve failed. If they take the message and say someone that I’m getting my R390 a month or whatever is in trouble, and goes to that person’s house, the system works. So the weakest link is always the people and not the technology (interview, David Green, 27/ 06/ 08).

Another area that needs further research is the cultural implications of cellphone usage. As Kaplan (2006) aptly points out, the premise of cell phones for development is based on the developed world model of personal cellphone ownership, which may not be culturally transferable to the developing world where shared mobile telephone use is important. But in South Africa, the popularity and wide penetration of cell phones (and individual uses thereof) seems a clear indicator that it may be the new mass medium through which to reach potential audiences with health related information and messages targeted

at pro-social behaviour.

The successful rise of online banking via cell phones for sectors of the population unable to access the Internet, is only one indicator of a new cellphone culture here. There will always be financial and regulatory barriers, with buy-in needed from government and regulatory reforms required for proper operation of basic and value-added telecommunications services, if mobile telecommunications are to be used for healthcare initiatives (Kaplan 2006). But without championing the modernisation paradigm, it is clear that cell phones could be one way to reach large numbers of people, particularly youth. While inter-personal communication is probably still most effective in the arena of persuasion, cell phones can play a key role in increasing knowledge and awareness of health issues and desired behaviour.

But there are obviously still several disadvantages, the major one being that those who will receive any kind of cellphone messages will need to opt-in and subscribe, which might mean that those who really need the information are bypassed, with those already on the steps to behaviour change the only ones receiving the information. There are also still some technical challenges, the main of these being that people often can't charge their cell phones in rural areas. While the technology exists in the form of solar powered chargers, these are not freely available in Africa. Some have found ways around this, such as using car batteries to charge their phones, but this is still fairly limited. There also appears to be a trend of single and limited pilot projects in the field of cell phones for health, and more extensive piloting is required, together with economic modelling, in order to determine the benefits of the health sector embarking on larger implementation (Spur, 2005). The main reason for these short-term projects is that while there is government policy to roll out pilot projects, once a project is tested, an often lengthy and expensive tender process is followed (Shackleton, 2007).

Other infrastructural challenges include lack of consistency in the national health arena, with health information systems varying widely between provinces and health institutions. As a result, even though the Department of Health's National Antiretroviral Treatment guidelines call for the use of technology to promote adherence (Shackleton, 2007), South Africa public sector institutions largely engage with mobile solutions in an isolated and case-specific manner. There is no comprehensive strategy guiding choice around the use of mobile

technology, which results in these limited full-scale implementations (White & Patel, 2005).

Moreover, these kinds of interventions, while relatively cheap or free to the user, can be costly to the NGO or service provider. More work is needed to persuade cellphone service providers and networks to partner existing projects.

I know first hand ... that the incremental costs of carrying an SMS on the networks is zero cents. So every single cent that the network charges you to carry an SMS is, after overhead, pure profit ... they're making millions and I certainly believe there's an opportunity for them as well as government to come to the party. I'm currently paying 22 cents per message and internationally we send out a million per day" (interview, David Green, 27/06/08).

Despite the challenges, cell phones in South Africa are a widespread and popular technology; and so it seems likely that they might be successfully applied both in the provision of healthcare, as well as in messaging and communication campaigns. Cellphone based services may not necessarily be more successful on their own, but together with other media, may help in the provision of more effective multimedia campaigns. The problematic nature of persuasion with regard to changing attitudes and behaviour will always remain, but cellphone technology may be a key element in the chain of knowledge provision and dissemination of information, both as part of communication campaigns and between health workers.

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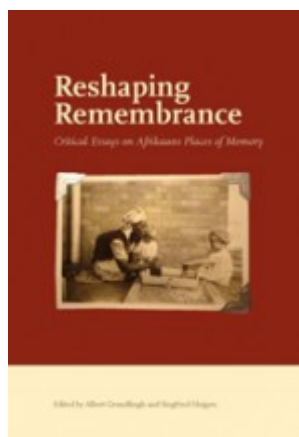
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Reshaping Remembrance ~ Critical Essays On Afrikaans Places Of Memory



Albert Grundlingh & Siegfried Huigen (Eds.) – Reshaping Remembrance. Critical Essays on Afrikaans Places of Memory – Rozenberg Publishers 2011 – Savusa Series 3 – ISBN 978 90 3610 230 8 – Editing: Sabine Plantevin.

