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Review article

How effective is HIV and AIDS Communication in Africa?

By Eliza M. Govender

Abstract

This review article will connect three perspectives in health communication: a shift from mass media to participatory, dialogical processes of communication, a transition from a focus on individual behavior change to social change and a transformation of the perception of HIV and AIDS as a health problem to a development problem. In essence, the discussion about the transitions of these three perspectives is evidently about the old and new paradigm of development in addressing HIV and AIDS. I argue that the new paradigm still poses detrimental challenges to the success of HIV prevention initiatives through a recurring lack of acknowledgement of the “real context” in addressing HIV and AIDS. The context in light of the numerous unsuccessful HIV and AIDS initiatives should now focus on the compromise of various partners towards attaining an achievable level of participation. Independent of the transitions in these three perspectives, a new paradigm to HIV prevention needs to re-negotiate the context of attainable participation and also magnify the importance of partnerships between donors, government and civil society which is central in addressing HIV and AIDS. On this level, the new development paradigm essentially capitalizes on participation through partnerships which is a new context for addressing HIV and AIDS.

Key words: evolution of HIV/AIDS research in Africa, participatory approaches to HIV/AIDS communication, partnership of donor agencies, government and civil society in HIV/AIDS

Introduction:

A fundamental entry point to understanding HIV and AIDS prevention strategies is to explore the three different communication

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perspectives which have evolved over time in addressing the pandemic. The first is a steady shift from mass media interventions to participatory, dialogical processes of communication, the second a transition from a focus on individual behavior change to social change communication and the third is the transformation of the perception of HIV and AIDS as a health problem to a development problem.

In essence, the discussion about the transitions of these three perspectives is evidently about the old and new paradigm of development in addressing HIV and AIDS. I argue that the new paradigm still poses detrimental challenges to the success of HIV prevention initiatives through a recurring lack of acknowledgement of the “real context” in addressing HIV and AIDS. Whilst considerations of cultural, economic, social and political factors all contribute to the effectiveness of HIV and AIDS communication, the enabling environment or the real context is omitted. The context in light of the numerous unsuccessful HIV and AIDS initiatives should now focus on the compromise of various partners towards attaining an achievable level of participation, amidst ongoing disregard for community engagement, domination of donor agendas and ongoing quick fix solutions to long term problems of HIV infection. Independent of the transitions in these three perspectives, a new paradigm for HIV prevention needs to re-negotiate the context of attainable participation and also magnify the importance of partnerships between donors, government and civil society which is central in addressing HIV and AIDS. On this level, the new development paradigm essentially capitalizes on participation through partnerships which is a new context for addressing HIV and AIDS.

This review article will examine these three perspectives within the old and new paradigm, appealing for a review of a context for participation and partnerships between stakeholders when addressing HIV and AIDS with examples from an African context.

The Old Paradigm: Mass media, individual change and focus on health problems - linear communicative processes

The genesis of the field of communication and development, one may argue, lies in the organized development assistance programs following World War II (Melkote and Steeves, 2001). Silvio Waisbord (2001) and Srinivas Melkote (2003) associate the origin of development communication with the post-war theories of development and social change. These theories perceived the world problems as the absence of

progress in the developing world in comparison to those in Western societies (Waisbord, 2001). The rise of “communication for development” (sometimes referred to as “development communication”) was a communication response to aiding the process of development. Central to these development processes was the ongoing refining of what constitutes development and how communications will contribute to establishing the essence of the post-war development initiatives. From the outset, communication for development has been a strategic tool to persuade people to change and enhance development processes (Tuftte & Mefalopulos, 2009).

The early 1960s associated development with “modernizing the traditional” and the transfer of Western ideas and technological advancements to Third World countries. This ongoing transfer of Western ideas was later manifested through modernizing the communication responses to health issues such as HIV/AIDS. Ironically, whilst Western societies in some cases successfully attempted to modernize African countries through mass media interventions, challenging behavioral practices to address HIV intensified at the individual level.

The modernization approach overlooked the complexities that perpetuate the pandemic in Third World countries and led administrators and researchers to ignore the real social and cultural contexts within specific countries. The paradigm drew on a “stereotypical view of traditional individuals” and suggested that their so-called backwardness, laziness and ignorance were the fundamental cause of underdevelopment (Melkote and Steeves, 2001, p. 90). Individuals and their traditional cultural values were blamed, rather than taking into account infrastructural and political factors. In the context of HIV and AIDS, individuals were perceived to be in a position to make rational decisions. It was assumed that communicating safe sexual choices would transform the individual into a modern citizen, aiding the process of communicating and responding to HIV prevention. The communication process was assumed to be a transmission of the knowledge of experts to the uneducated. The mass media were perceived to be the instrument for one expertly designed message to reach millions of uneducated in a persuasive advertizing campaign style. This communication strategy aimed at individual change in attitudes and behavior with the assumption that media messages had a powerful impact in underdeveloped societies (Servaes, 2008, p.2).

Communication was seen as a pivotal component of development, and crucial for modernizing the behavior of those affected and infected and to address the challenges of HIV and AIDS. An example is the loveLife billboard campaign in South Africa, launched in 1999, which purported to use “youth-focused television and radio programming, magazines and billboards to promote sexual responsibility and to link young people to counseling and clinical services” (loveLife website). The loveLife campaign is widely recognized as having failed to curb the HIV and AIDS epidemic as it uses branding as an instrument to change behavior without taking into account significant variances in culture, religion, belief systems and socio-economic contexts in South Africa (Jordaan, 2006, p. 111). Richard Delate (2007) argues that the branding strategy employed by loveLife not only proved ineffective but actually produced negative consequences: “...the representation of the loveLife lifestyle brand has given rise to a brand identity that positions adolescent sexuality as something that is cool and that everyone is engaged in” (Delate, 2007, p. 4). The loveLife campaign’s unintentional consequences were partly due to its failure to situate the campaign within the audience’s contexts.

The love-life campaign is explicitly located in a paradigm that assumes young people are motivated by individualistic aspirations to consumption. Linking HIV prevention to a lifestyle of consumerism was a completely misguided move, considering that the majority of young people that loveLife was targeting fell into South Africa’s lower-income bracket (Parker, 2004). The loveLife campaign is an example of exogenous development communication that ignored the community-like ties among young people and failed to enter into the communication networks which stem directly from the communities themselves.

Critics of the modernization paradigm suggest that the top-down flow of communication did not bring the process of development to its full potential because it lacked an in-depth knowledge of the true challenges facing the people in these developing countries (Rogers, 1969; Melkote, 1991; Servaes, 1999). Without knowledge of the audience, without community consultation or participatory processes of relating HIV/AIDS information to the local culture, campaigns are inevitably unsuccessful, as the failure of the loveLife campaign shows. The field of development communication therefore later accommodated a focus on local dialogue and local change where participatory approaches and interactive solutions are based on interpersonal

communication (Lie, 2008, p. 281). This shift in perspective will be analyzed in the discussion of the new paradigm below. Panos (2001), however, argues that in essence there should be a focus on appropriate mixes of different paradigms, and the various communication approaches for responding to HIV and AIDS should not be used exclusively.

Behavior Change Communication

The paradigmatic shifts of communication for development were also evident in the design of communication strategies to address HIV and AIDS. Developing countries placed emphasis on the behavior of individuals, escalating the importance of behavior change communication (BCC) which had been the popular and dominant framework during the modernization era for health issues around the world. BCC is premised on the belief that the urgency of the pandemic necessitates a high focus on individual behavior, and it thus tries to encourage people to make informed choices (Deane, 2002). It involves promoting particular behavior or social norms via communication interventions (Tufte & Mefalopulos, 2009).

In the case of Kenya's 2010 HIV and AIDS report to the UN's General Assembly, the country's strategy encourages the use of BCC to promote sexually responsible behavior (Kenyan National AIDS Control Council, 2010). The report suggests that BCC has been successful in achieving positive behavior change, particularly amongst young people, to combat HIV transmission. Recent studies in Kenya "show an increase in condom use, delay in sexual debut and reduction in number of sexual partners" (Kenyan National AIDS Control Council, 2010, p. 14). While positive reports encourage the use of BCC strategies, the influence and application of BCC cannot be over-rated. In the case of Kenya, it is difficult to ascertain whether positive sexual behavior change was a direct result of the exposed BCC strategies or a combination of other social, political and economic factors. One of the major flaws of the BCC approach is the dependence on behavior transformation, neglecting other important determining factors. Many communications and health promotion programs assume that behavior alone needs to be changed, when, in reality, such change is unlikely to be sustainable unless it also involves different kinds of social change (UNAIDS, 1999, p. 23).

HIV and AIDS communication interventions, therefore, need to adopt a more holistic approach where other determining factors are

also considered. An important factor emerging in many studies in an African context is the need to take into consideration local African cultural values and practices. Communication initiatives have a chance of succeeding only when situated within the cultural context of the target audience (UNAIDS, 1999). Early HIV and AIDS initiatives failed in the African context as they were created for a Western context, where individualism instead of community orientation was favored (Airhihenbuwa and Obregon, 2006; Rawjee, 2002). Similarly, Kunda and Tomaselli reiterate that “effective health communication interventions depend on understanding the knowledge, attitudes and practices of people from given cultural vistas” (2009, p. 96). They highlight a case in South Africa, where words such as “BMW Z3” and “Channel O” are used to describe HIV, as this luxury car and music channel depicts a modern, consumerist lifestyle, thus establishing an association with the virus (Kunda and Tomaselli, 2009). Whilst behavior change interventions on its own poses crucial challenges in light of the modernization era, a holistic approach which considers all conceptual and contextual factors will promote the success of any response to HIV/AIDS.