In any society in the throes of transition, there is a particularly acute need to reflect upon aspects of the past that used to represent firm beacons enlightening the way ahead. This inevitably involves a broader re-appraisal of the processes which contributed to the formation of a specific historical memory in the first place.

Reshaping Remembrance includes a number of critical essays on dimensions of

collective Afrikaans historical memory in South Africa. In the light of radical changes in the country, scholars from various disciplines reflect on the dynamics of historical consciousness symbolically present in various areas: the 'volksmoeder' image, historical events and monuments, language and music, rugby and architecture.

This work hopes to resound with a well-established intellectual tradition in Europe dealing with '*places of memory*' or '*lieux de mémoire*'.

Contents

- [1. Siegfried Huigen & Albert Grundlingh – Koos Kombuis and Collective Memory](#)
- [2. Elsabé Brink – The 'Volksmoeder' – A Figurine as Figurehead](#)
- [3. Gerrit Olivier – The Location](#)
- [4. Hein Willemse – A Coloured Expert's Coloured](#)
- [5. Kees van der Waal – Bantu: From Abantu to Ubuntu](#)
- [6. Ena Jansen – Thandi, Katrina, Meisie, Maria, ou-Johanna, Christina, ou-Lina, Jane and Cecilia](#)
- [7. Albert Grundlingh – Rugby](#)
- [8. Marlene van Niekerk – The Eating Afrikaner: Notes for a Concise Typology](#)
- [9. Lizette Grobler – The Windpump](#)
- [10. Hans Fransen – Glorious Gables](#)
- [11. Lou-Marié Kruger – Memories of Heroines: Bitter Cups and Sourdough](#)
- [12. Lize van Robbroeck – The Voortrekker in Search of New Horizons](#)
- [13. Christine Antonissen – English](#)
- [14. Siegfried Huigen – Language Monuments](#)
- [15. Rufus Gouws – The Woordeboek van die Afrikaanse Taal](#)
- [16. Luc Renders – And the Greatest is ... N.P. van Wyk Louw](#)
- [17. Albert Grundlingh – Why have a Ghost as a Leader? The 'De la Rey' Phenomenon and the Re-Invention of Memories, 2006-2007](#)
- [18. Stephanus Muller – Boeremusiek](#)
- [19. Stephanus Muller – Die Stem](#)
- [20. Annie Kloppe – 'In ferocious anger I bit the hand that controls': The Rise of Afrikaans Punk Rock Music](#)

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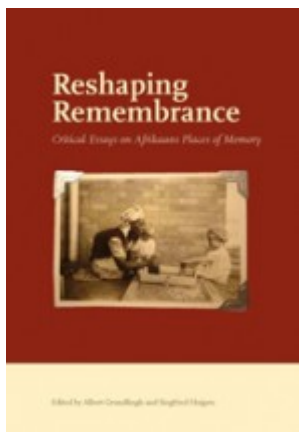
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Reshaping Remembrance ~ Koos Kombuis And Collective Memory: An Introduction



As the year 2006 gave way to 2007, a song and an accompanying music video about the Boer general Koos de la Rey caused quite a stir in South Africa. When this song was played in bars and at barbecues, young white Afrikaners would stand with their fists clenched against their chests and sing along: 'De la Rey, De la Rey...' And tears would flow. According to news reports, the 'De la Rey thing' had made many of them 'proud' of their roots. Worried ANC politicians expressed concern because they saw this as the start of an

ethnic revival that could disrupt South Africa. The phenomenon even made it to the world press.

One of the more balanced reactions to the De la Rey song is an article by the Afrikaans beat poet Koos Kombuis on *Litnet*, '*Bok van Blerk en die bagasie van veertig jaar*' (Bok van Blerk and the baggage of forty years).^[i] In this article Kombuis confesses his conflicting reactions to the song. Rationally, he rejects the song and the Boer War elements in the music video. He sees it as 'a call to war, a sort of musical closing of the ranks'. Some months before Kombuis had distanced himself publicly from his Afrikaner identity in a Sunday newspaper, from the 'baggage that has been forced on me by people who have now been trying to prescribe for forty years who and what an Afrikaner is. What an Afrikaner is supposed to believe in. Whom he should vote for, which shit clothes he should wear and how he should spend his public holidays'.^[ii] This notwithstanding, Kombuis is unable to offer any resistance to the emotional appeal of the song: 'Why, if I experienced my resignation from Afrikanerdom as such a gloriously liberating step, do I feel so inexplicably profoundly touched by the De la Rey song? It is embarrassing'.

In reply to Kombuis's question 'why', it can be surmised that both the song and the video, with their images of the leadership, a concentration camp and Boer fighters, draw on the collective memory of white Afrikaners, on something they learned within the family and, especially for the older ones, at school and in church. Kombuis's reaction already points in this direction when he says that when he hears the song, he longs to be back at Sunday school and 'feels like rejoining the army on the spot and shooting the hell out of the Kakies and other K stuff'.^[iii]

The role of collective memories was first investigated seriously by the French sociologist Maurice Halbwachs in his ground-breaking works *Les cadres sociaux de la mémoire* (The social frameworks of memory) and *La mémoire collective* (The collective memory). These publications from 1925 and 1950 were rediscovered in recent years by historians doing research on memory. According to Halbwachs, every one of us obviously has his own memories, but at the same time we also share group memories.

One remembers as an individual, but in this one is not alone. The environment in which one grew up and in which one lives forms a framework which determines

the shape and content of memories and helps to codetermine identities. Groups can even produce memories in individuals which they never 'experienced' in a direct sense.

Collective memories are fluid as regards past events. The interests and requirements of the present determine collective memory. As generations pass, memories fade away. The period of collective memory is generally estimated as going back one hundred years from the present. Within the confines of three or four generations, the past still remains 'warm' – it maintains a link with the living. The past predating this period cools down and becomes part of the domain of historical memory, the terrain that is kept alive artificially by specialist historians. Here, too, the influence of the present is not absent, because only certain aspects of the vast area encompassed by the past are researched by historians.[iv]

Halbwachs argues that social groupings form the memories and identities of individuals. Kombuis's compulsive thoughts of Sunday school and the South African Defence Force also indicate the direction in which his reactions to the De la Rey song are determined. It was Sunday school and the Defence Force, among others, that shaped his memories and that cause him to be touched by the De la Rey song.

The book *Reshaping Remembrance* contains a series of critical essays about a number of collective Afrikaans memories – memories which have already almost gone cold as well as the more recent ones, such as the De la Rey song. The original Afrikaans version of the book sought to encourage Afrikaans readers to reflect on their memories. It may be gratifying to get high and forget about things that bother you and feel proud of your origins, but it would be unwise to suppress the problematic aspects of the past. It is, for one thing, not conducive to dialogue with other citizens of South Africa. Given the burden of apartheid guilt, the memories of Afrikaans-speaking whites cannot unfold in the present without reservations or nuances. 'They' will still hold you responsible, no matter how hard you try to forget. After all, at present it is 'they' who set the debate, who put whites more or less in the position of the 'other'. Censored, sanitised memory is not healthy either. It is better to come to grips with the past, not to push it away behind a barrier of protective wishful thinking. Freud showed that the latter could cause nightmares.

The approach followed in this book differs from the way in which the collective

memories of Afrikaners were dealt with twenty years ago. In the publication of the Federation of Afrikaner Cultural Bodies (FAK), *Afrikanerbakens* (Afrikaner beacons) of 1989, a series of historical monuments, resorts, church buildings and statues were described. 'Together they want to express the story of the Afrikaner', as the editor put it.**[v]** The style in which the 'beacons' were described was not detached from the spirit of the time prevailing in the late 1980s, when the National Party was coming under increased domestic and foreign pressure because of apartheid. With white domination tottering and the future uncertain, a need was felt to leave a tangible record of what could be regarded as 'Afrikaner beacons' for posterity. But at the present juncture even the concept of 'Afrikaner beacons', with its associations of immutability and prescriptiveness, is an anomaly.

In this book on collective memory among Afrikaners, the contributors have examined so-called memory sites. This term does not necessarily refer to physical, topographic sites. Following in the footsteps of Pierre Nora and Jan Assmann, the term memory site is used in a metaphorical sense in this book. According to Assmann and Nora the collective memory 'crystallizes' around certain points of attachment to the past that develop into symbolic figures. In this way the past develops into a reality that has a persistent formative force. Such sites of memory can be both material and immaterial: buildings, places, events, acts, books, people. In media theory terms, one could call them icons. Such places are memory sites not because of their materiality, but because of the symbolic function that they fulfil. 'Site' is therefore also understood here in the metaphoric, heuristic sense, much in the same way as a topos in classical rhetoric. At a memory site, memories are found. The memories can be consoling, but often painful as well. Take examples of German memory sites: there are the fairytales of Grimm and the poet Goethe, but also Hitler's bunker in Berlin, the Berlin Wall and Auschwitz.**[vi]**