While Uganda was commended for its success in reducing HIV prevalence, two conflicting debates emerged about the country’s experience (Singh, 2003). The first was the relative contributions towards the success of reducing and sustaining HIV rates in Uganda by using the three ABC behavior change approaches (abstain, be faithful, condomize). The second debate stems from the question of what caused these behavior changes. The Alan Guttmacher Report on the “ABC” in Uganda addresses these two debates by reviewing evidence from surveys conducted in Uganda in 1988, 1995 and 2000. The findings demonstrated that the progress of the three-component ABC approach contributed to bringing about and sustaining reduced exposure to HIV in Uganda. These results are consistent with current prevention efforts which highlight the importance of an integrated approach to combating the HIV pandemic worldwide (Singh et al, 2003, p. 8). While behavior change was instrumental in mobilizing the people of Uganda, the relevance of their multiple-level approach cannot be negated. Uganda’s success was largely attributed to the evidence that the country was proactive in all areas of promoting HIV prevention, making the relevance of social change significant. Social change will later be discussed under the new paradigm.

Airhihenbuwa (2000, p. 5) argues that the flaws in the application of commonly used “classical” models in health communication are a result of contextual differences in locations where these models are applied. Behavior change theories are limited by a range of conceptual and contextual factors. These factors do not negate the value of “choice-based” behavior change approaches, but there has been an over-reliance and over-investment in BCC (Parker, 2004). Airhihenbuwa proposes that HIV and AIDS communication strategies should be grounded in sound theory where the resulting framework is flexible enough for application in different regional and cultural contexts (see also Kunda and Tomaselli, 2009). In addition, Tufte & Mefalopulos (2009) point out the problematic lack of participatory elements in early models of communication where the focus was on the elements of individual behavior change and did not take into consideration the social and cultural factors that were actually present and important factors. Clearly, the faith placed in behavior change communication approaches was explicitly encapsulated within the modernization paradigm with its top-down didactic approaches to HIV prevention, highlighting set models with definable linear, step-by-step solutions. Participation and the dialogical interactive nature of community engagement and consultation were not considered as a process of promoting positive behavior change. A number of critics of the predominantly Western theories of behavior change have noted that behavior change does not occur in isolation but within a framework of various factors such as the individual motivations, local community support and availability of resource agencies in a nation. Studies about HIV and AIDS over the years have shown that the pandemic is a social condition more than an individual problem. Hence, a more social approach is needed to combat it (Ford et al., 2003; Airhihenbuwa & Obregon, 2000; Airhihenbuwa et al., 2000; Melkote, 2000, UNAIDS, 1999b; Panos, 2003; UNFPA, 2002; Deane, 2002; Singhal, 2001).

HIV/AIDS as a health problem

Although the first HIV and AIDS cases were diagnosed in the United States in 1981, it only received media attention in the mid-1980s by which time more than 10,000 individuals were diagnosed with AIDS (Dearing and Kim, 2008). This resulted in a highly institutionalized system of biomedical and health discourses developed in Western countries with the construction of HIV and AIDS as largely a health crisis and ignoring the socio-economic, political and cultural

contexts. This rippled down to developing countries where analysis of the causes of the AIDS crisis was located outside of the government and organizations addressing AIDS and the communities living with the virus (O'Manique, 2004).

The extensive focus on behavior change approaches proved a failure in light of the rapidly increasing rate of transmission of HIV in South Africa. While HIV and AIDS has asserted itself as a global epidemic, Sub-Saharan Africa has struggled the most with the virus, with 1.9 million people becoming newly-infected in 2008 alone, bringing the total of HIV sufferers in the area to an estimated 22.4 million (UNAIDS, 2009). South Africa, in particular, has been especially hard-hit and is home to the largest number of people infected with the virus (UNAIDS, 2008).

The modernization paradigm was governed by the pursuit of economic development as a way of modernizing the traditional way of life. In South Africa, findings of the HSRC survey (2009) and the national tertiary education study (2009) demonstrates that sexual choices are no longer interlinked with poverty, the lack of basic resources and one's economic status.

Studies conducted by Mulwo (2009) and Kunda (2009) both provide evidence of the intergenerational and transactional sex which extends beyond Maslow's (1943) first level of physiological needs to include basic living requirement items which promote self esteem and status through good material possessions in some instances. Students who are residents at the University of KwaZulu-Natal will engage in transactional sex for fancy cell phones, rides in BMW's and Levi jeans. This compels an ongoing review of the economic contexts which influence HIV transmission, without solely attributing this to poverty, lack of economic development and the need to review people's poverty-stricken status in assessing the spread of HIV. The field of development and health communication therefore requires a move away from a linear process of understanding this pandemic as a health problem and compels a review of the real context in addressing HIV and AIDS.

In the past, the South African government became notorious for its denial of the severity of the HIV and AIDS pandemic and its initial refusal to acknowledge the efficacy of ARV's (Amon, 2008). In particular, the late Minister of Health, Dr Manto Tshabalala-Msimang, was heavily criticized for her controversial public statements that beetroot and garlic could be used as "remedies" for HIV and AIDS

(Knight, 2006). Such statements, while obviously grossly incorrect, suggest the strong focus on HIV and AIDS as purely a health problem that can be “fixed” by health solutions. Aside from the scientific inaccuracy, such comments reveal the government’s initial perception of HIV and AIDS as a medical issue, rather than as a larger development issue. Former president and South African icon, Nelson Mandela, forced open the debate in 2003 when he stated at the 14th International AIDS Conference in Paris that “AIDS is no longer a disease, it is a human rights issue”. Such a statement suggests the broader and more encompassing approach that is required if any substantial and sustainable change is to be made in the struggle against HIV and AIDS.

In a significant way, awareness, education, and behavior change communication interventions described above correlate with Everett Rogers’ assumption that modernization could not occur unless the communities were individually and collectively persuaded to change their traditional ways of life (Melkote and Steeves, 2001). The main aim of these media-based communication campaigns was to provide correct information about transmission and prevention often with the assumption that this will lead to behavior change. These campaigns are characterized by a one-way flow of communication and prevention messages where the target audiences are not involved in any processes of decision making, ownership or sharing of ideas. Additionally, this approach does not take the target group sufficiently into account when designing messages, and has shown to have failed in a number of instances.

The models of behavior change which originated from the First World countries were applied in the Third World countries with the hope that they would generate similar responses. However, McKee (2008) points out, that the conditions under which these behavioral change theories were used in the Western world and in the developing world countries differed significantly. In the South African context all the evidence points to the fact that the awareness and BCC campaigns had minimal impact on the HIV epidemic. Furthermore, the AIDS control regime did not align with South Africa’s history and identity. With the South African government’s negative experiences with “Western” public health campaigns, leaders instead emphasized the need to find African solutions to African problems (Youde, 2005). HIV and AIDS messages that are created by “experts” and then transmitted to the audience in a one-way, linear manner are doomed to

fail. When students at the University of KwaZulu-Natal in South Africa were questioned about their perceptions of South Africa's Abstinence, Be Faithful, and Condomize (ABC) Campaign, 91 per cent suggested the importance of young people being active participants in HIV/AIDS communication (Govender, 2010). The students did not support or relate to the ABC campaign because they believed that its contradictory and confusing messages stemmed from a failure to have engaged or consulted with them as the target audience. It is clear then that instead of top-down behavior change communication, more participatory approaches are needed. The importance of participation in the context of HIV and AIDS messaging is explored in the following section.

A new paradigm: Participatory processes, social change and development problems? Dialogical processes of communication

Development communication theory has evolved over the decades from a reliance on the dominant modernization paradigm to emphasize participatory approaches such as communication for social change (CFSC) and participatory development (CFPD). The paradigm of "Another Development", also known as Participatory Communication, strongly promotes "the opening of dialogue, continuous source and receiver interaction, thinking constructively about the situation, identifying developmental needs and problems, deciding what is needed to improve the situation, and acting upon it" (Nair and White, 1993, p 51). These elements, often described as ideal or genuine participation, are not only associated as an answer to economic development, but also crucial in facilitating better learning and the development of critical thinking and critical consciousness. The progression from the top-down, linear flow of communication to more interactive dialogue, is supported by many scholars as the cornerstone to facilitate discussion. Central to the discussion is the feedback where people involved have the ability to discuss, negotiate and make collective decisions.

Participatory communication, commonly associated with the Brazilian educator, Paulo Freire, and his writings on critical pedagogy, was soon employed as a means of engaging HIV positive people in collective dialogue about their lived experiences. It was further acknowledged as a means of program implementation where the dialogical processes of communication were associated with community empowerment, social mobilization, advocacy and giving voice to civil society and marginalized communities. While Freire's

focus was directly on education, his ideas have been related to human development in a more holistic sense, and have been adapted to suit a much broader development context, zooming in specifically as a rights-base approach in addressing HIV and AIDS. Freire suggests that critical thinking can be developed by democratic participation, and therefore active participation is the heart of many areas of development (Freire, 1983).

Beyond the participatory levels of engagement with people in the African continent who are in dire need of treatment, care and support, participation resonates with the Universal Declaration of Human Rights which identifies democratic participation as a human right. The right to good health care among others compelled governments to recognize the needs of citizens through the ongoing verbalization and active dialogue of their social and economic needs. Freire perhaps would call this critical consciousness. Jan Servaes (1999) on the other hand referred to this as the “multiplicity paradigm” because it rejects the view that development must always pass through the North Atlantic experience and affirms that different cultures have different paths toward development. This takes into account the importance of cultural contexts. The cultural differences present in the world require a multiplicity of development approaches, each one tailored to suit a specific context (Servaes and Malikhao, 2005).

The review of HIV and AIDS communication processes over the last 20 years in the report “Missing the message” shows that the “message is missed” when interventions lack community participation and involvement (Scalway, 2003). While the expert formulation of HIV and AIDS prevention messages is important, the environment in which these messages are created and received must be conducive for development and sustainability (Scalway, 2003). To Scalway this environment means creating a context for bringing in local culture and local social networks through dialogue and giving voice to people. Increasingly, it became clear that the linear communicative model of development showcased through the modernization paradigm, was of limited value in responding to the HIV epidemic. Participation promoted dialogue, communication engagement and critical awareness of people’s lived experiences. In so doing it ignited the need for community empowerment and mobilization as a response to HIV and AIDS.

Grassroot Soccer (GRS) operating in South Africa, Zambia and Zimbabwe is an organization employing innovative participatory

approaches and draws on the popularity of soccer as a sport to assist young people in learning about HIV and AIDS (Grassroot Soccer, 2010). While the focus is on encouraging young people to adopt sexually healthy behaviors that prevent the spread of HIV/AIDS, GRS does not employ rigid processes of communication but aims to bring about behavior change, in participatory ways. The organization's approach has been described as "fun with Freire", merging entertaining and dialogical methods (Colucci, 2010). Open discussions on HIV and AIDS are encouraged between the young participants and the soccer coaches to "empower youth through a style of education that fosters self-efficacy, and critical and independent thought" (Colucci, 2010, p. 91). The success of GRS can be attributed to the use of soccer culture, because it is one of the most popular sports and pastimes in Africa. Freirean pedagogy suggests that participation should be located within the beneficiary's cultural context, bringing to the forefront the relevance of education and development to that culture.

Uganda's approach to HIV and AIDS infections has been the most cited country as an example of successful prevention. Estimates by the US Census Bureau and Joint Nations Programme on HIV/AIDS (UNAIDS), showed that national prevalence of new infections peaked at around 15 per cent in 1991 and fell to 5 per cent by 2001. The country's success in reducing HIV and AIDS infections is attributed to its approach of promoting "abstinence", "be faithful (to one partner)", and "use condoms" (ABC) especially for those who were unmarried and sexually active (Singh et al, 2003, p. 6). The Ugandan prevention approach has gone out to the public via every imaginable channel, and has been appropriately tailored to different groups based on age, gender and risk categories (Green, 2004, p. 5). These appropriately tailored approaches reflect the emphasis of addressing the needs of Uganda beyond broadcasting in a linear, didactic approach to communication.

Social Change Communication

The paradigmatic shifts in communication for development later had significant impact on HIV prevention initiatives. Critics of BCC programs called for a move towards a social change communication approach, which recognizes people and communities as agents of their own change, it emphasizes community empowerment which creates an environment of change that is process oriented, provides a voice for

communities and opportunities for dialogue (Deane, 2002, p. 1). Simultaneously, communication responses to HIV and AIDS must take into account the context in which the pandemic is embedded (Cardey, 2006). Behavior change can usually be an outcome of social change and requires addressing social issues such as norms and values, stigma and discrimination, hegemonies, ideologies, power relations and repressive domination within a specific cultural, political and economic context (Lie, 2008, p. 285).

The "In Schools Programme" facilitated by Copperbelt Health Education Project (CHEP) in Zambia recognizes the importance of considering not only medical but also social and economic issues surrounding HIV and AIDS. While CHEP's central focus is on educating students about the virus, it also helps students to gain valuable skills such as literacy and numerical skills (World Bank, 2003). CHEP also addresses larger social issues surrounding HIV and AIDS such as gender inequality and cultural norms regarding sexuality, suggesting that a broader social change approach to the pandemic needs to be adopted. Melkote (2000) states that social change is a complex, disordered, unstructured, and quite often uncontrollable process. Having knowledge of what to do and why to do it may not be sufficient, in many cases, to change behavior. A shift beyond behavior to a focus on social/cultural change is crucial. Change interventions must then deal with what is circulating within the social domain, since social change does not take place at an individual level but in circulated culture and in shared beliefs (Lie, 2008, pp. 282-283).

However a move towards social change approaches still causes a significant sense of strategic confusion. Much of the debate at the Communication for Development Roundtable in 2004 focused on the need for long-term strategies which integrate both behavior and social change approaches, and a shift towards developing communication strategies that provide people with a voice as well as sending them a message. Still, so little focus has been placed on communication coordination (FAO, 2005).

Unlike behavior change which glorifies rational thinking and the ability to make concrete decisions, social change recognizes that people need the necessary skills and power to deal effectively with social change in a world that distributes needs, resources, and power unequally. Empowerment means not only development of personal confidence but also capacity to get and use information, capacity to participate in and manage local organizations and capacity to deal with

power structures. Empowerment therefore becomes a process well suited to deal with social change in general and with inequitable structures in particular. Whilst social change is fundamental in a community through dialogue for collective action, empowerment of the people is crucial to ensure effective development. All programs and campaigns should therefore reconsider the levels of empowerment given to the people before interventions are implemented in communities, ensuring the equal sharing of knowledge and solution alternatives among the “beneficiaries” and “benefactors” (Melkote, 2000, p. 47). The move away from the dominant modernization paradigm to a focus on participatory and empowerment initiatives has led to the development of various communication and development models. One of the prominent models developed in the late 1990s was the Communication for Social Change theory (CFSC).

CFSC is defined as a process of public and private dialogue through which people define who they are, what they want, what they need and how they can act collectively to meet those needs and improve their lives (Gumucio-Dagron and Tufte, 2004). It supports processes of community-based decision-making and collective action to make communities more effective and build more empowering communication environments. CFSC suggests that social change can only be effectively facilitated when the community and partners determine the levels of participation and ownership between the development support communication professionals and the community. Only when these communication professionals hand over all levels of participation to the community is effective ownership awarded and active dialogue for collective action made possible.

Green (2004) commends the success of Uganda in the combination of the ABC strategy, rooted in a community-based national response which reaches different population groups, with different interventions appropriate to their needs. Gilchrist (1990) and Green (2004) make a crucial point in addressing ABC when they suggest that interventions should be population specific. In other words, a prevention message should be designed to reflect the specific needs of the community through identifying the context.

Holistically the complexity of HIV and AIDS demonstrates the need for more social change approaches. Ongoing research has tremendous benefits for holistic approaches where understanding the social context of people and specific sexual behavior patterns can contribute to the level of change. The Human Science Research Council/Nelson Mandela

survey (HSRC) in South Africa (2002) was the first systemically sample-based community-driven survey on HIV prevalence in South Africa and showed that the knowledge of HIV and AIDS is generally high, with sexual behavior changes encouraging low numbers of sexual partners and high levels of abstinence among the youth. The HRSC survey in 2005, 2008 continued to track the prevalence of HIV among young South Africans. Central to these studies is the importance placed on identifying people's attitude, knowledge and practice in light of the pandemic. These various studies supported the continuous research process producing results of South Africans' behavioral patterns and providing information for HIV interventions. This demonstrated that even though HIV is addressed from a social change perspective, that individual behavioral understanding still remained crucial in formulating interventions.

The Scrutinize campaign, launched in 2008 uses a multimedia approach to engage young people and adults in discussions about safer sexual practices. The initiative demonstrates the instrumental role taxi drivers play in communicating messages as the campaign uses a taxi driver to relate correct information and awareness about HIV. Over a decade earlier, BCC interventions included the government's attempts to educate the masses through the transport system, by placing posters on taxi vehicles country-wide and encouraging taxi drivers to play cassettes with HIV and AIDS messages to encourage passengers to change their sexual behaviors while transported (Grundling, 2001). The difference between the earlier initiative with the taxi driver and the Scrutinize campaign is based on extensive research on what constitutes a successful communication campaign. The role of the taxi driver has not changed, instead the communication approaches and strategies have been revised to reflect people's behavior patterns and context of lived experiences.

HIV and AIDS as a development problem

The Millennium Development Goals (MDG) identifies HIV and AIDS as the sixth development goal, aiming to halt and reverse the spread of HIV by 2015, positioning the pandemic more as a broad development issue, rather than only a health problem. The UNAIDS, World Bank, Gates Foundation and Global Fund to fight AIDS, Tuberculosis and Malaria, and the President's Emergency Fund for AIDS Relief (PEPFAR) have become leading authorities in the current global governance of AIDS in Africa and are instrumental in shifting

the focus of HIV and AIDS to a development instead of a health problem since the late 1990s (O'Shaughnessy, 2007). Consequentially, O'Shaughnessy (2007) suggests that the much needed financial resources at the disposal of the donor agencies have ensured an adoption of the discourse of AIDS as a development problem. Tanzania's National HIV and AIDS Communication and Advocacy Strategy 2006-2010 adopts a holistic approach to combat HIV and AIDS.

The strategy places emphasis on using a "continuum of care" model, which situates the pandemic as existing in an environment of various contextual forces such as culture, gender relations, spirituality, socioeconomic status and government policy. The strategy emphasizes that communication must be used to encourage people "to see HIV and AIDS not as an individual's health problem, but as a social development issue". The Tanzanian government has chosen to approach the multi-faceted problem of HIV and AIDS from multi-faceted perspectives as the government believes that the key to this approach is using participatory methods, where citizens are encouraged to be at the forefront of actively educating others about HIV and AIDS.

Cultural factors are now perceived as being central to an HIV and AIDS approach or program. Lie (2008) describes culture as a text and not context. This means that culture cannot be added to a situation but that a situation cannot exist without culture. Culture is, therefore, the basis for action. If culture is the text, then the question remains what is the context for HIV. The context is how HIV is addressed in light of the various impositions of culture. Context has been the buzz word in addressing HIV and AIDS. Parker (2004) outlines the importance of reflecting on the context for sexual behavior which includes social, economic and cultural conditions.