Although this book links up with similar books such as the French *Les lieux de mémoire* (The Realms of Memory, 1981-1992), the German *Deutsche Erinnerungsorte* (German Places of Memory, 2001) and the Dutch *Plaatsen van Herinnering* (Places of Memory, 2005-2006), it differs from these in that we have restricted ourselves to the past century. Afrikaners as an 'imagined community', a group of individuals who view themselves as a nation, have not been in existence for much more than a century, according to the Afrikaans historians Floris van

Jaarsveld and Hermann Giliomee. Moreover there is a trend, even among Afrikaans-specialist historians, to restrict historical interest to the preceding century. At the time when the Great Trek was commemorated, historical interest still went back as far as 1838, but at present the Anglo-Boer War increasingly seems to be the limit. European historical consciousness goes back further and is more strongly established, because until recently the French, for example, were still taught that the Gauls were their ancestors. The shorter time frame is another reason why this book covers a smaller scope than the multivolume European works.

The book ignores more potential topics than it includes. The limited pool of Afrikaans researchers available and their particular research interests more or less dictated the choice of topics for this book. For example, we as editors would also have liked to include essays on the Dutch Reformed Church, the Pickup Truck and the Ox Wagon, the secret Afrikaner Broederbond and the National Party, the poets Breyten Breytenbach and Ingrid Jonker, the Border of the Republic and the Army, the Afrikaans publishing giant Naspers and the South African Broadcasting Corporation, the Farm and the Small Town, the General Dealer, the South African Railways, the Mine and the Kruger National Park, Verwoerd and Mandela, Mandela's Afrikaans defence lawyer Braam Fischer, the Soweto Uprising in 1976, the university town of Stellenbosch and Pretoria, the capital of South Africa. As it is, the book covers both material and immaterial culture, the sublime and the banal, with a special emphasis on race and language, because these two elements used to dictate who was considered to be an Afrikaner.

The following contributions are essays such as Montaigne understood this genre – writings in which certain problems are examined in a personal way. The essays were expected to contain critical analyses of memory sites. Each contributor was allowed to choose his or her own emphasis within the overarching point of departure of the book. The authors' brief was also to do this with detachment in order to stimulate the reader to reflect on the subject instead of identifying himself or herself emotionally with it. However, maintaining a critical distance does not of necessity exclude intense involvement with the material.

NOTES

i. Litnet, 28 November 2006.

ii. Rapport, 15 January 2006.

- iii. Also compare Grundlingh's essay on the 'De la Rey' song in this book.
- iv. classiques/Halbwachs_maurice; P.Nora, 'Between memory and history: Les Lieux de Mémoire', in: *Representations*, Spring 1989, 7-24; P.H. Hutton, 'Sigmund Freud and Maurice Halbwachs: The problem of memory in historical psychology', in: *The History Teacher*, February 1994, 145-158; J. Assman, 'Collective memory and cultural identity', in: *New German Critique*, Spring/Summer 1995, 125-133; S.A. Crane, 'Writing the individual back into collective memory', in: *The American Historical Review* 102(5), 1997, 1372-1385; J.K. Olick & J. Robbins, 'Social memory studies: From 'collective memory' to the historical sociology of mnemonic practices', in: *Annual Review of Sociology* 24, 1998, 104-140; J.K. Olick, 'Collective memory: The two cultures', in: *Sociological theory* 17(3), 1999, 333-348; P. Hutton, 'Recent scholarship on memory and history', in: *The History Teacher*, August 2000, 533-548.
- v. M.J. Swart et al. (eds), *Afrikanerbakens*. Auckland Park: FAK 1989.
- vi. F. Yates, *The art of memory*, London 1966; P. Nora, 'Between memory and history: Les Lieux de Mémoire', in: *Representations*, Spring 1989, 7-24; J. Assman, 'Collective memory and cultural identity', in: *New German Critique*, Spring/Summer 1995, 125-133; E. François & H. Schulze (eds), *Deutsche Erinnerungsorte*, I. Munich 2001, 9-24; H.L. Wesseling, *Plaatsen van herinnering. Een historisch successverhaal*. Amsterdam 2005.

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