The debates about poverty as a context to be recognized for HIV and AIDS interventions still continues and is valid today, but HIV and AIDS is not restricted to people of low economic conditions. In South Africa, for example, HIV positive people such as Supreme Court Judge Edwin Cameron, famous AIDS activist Zackie Achmat, Nelson Mandela's son Makgatho Mandela, iconic palywright Gibson Kente cannot be considered low income, poverty stricken people. Economic factors are therefore just one of many contextual factors which need to be considered, emphasizing the importance of holistic responses to HIV/AIDS. In the context of development, economic supremacy and

consideration takes pre-eminence over other important factors. Economic factors are only one of the contexts among psycho-social, cultural and political factors which contribute to the pandemic. The context of participation and the dialogical interactive process of identifying solutions within communities has still not been fully utilized, as will be discussed later.

Associating economic factors in developing countries as a contribution to the pandemic, enhances HIV as a development problem rather than a health problem. HIV could have perhaps been a result of a health problem as in the cases of many high profile South Africans. It could further be a health problem when research on people's true sexual practices are not considered in communication responses. To then make a shift for HIV and AIDS from a health problem to simply a development problem, completely eliminates the possibility of addressing HIV as a health problem when health issues are obviously also involved. HIV is not just a development problem which needs ongoing economic assistance from modernized countries. While economic aid can support development in Africa, developing countries still need to be cautious that a strong focus on development as a central problem to HIV and AIDS does not precipitate a diffusion of Western approaches packaged as assistance to HIV prevention.

Beyond an economic context, issues such as stigma and discrimination contribute significantly to the negative reception of HIV/AIDS. Many communities in Africa are still challenged by the silence of HIV prevalence in communities. Tomaselli (2009) still argues that people are not ignorant of HIV and AIDS. The real disease is that of denial, aimed at avoiding stigma on an individual, communal, national and continental level. The continuous challenges that stigma and discrimination pose requires people to re-evaluate how they define certain problems. Sometimes this re-evaluation requires adjustments to communities' attitudes, beliefs and perceptions about AIDS. Changes in how communities perceive people living with AIDS requires attitudinal change but from a societal level.

In this instance, HIV/AIDS needs to be addressed from a health perspective where communities become aware and understand the biological implications of HIV and provide care and support rather than addressing it as simply a development problem embedded with stigma and discrimination. HIV and AIDS perceived from the perspective of development, begs the question of whether a development approach is capacitated to offer relevant communication

strategies. An HIV and AIDS approach, even if it is from a broad development perspective, is doomed to fail if it only employs top-down, one-way communication. Ultimately, HIV and AIDS communication programs need to respond with a culturally sensitive, participatory approach to development issues which are affecting and escalating the pandemic.

So what is the context?

Governments, academics and civil society are still reaching for new solutions to what appears to be an old problem. The question still remains, whether HIV and AIDS is really an old problem or are our approaches to this pandemic just inundated, repetitive and stagnating? Are we failing to extend beyond limitations that sometimes people place on eradicating this pandemic? Change needs to be enacted from institutional, governmental, and community levels. Dialogue and participatory communication are supported as means of social change, through a process of defining who people are, what they want and how to go about getting what they want (Figueroa et al, 2002).

Guttman (1997, 2000) highlights the essence of addressing a social problem as dependent on how the problem is defined. Addressing HIV prevention in this context would require people in various communities throughout Africa to identify how they perceive HIV and AIDS and the implications of the virus on an individual, community and social level. Participation of the people in this instance would then be about more collective dialogue, collaboration and working together for collective action. Central to addressing HIV in countries of Africa would be to reach a consensus about what real participation entails. UNAIDS (1999) makes a plea for a new context-based direction for communication and proposes five domains of contexts which include government policy, socioeconomic status, culture, gender relations and spirituality. Rather the HIV pandemic should be approached from an understanding of all these contexts within the ever-growing need for participatory communicative responses.

HIV and AIDS communication in Africa therefore requires a move away from debates about whether HIV is a health related problem or a development problem. Consideration of all contextual and conceptual factors of HIV, though important, has not succeeded in combatting the spread of HIV. There is a need for health practitioners and researchers to review the real context. I argue that this real context demands participation, and requires us to review, recognize and apply ways of

promoting genuine participation. The ongoing dilemma of donor agency and conflict of power relations epitomizes the recurrence of the modernization era in what appears to be a debate about empowering, development, dialogue and diversity era. The case of Africa demonstrates the need to review the context of participation as a possible remedy to many failures of HIV prevention strategies. Amidst many conceptual factors which influence the silencing of the African voice, attainable participation needs to be renegotiated.

The contextual and conceptual factors in addressing HIV prevention are continuously referenced in the African context and, in many cases, incorporated into message design. However, the context of attainable participation is still unaddressed. Melkote and Steeves (2001) describe the conflicting contexts or metaprocesses of participation as an ends-approach, or a means-approach. The latter perceives participation as a means to achieve certain development objectives while the former is a process of ensuring the attaining of people's basic human rights through a process of participation and empowerment. Gerace and Lazara (2006) suggest that the question is no longer about achieving goals but an issue of priorities. Arguing strongly to place value on process, they consider the need to counter tendencies among those who hold power to emphasize their power rather than give greater attention to community participation and decision making. They later emphasize the need to consider the concept of responsibility and developing people's ability to express themselves. Central to the argument about the effectiveness of participation in the process of contributing to combating the spread of HIV on some level is the need to reconsider the role of participation between communities, donors, government and civil society. Parker (2004) suggests that a number of contextual and conceptual factors need to be included when reviewing HIV communication one of which includes the need to strengthen individual and community motivation to become involved in responding to the epidemic with a consequent need to invest in civil society responses.

According to Andrew Moemeka (1997), many development projects are still planned and executed without the participation of the target social system. Countries like Canada, Sri Lanka, South Africa and Afghanistan have seen development projects fail after implementation because the target social systems were not involved in the planning or implementation of these projects (1997). Soul City, South Africa's entertainment education multimedia and participatory initiative has

offered a long-running television series and subsidiary support programs. Focused on a range of health and development issues, HIV and AIDS have been addressed through numerous advocacy and community projects. Soul City's more direct efforts to encourage participation were established through the development of Soul Buddyz Clubs, which encourage dialogue among South African youth regarding issues such as violence and HIV and AIDS. Soul City recognizes the importance of engendering participatory social change.

Over the years, Soul City has developed its program to encourage community engagement, advocacy and empowerment. Soul City's work with South African's Domestic Violence Act illustrates the importance of partnerships, including direct lobbying of government, community mobilization and media advocacy, which all contributed to bringing the Act to a speedy realization (UNAIDS, 2007, p.14). While the field of development communication tends to be dichotomized along the lines of a top-down mass media approach versus a participatory interpersonal communication approach, the two do not necessarily exist on opposite ends of a spectrum (Morris, 2005). Soul City has been one of the pioneers in terms of creating development synergy by simultaneously employing the mass media and more participatory grassroots approaches (Tufte, 2001). For example, the television series has proved to be a conversation stimulant, encouraging families and peer groups to engage in dialogue regarding issues depicted on the series (Gumucio Dagron, 2001). Of paramount importance is acknowledging that the success of Soul City's combined media and community initiatives is the importance of participation and partnerships.

Soul City recognizes the importance of social change at the societal level, where various groups within a society mobilize to bring about transformation. In order for the new paradigm of participation to succeed in the context of HIV and AIDS, partnerships must be created between governments, donors and civil society since "partnerships, joint implementation and responsibility between government and civil society have proven to be critical elements in achieving national responses to HIV and AIDS Alliance 2007, p.4). Sustainable progress is impossible as long as attainable participation and partnerships are not achieved.

Caroline Halmshaw and Kate Hawkins (2004) argue that it is imperative that local community organizations are engaged as partners since their involvement plays a major role in ensuring that local

cultural context is considered when addressing HIV and AIDS. While donors are responsible for providing the important funds, and government often plays a central role in disbursing these funds, it is the local NGOs and civil society at large that directly use these funds to address health issues. Central to the success of effective HIV and AIDS communication interventions now lie in the sincerity and collaboration of partners. Halmshaw and Hawkins call for a review of “marriages of convenience” between governments and local NGOs, where funds are distributed by the former to the latter, simply for political purposes. True partnerships need to be participatory and dialogical in nature, where there is open communication between the parties involved so that effective HIV and AIDS strategies and programs can be designed and implemented (Halmshaw and Hawkins, 2004).

The real context is the success of “real participation” through collaboration with various stakeholders to address HIV and AIDS. Real participation in this sense refers to a realistic view of attainable participation given the various contextual factors. Successful HIV prevention programs will then have the capacity to blend participatory methods of community dialogue and empowerment with mass media approaches and other forms of informational and motivational communication and advocacy. The goal of such programs will then act as a catalyst for action at the individual, community and policy levels (UNAIDS, 2007, p.12).

Conclusion

Lie (2008) describes HIV and AIDS as a socially complex problem explaining that HIV/AIDS is more than a health issue and affects all sectors of life. It requires a multi-sector stakeholder process and involves a trans-disciplinary approach of bringing together different perspectives and knowledge. This complexity calls for a complex communication approach, accommodation of multi-stakeholders, a multi-sectoral approach and sensitivity to norms and values. A complex communication approach translates into one which is mindful of the challenges of participation and begs for a context specific approach to the use of participation for HIV and AIDS prevention.

Essentially, if HIV and AIDS is defined as a development problem, then this review demonstrated that through the three communication perspectives, HIV and AIDS communication is tending to go through a cyclic process taking us away from a focus on modernization to community participation and then back to development due to the

emphasis on economic factors in a modernization context. If HIV and AIDS is shifting from a health problem to a development problem, it then needs to be redefined more specifically as participatory development. Research demonstrates that currently development tends to be defined as an economic process rather than a social and cultural process. If this is the perspective, then development defined by international donors dominates the development goals with donor agendas, number counting and statistics which prove the success of their interventions but minimalizes change at the grassroots or developing country level. Often the approaches adopted by donor agencies conflict with what works in African countries.

This begs a review of whether identifying HIV and AIDS as a health problem or a development problem is really necessary. Instead, it becomes a circular process of handing back development goals into the hands of Western countries.

The question no longer remains whether behavior change or social change is relevant, whether mass media or interpersonal communication is adequate but rather whether a focus on HIV as a development instead of a health problem forces all approaches to HIV to focus on Western development approaches rather than local efforts. The issue would then no longer be about health or development but rather about the context of local participation. What is the level of participation that governments, civil society and the media demand in light of the conflicts between the three perspectives? Are the arguments about development and health really valid, or is assessing the level of participation the real context for change? These are some issues that Africa still needs to address. The above dilemma is one of many facing African countries daily. The question of what participation means in the context of AIDS followed by the complexities of disclosure, diagnosis, right to know your status, treatment, care, support and prevention makes HIV and AIDS a multi-faceted problem and an multi-level challenge. For as far back as literature can trace, HIV and AIDS has featured in every discipline with questions of cure, prevention, treatment and care. Central to these areas are ways in which people can be informed about how to ensure safer and better sexual practices. Research is inundated with material on the role of participation, critical evaluation of participation methods and the significance of empowerment in the process of participation. While the communication specialists argue about the correct processes of

communication, highlighting that the process is as equally empowering as the outcomes, millions of people are still dying from AIDS daily.

The question that now needs to be addressed is whether participation should be defined in the context of AIDS or whether AIDS is defined in the context of participation? This review article is an attempt to shed some light on research dealing with the communication perspectives in combatting HIV and AIDS. Our conclusions challenge readers to question the context for participation in addressing HIV and AIDS instead of the context of AIDS itself.

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Newspaper coverage of health issues in Nigeria

By Vitalis Torwel and Coboh Rodney

Abstract

This study examines how Nigerian newspapers constructed shared understandings of issues and problems of health, how the problems and issues were defined, what solutions were proffered, and whether the framing of the newspaper articles empowered readers to attain greater health. The study found that HIV-AIDS, cardiovascular maladies, cancer, reproductive health, problems of health policies and management as well as high cost of medicines, and fake and adulterated drugs topped the agenda of newspapers during the period. In addition, most newspaper articles provided readers with information and knowledge base on health which they can use in their daily lives and also endorsed scientifically proved natural health protectors for their management of diseases and ailments. In spite of obvious limitations, the study has shown that Nigerian newspapers pay attention to issues and problems in the health sector and their coverage can mitigate different health conditions with the knowledge they create and the choices they offer. The study suggests further research in magazines for better assessment of the role the health media play in society's health.

Key words: health communication in Nigeria, newspapers and health information, sources of health information for media in Nigeria

Introduction:

Mass media play a central role in informing the public about health and medical issues (Thorson, 2006; Alexander, 2005; Moyer, 1995). Print media especially perform necessary functions of providing information that will empower readers to action and are an alternative source people rely on for health information about new health risks, disease outbreaks, domestic and international alerts and healthy living. To learn about health information, people look to numerous sources: newspapers, magazines, and television, radio, Internet, friends, and relatives, medical sources.

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News media are a major sources of information about health issues for both the general public and for health professionals and, according to Wilson, Booth, Eastwood, and Watt (2008), new media can have an influence on decisions about health policies and medical care. Holder & Treno (1997) explain that media serve as a forum in which the consideration and presentation of public health issues are presented and are recognized as powerful mechanisms to promote the awareness and education regarding public issues. How media are constructing shared understandings of health problems in Nigeria and what health issues are presented and made more salient and newsworthy to the public is an important question. News media can play a critical role in awareness and education on public issues and probably influence decisions about health policies and medical care.

Enough evidence exists to show that the health sector in Nigeria has suffered dramatically over the years as have other public service activities. A study produced by the Amsterdam Institute for International Development AIID on Nigeria's health sector says Nigeria's health indicators have stagnated or worsened during the past decade.

Life expectancy is 44 years, lower than the African and developing country average, and infant mortality is almost double the developing country average. An estimated 3.5 million Nigerians are infected with HIV, and access to prevention, care and treatment is minimal. The burden of healthcare financing lays mainly with individuals with private expenditures equalling 70 per cent of total health expenditures and out-of-pocket expenditures totalling 90 per cent of private expenditures (Gustafson-Wright and van der Gaag, 2008, p. 1).

Participants at the Nigerian National Health Conference held at Abuja Sheraton Hotel and Towers, 28-29 November 2006, aimed to develop a health agenda for Nigeria in the twenty first century, similarly observed that:

Nigeria still has one of the worst health indices in the world and sadly accounts for 10 per cent of the world maternal deaths in child birth whereas she represents 2 per cent of the world population, as at year 2000; that the Nigerian health system is dysfunctional and grossly under funded and the country lacks an integrated system for disease surveillance, prevention and management; and that social correlates of ill-health including hunger, poverty, illiteracy, lack of clean water, poor sanitation,

poor housing, gender disparity and unemployment are still prevalent (National Health Conference, 2006).

All three levels of government, the federal, state and local government areas, have responsibilities for the provision of health care. The federal government sets overall policy goals, coordinates activities, and ensures quality, training, and implements sector programs such as immunization. The states and local government areas are responsible for all financial aspects of primary and secondary health care departments including personnel costs, consumables, running costs, and capital investments. But Johnson (2000) says communication levels are poorly developed and data for planning purposes and management are sparse and these rarely function effectively. Worse still, available resources are often not employed in a cost-effective manner where they would bring the highest benefit.

Hence, according to Utomwen (2009, June 1), failure in the system is due largely to large-scale corruption, inefficiency, misplaced priorities and inadequate funding. Inadequate financial resources for the health sector are a major problem resulting in scarcity of drugs, medical supplies, and deterioration of facilities. In fact, one of the main reasons for the very low utilization rates for public sector hospitals and clinics has been poor standards of facilities and care.

The print media, particularly newspapers, have been found to be effective media for influencing the general public as well as opinion leaders on issues of public health (Evans & Ulasevich, 2005) and newspapers are one of the most accessible and affordable sources of information. Although a report evaluating media coverage of HIV AIDS, TB and Malaria in five sub-Saharan African countries by Africa Women's Media Centre (AWMC, 2004) found very little coverage of health matters in the newspapers assessed, newspapers are still best suited for explanations and in-depth analysis because of the length allowed for in print and the relative ease of access. And because newspapers are fairly widespread in Nigeria, they are an important vehicle for disseminating information health issues to the larger population. The role of the media in the health sector has frequently been highlighted, criticized and questioned but no systematic and critical assessment of coverage of the health sector in Nigeria has been undertaken.

The importance of media in the public's health knowledge

The function of the media in dealing with public health issues has been extensively examined. Selection of news stories is well recognized

as an agenda setting function of the media, and by it, the media serve as a forum for consideration and presentation of public health issues. Hence the media are regarded as powerful mechanisms to promote awareness and education on public health issues (Holder & Treno, 1997). Past research suggests that the media do indeed play a primary role in policy making processes by informing the public of relevant issues and shaping public thought surrounding those issues (Wakefield, Smith and Chapman, 2005). Collins (2006) for instance, recognized print news in particular, as an integral source of public policy information as well as a medium to persuade public opinion, depending on selection and presentation of issues. Holder and Treno (1997), for instance, reported that media advocacy efforts served to increase news coverage of alcohol issues, to raise community awareness of drunken driving enforcement and to heightened perceived risk of driving while intoxicated. Similarly, Mortersen and Serritzew (2006) found that in municipalities with intensive coverage from local newspapers, the media strongly impacted local decisions, especially those made by local politicians.

In the area of health, therefore, the mass media play a central role in informing the public about health and medical issues. In the UK, according to Wilson, Booth, Eastwood, and Watt, (2008), daily national newspapers remain a major source of news for clinicians and consumers alike, with over ten million newspapers sold every day. This fact, perhaps, made Chewa, Mandelbaum-Schmid and Gao (2006) acknowledge that the mass media are an alternative source people rely on for health information. Psychologists also acknowledge that media are "heavily implicated in the construction of shared understanding of health "(Hodgetts & Chamberlain, 2006, p. 317).

Research has shown that "print media's dissemination of health information is important in shaping public beliefs and possibly behavior" (Moyer, 1995, p 147), hence the media can and do play a key role in shaping our understanding of medicine and science generally, especially about the ways in which decisions about effectiveness and cost effectiveness are made (Wilson, Booth, Eastwood, and Watt, 2008). There is considerable evidence, then, that the newspaper media perform a necessary function in providing information that will enable its readers to take action. Research, for example found that people who were subjected to an elevated level of cancer-focused news actively sought additional information about cancer (Nornik, Niederdeppe and Frosch, 1995).

In Nigeria, well-designed mass media campaigns have proved their ability to increase the use of family planning. Between 1985 and 1988, television promotion of family planning in the cities of Ilorin, Ibadan and Enugu helped increase the number of new and continuing contraceptive users (Piotrow et al, 1990). Research in other African countries confirms the strong association between exposure to family planning media messages and contraceptive use (Kiragu, Krenn, Kusemiju, Ajiboye, Chidi and Kalu, 1996). In the Kilimajaro Reproductive Health Programme KRHP in Northern Tanzania, radio was used and found to be an essential and powerful tool in educating and mobilizing communities for HIV prevention clinical trials and was particularly valuable in promoting actual participation in the clinical trials (Ngilangwa, 2007). Also the mass media were used extensively by USAID and WHO (1999) for the expanded program on immunization campaigns in transmitting information, and messages were found to be effective in reaching about half of the population.

Research has, therefore, confirmed the media as valuable, reliable and alternative sources people rely on for health information and for shared understandings of health. It is now incontrovertible that the media's dissemination of health information is important in shaping public beliefs and desired behavior or empowering readers to action to think, interpret and view health issues through critical, accurate and clear news presentation and interpretation. Nigeria paints a dismal picture with health indicators below what would be expected for a country with its level of GDP, where HIV prevalence has skyrocketed over the last 10 years to reach an estimated 5 million individuals, where infant and child mortality is the highest in the world, where socio-economic and regional differences suggest great inequalities in access to health care, and where private expenditures or out-of-pocket spending makes up 65 per cent of total health spending.

It is imperative that the media and journalists use their potential to reclaim the health sector in Nigeria, by improving discourse on the health situation and issues, shaping beliefs and empowering readers and spurring government to action, providing critical, accurate and clear interpretation and serving the surveillance function. A central question in this study is how media are constructing shared understandings of health problems in Nigeria? What health issues do newspapers present and make more salient and newsworthy to the public.

Research Methods

To help evaluate how effective are newspapers as important avenues and sources of more in-depth information regarding the health sector in Nigeria, content analysis was used to investigate print editions of the newspapers. The study focused on newspapers because they provide more substantive materials for analysis and often inform the agenda of broadcast news. Four newspapers: *The Guardian*, *This Day*, *Leadership*, and *the Daily Independent* were selected for the study. These newspapers were selected because of their national reach and readership. In selecting samples, we relied on procedures established by Stempel (1952) and drew three separate quarterly samples of 6 issues of each newspaper for a period of two years: 2007-2009. This period coincides with the first two years of the President Shehu Musa Yar'Adua administration and his seven-point agenda of national development which includes a comprehensive health agenda for the country. Altogether, 18 issues of each newspaper were sampled amounting to 72 issues in all. This sample size yielded a total of 378 relevant newspaper articles and stories on health.

Each issue of the newspaper was read in order to identify health-related issues and themes. To assess inter-coder reliability, two people (the researcher and an experienced undergraduate student) coded the first 100 stories together to help in examining the codes. The inter-coder reliability, based on percentage of agreement, was assessed for the dominant themes/issues/diseases, sources and types of article until the procedure established an acceptable level of agreement of 94.68% agreement between the coders, and one researcher coded the remaining sample.

An exploratory method was used to identify framing categories used in newspapers' coverage of health issues. Frames, according to Entman (1993) "define problems", "diagnose causes," "make moral judgements and "suggest remedies". In order to identify frames, we followed Lovejoy (2007) and formulated similar questions, according to the typical framing categories, to guide frame development for this study.

1. What diseases and health issues were highlighted?
2. What was blamed for these health issues?
3. What remedies for health problems were suggested?
4. How were the articles framed so as to empower readers to attain better health?

Each article was read to ascertain whether it contained empowering information. According to Bergsma (2004), the feeling of empowerment is essential to one's health and well being. Rappaport (1987) defines empowerment as a by-product of what happens when health articles provide readers with specific means to gain control over their health problems and actively participate in a path towards attaining better health.

Results

From the sample taken for the two years, 378 newspaper stories were published regarding health in Nigeria. Of these, 254, which are more than half, were traditional straight news accounts and 62 were articles. The articles discussed diseases according to causes, symptoms and treatment and either endorsed natural health protectors or made recommendations to life style changes or foods, vegetables, fruits, exercise, and nutritional values. About 34 of the health stories came as features. Features blended facts and comments on health issues distilling reality and its implications without making recommendations or policy options. Opinions and letters to the editor were nine each in number, while the newspapers conducted six interviews and wrote four editorials during the period.

Regarding news sources, most news items (33.95 per cent) were taken from government official sources, 24.35 per cent from scientific research, 12.92 per cent from professional and interest groups, 8.86 per cent from medical experts, 8.49 per cent from staff, and 4.06 per cent from international organisation. Drug manufacturing companies and other corporations represented 2.21 per cent, spokespersons and anonymous sources were each 1.48 per cent, individuals, 1.10 per cent, and media 0.37 per cent. An analysis of the distribution of articles across newspaper shows that *The Guardian* published the highest number of articles on health, 141 (37.30 per cent), followed by 99 articles (26.19 per cent) in *Leadership*, 95 (25.13 per cent) in *This Day*, and 43 (11.38 per cent) in the *Daily Independent*.

To answer question one regarding types of health problems, descriptive analysis were conducted. Among diseases and illnesses, HIV/AIDS was mentioned in most articles (46 times), followed by cardiovascular maladies such as heart disease, hypertension, stroke, cirrhosis, high blood pressure, blood transfusion problems and smoking-related ailments (42 times). The third most mentioned disease was cancer (24 times). Next to cancer were reproductive health

problems (23 times) such as abortion, conditions of low sperm count, sex education, maternal mortality, and the phenomenon of test tube babies. Reproductive health was followed by diabetes (19 times), common cold, influenza, bird/swine flu and Lassa fever (16 times). Mental illness, malaria and polio were all mentioned 13 times each, children's health, including breast feeding and infant mortality (9 times), tuberculosis (7 times), cholera, glaucoma, meningitis, obesity, sickle cell were all mentioned 4 times each. Ulcer and STDs both were mentioned 3 times each. Arthritis, insomnia, skin infections, glandular fever, autism, and measles all appeared only twice. Gout/goitre, haemophilia, epilepsy, diarrhoea, and leprosy were all mentioned once only.

On coverage of health issues, health policies and management problems featured most frequently (48 times). The dominant policy issues were those of the National Health Insurance Scheme, medical treatment of public officials abroad, registration of health practitioners, and the progress of the National Health Bill in the National Assembly. Issues of health management include safety standards, attitude of medical staff in public hospitals, funding and facilities, education and training. Another issue mentioned frequently by the newspaper was the issue of fake, illicit, adulterated, and substandard drugs and products, drug trafficking and food poisoning,

Next to hard drugs is the issue of compensation for victims of the 1996 Trovanfloxacin clinical trial tests by Pfizer in Kano which claimed the lives of 200 children and maimed several others. This compensation issue feature about eight times in the newspapers. Industrial unrest in the health sector also featured frequently, mostly dealing with a series of strikes embarked upon by resident doctors. Other issues that gained prominence during the period were those of corruption, high cost of medicines, problems of access to public health care services and problems of professional medical practice.

Answers to question two regarding the typical framing structure described by Entman (1993) of defining problems, diagnosing causes, making moral judgements, and suggesting remedies, were revealed in several issues of health in Nigeria. In defining the issue of the high cost of medicines, newspapers relied on WHO data identifyin Nigeria as one of the eight African countries where prices of drugs, particularly essential ones, are at the rooftops: "medicine procurement in public facilities is as much as five times more expensive in Nigeria than in seven other countries" (Ukwuoma, August 13, 2007). Newspapers

diagnosed causes of high medicine cost as government tariffs and taxes as well as “mark-ups by the distributor or retailer (which) were found to be up to 900 per cent of the manufacturers’ price” (Ukwuoma, August 13, 2007). Moral justification for importance of medicine prices, according to the newspapers, was based on the fact that “most Nigerians purchase their medicines out of pocket,”. Since “as many as 90.2 per cent of Nigerians live below the income level of N256 a day as well as government workers that earn a minimum wage of N479.00 per day, most cannot afford the cost of medicines. Hence “high medicine prices constitutes a major barrier to access to health care” (Ukwuoma, August 13, 2007). Suggested remedies include a review of the procurement policy and empowerment of NAFDAC to consider medicine prices before issuing authorization to importers and manufactures.

On the issue of tuberculosis prevalence in Africa, Africa Public Health Alliance (APHR) identified Nigeria as having the highest tuberculosis rate in Africa with “an estimated 0.7 million cases” (*Leadership*, November 12, 2007) and “the highest level of TB in relation to HIV positive adults.” The low capital expenditure on health and “dependence on external resources” and “the low number of health workers, including doctors, pharmacists and nurses” (*Leadership*, November 12, 2007) were diagnosed as main factors for the increasing number of TB patients. Remedies suggested included investment in health infrastructure, training, and retention of personnel, increasing the number of doctors and nurses, increasing health financing by up to 15 percent of annual budgets, and maintaining the expenditure at between 70 and 90 percent for five years.

On the issue of maternal and infant mortality, *This Day*, used a UNICEF Report to define Nigeria’s increasing problem of maternal and child deaths. The article affirms that one Nigerian woman dies every 10 minutes from complications of pregnancy and childbirth, while 500 newborns die daily in Nigeria. About one million out of about 5.9 million babies born in the country every year die before the age of five (Editorial, 2009 March 5). The newspaper diagnosed causes of Nigeria’s increasing maternal and infant deaths as mainly stemming from poor primary health care and emergency obstetrical services associated with child birth.

In its moral judgement, mothers and children deserve the best of health care and, since children are our future, any nation that toys with the destiny of its children is tottering on the edge of collapse. The

newspaper proposed the deployment of an all-encompassing Integrated Maternal Newborn and Child Health Strategy and suggested comprehensive action based on high impact intervention packages that address the main causes of maternal, newborn and child morbidity and mortality in an integrated, partnership approach at all levels.

A central question in the study was whether newspaper articles contained empowering information or were framed in such a way as to enable readers to adopt better health practices. An exploratory method was used to identify frames used in newspapers coverage of health in Nigeria. Two main framing categories, informational and medical, were identified. Within the medical frame, some of the sub-frames listed by Lovejoy (2007) such as “science and health knowledge” and the “science-indorsed health protectors” also appeared.

The “informational frame”, which was the most prominent in the sample, was used mainly by the newspapers to create awareness of occasional free medical services available and donation of relief materials. There was a call for action to deal with the outbreak of diseases, court actions, increasing cases of HIV/AIDS, and strike actions. The articles pointed out the need for vocational skills training programs for AIDS victims, improving staff attitudes in government hospitals, and immunization and sensitization campaigns. There were concerns over the President’s deteriorating health and the lack of reality checks on health data reports. The informational frame called attention to the outbreak of meningitis and Lassa fever. *This Day* relied on government officials to confirm that the two deadly diseases have killed 333 persons in 22 states within two weeks (Oji, Ojeifo, Thomas & Awofadeji, March 5, 2009). The newspaper cited as sources the Minister of Health, the Federal Ministry of Health, Commissioners of Health and the Senate regarding outbreaks in two of the affected states. Attention was called to the loss of lives and the need to provide information and create awareness. The information frame adopted only the traditional straight news account format which merely defines the issues and events without attempting to diagnose causes, make moral judgments, or suggest remedies.

In assessing empowerment, the “medical frame” became more noticeable. The “science and health knowledge frame” provided information about scientific findings, medical discoveries and new pharmaceuticals, and discussed ailments by defining them, diagnosing causes, symptoms, treatment and preventive measures. With this

framing not only was there communicated something of the benefits of science and medical research but it also helped readers to detect ailments in their early stages. *The Guardian* (August 23, 2007), for instance, in a story titled "Researchers link alcohol to HIV disease progression and stroke risk" advised HIV-infected persons when it said research has found "a link between alcohol consumption and HIV disease progression in HIV-infected persons," and that "alcohol may adversely affect immunologic functions in HIV-infected persons by various mechanisms".

In another story titled "Local free extract shows promise in treating venereal diseases and infertility," *The Guardian* (August 23, 2007) again put at the disposal of readers research knowledge which confirmed the traditional medicinal value of Sausage Tree extracts in the treatment of fertility abnormalities and sexually transmitted diseases (syphilis and gonorrhoea) especially in male and female adults.

The sub-frame of "Science endorsed health protectors" endorsed natural health measures including herbs, fruits or nutritious food groups or normal foods with vitamins, minerals, herb supplements, exercises, relaxation and sleep as possible remedies for mitigating severity of diseases and ailments. For example, a story by *This Day* (September 9, 2007) titled "Hydrotherapy" demonstrated how the use of water at various temperatures and states , ice, steam, bath and inhalations, showers and hot towel can help the body to heal and create different physiological reactions. In another story titled "A plant-based diet may halt spread of prostate cancer", *The Guardian* (March 20, 2008) endorsed diets rich in soyabeans and legumes and legumes found in nuts, cereals, fruits, berries and vegetables as well as tomato, garlic, and coconut as efficacious for the management of prostate cancer. Another news story, based on a study with a large population sample, examined the association of regular tea consumption with the risk of breast cancer. The study endorsed consumption of up to three or more cups of tea a day for reduction of breast cancer risk, as consistent for invasive breast cancers and for ductal and lobular breast cancer (*The Guardian*, February 20, 2009).

Some of the medical intervention frames highlighted "new pharmaceuticals and medical equipment". *The Guardian* (February 26, 2009), for instance, heralded an experimental drug known as A-002 as a prospective panacea for effective treatment and prevention of hardening of the arteries and heart disease. *This Day* (February 22,

2008) announced a Designed Electromagnetic Pulsed Technology (DEPTH Impulse) device which, it says, heals all kinds of ailments naturally under the influence of the electromagnetic field created by it.

Summary of findings

This study was undertaken to find out what framing strategies newspapers used to create shared understandings on problems in the health sector in Nigeria. Results show that most news on health came in the traditional fact-based approach and this was the preferred form in which newspapers presented health information. The study also found that the most frequently used sources of news on health by newspapers were government official sources. The medical problems most frequently brought forward in this period for public attention and debate were HIV-AIDS, cardiovascular diseases, cancer and reproductive health. Among issues of greatest salience were those of health policy and bad management, the high cost of medicines, fake and adulterated drugs. The government was held responsible for most of the problems in the health sector.

The health issues that the newspapers encouraged readers to take action on varied considerably. Some articles provided knowledge on health practices which readers could make use of in their daily lives. For example, articles advised readers, with the endorsement of scientific research, to use natural and nutritious food that had vitamins, minerals and natural herb supplements that would protect their good health. Readers were encouraged to use simple remedies such as increased water intake and more sleep as protection against infections and to cure minor ailments.

Other medical intervention frames were also found to be empowering since they explained some ailments in terms of requiring medical intervention and the articles were written to show the benefits of latest medications, technology, and procedures. Thus, the articles not only inform but place emphasis on the depicted medical interventions as the answer to ailments and were written for both the individuals who either already suffering from some of the ailments or are considered high-risk.

Discussion

This study was conducted to discover the image of the health sector being created by newspapers. The study found that newspapers framed health issues differently from events, diseases, and ailments.

Health issues such as the high cost of medicines, prevalence of TB, maternal and infant mortality, followed the typical framing process suggested by Entman (1993) of defining problems, diagnosing causes, making moral judgments and suggesting remedies.

Events, diseases, and other problems in the health sector were cased in the informational frame to create awareness on them and the knowledge necessary to take action. Diseases and ailments were framed as problems that can be solved through medical and scientific knowledge. This type of framing supported pre-eminence of the medical frame found in previous studies by Clarke & Binns (2005) in their analysis of mass print media. It must be noted that most stories covered in this study were designed for general readership. Most stories therefore did not focus on a particular disease or ailment to emphasis optimism in the readers' ability to overcome threat of such diseases. Nevertheless, the stories served as phenomenal sources of empowerment and direction towards greater health.

Many previous studies have assessed the efficacy and empowerment of health coverage (Wackerbarth, 2005; Mckay & Bonner, 2002). Similarly, this newspaper coverage of health found empowerment as an ingredient within the medical frame. With the use of pictures, drawings and other illustrations, newspapers empowered readers by giving them information, creating knowledge, and making recommendations which readers can take away and incorporate into their lifestyles and lives. We may not be in a position to assess the effectiveness of health articles and empowering information but the articles obviously provided a strong theme of empowerment as they provided reader with health and scientific knowledge and sought readers' enlistment into health choices to reduce own personal risks.

Additionally, newspapers provided regular readers with an abundance of articles that treated diseases and ailments by their definition, causes, symptoms, treatment and preventive measures and endorsed certain foods and herbs – African oil bean for control and treatment of diarrhoea, cancer and tobacco related disease; bitter-kola for boosting sperm count and healing testicular damage; low weekly exercise to reduce high blood pressure; cabbage to boost immune system; breadfruit to help combat diabetes, and dark fruits to fight cancer. It is absolutely possible for an avid reader of newspapers - to savour knowledge and use important recommendations among the many. Most of the straight news account on important problems of health may be one sided but they provided a feeling of shared

understanding on some of the pressing health problems afflicting our society. The medical frame was particularly useful for those individuals who need information about some of the diseases and ailments and who seek what remedies exist for treating and managing such conditions.

While this study acknowledges the fact that inaccurate reporting can attenuate understanding and use of value gained (Adelman & Verbrugge, 2000; Chew, Mandelbaum-Schmid & Gao, 2006), it adopted the framing method to focus on meaning rather than on accuracy. This can be seen as a major limitation of the study albeit it does not discount the importance of assessing the accuracy of health stories. Another study limitation is that only newspapers were analyzed. Magazines would have offered a combined, more even distribution of health news frames. It is also possible that newspapers miss those who need these health messages most but due to their below poverty earnings they are not able to afford purchase newspapers or are hindered by their low literacy background.

Qualitative analysis used as study technique in this study to analyze newspaper content does not allow one to draw any causal inferences between media and behavior. Besides, studies are mixed on how closely health reporting influences health behaviors and attitudes (Dutta - Bergman, 2004), in spite of the rapid growth of health media. Also, this study made use of a limited sample of newspapers dealing with health issues in Nigeria. These findings are therefore not representative of all health articles in Nigerian print media.

Conclusion

Despite these limitations, this study showed that Nigerian newspapers focus substantial attention on health matters, and their coverage can mitigate different health conditions by empowering readers with knowledge and choices that can help mitigate their conditions. Frequent reports on medical products, services, and technologies tended to make readers, especially those who actively seek such information, aware of treatments available to them. Further research should investigate coverage of health in magazines as well as specialized health magazines aimed at specific readers. Additional quantitative studies can assess the influential role that health media play in society's health decision-making and in helping to shape the health of our nation.

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VITALIS TORWEL AND COBOH RODNEY



The failure of radio to communicate knowledge of sickle cell disorder in Nigeria

By Edidiong Umana and Ayobami Ojebode

Abstract

The study aimed to find out how much residents in Akwa Ibom knew about the sickle cell disorder. In a survey of 300 people, we discovered that only few people (32.9%) had adequate or fairly adequate knowledge of sickle cell disorder (SCD); only about 45% were definite that they would not marry a carrier if they too were carriers. Radio, the most important source of health information for about 73% of our respondents and though praised for health education and information in Nigeria, says nothing about SCD. Workers in the radio station were themselves not aware of the prevalence of, or they felt incompetent to educate their listeners about, SCD. It is our belief that these people know little or nothing about SCD because radio says nothing about it. There is need for non-media forces to call media attention to and in fact use media to educate people about SCD in Nigeria. Nigeria government also must show commitment to SCD education.

Key words: Sickle cell disorder, SCD, Nigeria, radio

Introduction:

Unknown to many, the prevalence of the sickle cell disorder (SCD) in Nigeria is greater than that of HIV/AIDS. About 40 million Nigerians have the sickle cell trait and about 4 million have the full disorder (Azolibe, 2007; Ohaeri & Shokunbi, 2001). By implication, more than 25 per cent of Nigerians carry the sickle cell trait. If any two of these carriers marry and bear children, one out of every four of their children is most likely to have the sickle cell disorder. This calls for extensive

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education and information for unmarried Nigerians. This kind of health education and information is one of the roles for which the Nigerian radio has received substantial applause (See Ojebode, 2008; Adekunle, Olaseha & Adeniyi, 2004; Atanda, 1997). Yet, the question remains as to how well radio has performed in educating and informing Nigerians with regard to SCD. In this paper, we examine first the content of radio broadcasts regarding SCD and what factors enhanced or limited the performance of radio in SCD education and information. Then the study reports how much is known by radio listeners in Akwa Ibom region of Nigeria about SCD and whether this information is likely to lead listeners to take action regarding SCD.

Health challenges in Nigeria and the response of the broadcast media

Nigeria faces tremendous health challenges. Though it is one of the leading exporters of crude oil globally, it is poorer than many other African countries in terms of health performance indices. WHO (2008a) statistics show that life expectancy at birth for Nigerian men is 48 years; for women it is 49 years. This is lower than in Ghana, Gambia, Uganda, Senegal and Cameroun. Healthy life expectancy (HLE) for Nigerian men is 41 years; it is 42 years for women. Again, this is lower than the case in several African countries. For instance, in Ghana HLE is 49 for men, 50 for women; in Gambia it is 48 for men and 51 for women (WHO, 2008a). From every 1,000 children born in Nigeria, about 191 will die before they are five years old, as against Uganda's 134, Ghana's 120, Senegal's 116, or Gambia's 114. The same body of statistics shows that 447 among every 1000 Nigerian men are likely to die before they celebrate their 60th birthday. But in Senegal, it is 307 among every 1000 men; in Benin, Nigeria's neighbor, it is 349 and in Ghana it is 350 of every 1000 men.

HIV/AIDS prevalence is high in Nigeria: in 2007, there were 170,000 deaths resulting from HIV/AIDS (WHO, 2008b). There are about a million Nigerian children orphaned by AIDS (WHO, 2008a). Among young female Nigerians, the prevalence rate is 2.3; but it is 1.3 in Ghana among the same set of people. Among young Nigerian men, HIV/AIDS prevalence is 0.8 which is higher than Ghana's 0.4 (WHO, 2008b). The general HIV/AIDS prevalence rate in Nigeria is 3.1 which again is higher than what obtains in many African countries (WHO, 2008b). Nigeria is one of the few large populations to cross the 5 per

cent prevalence threshold having the fourth largest number of people living with HIV/AIDS in the world (WHO, 2004).

Health funding in Nigeria is poor. For the year 2007, whereas the total per capita expenditure on health in Uganda was \$130, and in Ghana \$93, in Nigeria it was \$45. Even much poorer countries like Senegal spent more on health per capita (\$69) than Nigeria (WHO, 2008a). This explains why Nigeria has consistently ranked among the lowest in health performance indicators globally. For instance, in 2005, it ranked 187th among 191 countries (DFID, 2005). A comparison of the figures in the last few years shows little or no improvement (See, Gureje, 2005; DFID, 2005; WHO, 2004).

While not exonerating the Nigerian government for the obvious neglect of its responsibility, many have called attention to the point that many of the health problems in Nigeria could be prevented by the affected individuals themselves if there would be proper information and education (Soola, 1991; Omotade, 1995; Gureje, 2005). Even while acknowledging the fact that the media are not an all-powerful magic bullet, some of these scholars have challenged the media to take the lead in educating and informing their audience in matters of preventable health conditions (Soola, 1991; Adekunle et al, 2004; Ojebode & Adegbola, 2007).

In response to that challenge, most broadcast stations in Nigeria, both commercial and state, devote substantial air time and effort to health education. Their efforts come in the form of health talks, interviews with guest physicians, health jingles and testimonials. In many respects radio takes the lead over television in health education (Adekunle et al, 2004; Ojebode, 2005; Ojebode & Adegbola, 2007). Radio is particularly suited to the Nigerian situation for a number of reasons. The total adult literacy rate is only 69 per cent (UNICEF, 2008), and health messages in handbills, newspapers and books will not reach many. The electricity power supply is extremely poor which makes television viewing infrequent. Radio is mobile, cheap to own and run (Olorunnisola, 1997). Radio jingles are especially potent educational formats in Nigeria (Ojebode, 2005). They are easily memorized and remembered by listeners, and when the facilities permit, they are applied.

Studies have been conducted that evaluate the performance of the media in disseminating health information in Nigeria in the areas of family planning (e.g Adekunle et al, 2004); HIV/AIDS (Onyechi, 2007;

Ojebode and Adegbola, 2007); malaria prevention (Greer et al, 2004; Goodman, Brieger, Unwin, Mills, Meek and Greer, 2007), oral polio vaccination (Makanju, 2006), cancer (Ojebode and Adegbola, 2007) and even in fighting schistosomiasis (Olaseha and Sridhar, 2006). We searched for a study on the use of mass media for educating Nigerians about the sickle cell disorder but, surprisingly, could not find any.

The magnitude of the sickle cell problem in Nigeria

The evaluation of the use of media in addressing the need for information regarding sickle cell disorders is important because of the enormity of the problem in Nigeria. According to Ohaeri and Shokunbi (2001), sickle cell disorder (SCD) afflicts about 100 million people worldwide. Of these, four million are in Nigeria. The magnitude of the disorder in Nigeria is best appreciated when one considers that more than one in four, or 40 million Nigerians, are carriers of the sickle cell trait and that, annually, 20 per 1,000 babies are born with the disease, translating to over 150,000 babies born annually with sickle cell anaemia (Sickle Cell Foundation, 2008; Akinyanju, 2007). If this is compared to other affected African countries, and indeed several others put together, it is evident that Nigeria has the largest sickle cell gene pool in the world (Akinyanju, 2001; Adeyemi, Adeniran, Kutu, Owolabi & Durosinmi, 2006). One newspaper has tagged Nigeria the "capital or headquarters of sickle cell disorder in the whole world" (*The Nation*, 2008, p. 18).

Certain socio-cultural and infrastructural factors contribute to the spread of the SCD in Nigeria. Many intending couples do not conduct genotype tests because insisting that a partner conduct blood tests is an implicit expression of distrust in their moral chastity. In many traditional Nigerian communities, this casts a slur not only on the intending spouses but, especially, on their parents. In some parts of Nigeria the parents, under the cloak of religion, literally "force" their daughters into marriage in their early teens. Such parents do not bother to find out the genotype of the intending husband nor are the girls given the right to question this.

The third possible reason for the spread of SCD is the poor state of the laboratories and the incompetence of laboratory staff in Nigeria. In our preliminary investigations for the study, we came across a middle-aged man who conducted his genotype test twice in the laboratories of different secondary health facilities and got two different results. Not

only this, it costs substantial money and waiting time to conduct any test in Nigeria (Greer et al, 2004; Goodman et al, 2007). In many villages, travelling to the city where the health facilities are, waiting in line for hours or days, and having to return on a later date for the results, costs a lot of money and time, and can be generally discouraging.

We strongly suspected that, added to all the reasons above, is ignorance. How much do Nigerians know about SCD, its causes, prevention and management? What are the sources of their information on SCD? How much and what quality of information do these sources of information offer? These were the questions that motivated this study.

The Study

The study began as a simple small-scale survey to ascertain what Nigerians know or believe about SCD, but our findings kept pushing the original boundaries of the study further. Our survey showed that radio was a major source of health information for our sample, so we decided to examine what SCD messages there were on radio. The findings of the content analysis led us to interview the radio station staff and health workers. The survey was conducted in Akwa Ibom state. By the 2006 census, Akwa Ibom has a population of 3.9 million, mostly fishing and farming families. The SCD prevalence rate in Akwa Ibom is unknown but there are no grounds to suggest that it is better than the national average. Akwa Ibom is among the few states in the country that do not have sickle cell clubs or centres.

To draw respondents for our small-scale survey, we adopted cluster and convenience sampling techniques. Each of the three senatorial districts in the state constituted a cluster, and from each of these we chose a hundred respondents giving a total of 300 respondents. Attempts were made to ensure that the selection cut across age, educational, marital, gender, religious and rural-urban categories in the society. The 90 per cent response to the questionnaire is very acceptable.

We interviewed 15 community health workers in three hospitals, and six staff of Akwa Ibom Broadcasting Corporation (AKBC) radio who were involved in producing and presenting health programs. We collected and analysed all the jingles and health talks that AKBC radio had aired in the previous twelve months and interviewed six members of staff with a 23-item interview guide.

The Findings

As Table 1 indicates, the knowledge of SCD in this sample of respondents is poor. We had three points of test: questions about the nature of SCD, about the causes of SCD and about the consequences of SCD. Only 32.9 per cent gave correct information on at least two of these three points of test. We rated such respondents as having adequate to fairly adequate knowledge of SCD. Eighty-one of them (30.0 per cent) gave correct information on just one of the three points. We considered these to have inadequate knowledge of SCD. A hundred respondents (37.0 per cent) had no idea at all or got it all wrong.

Table 1: Knowledge about sickle cell disorder

Knowledge of SCD	Adequate/fairly adequate	89	32.9%
	Inadequate	81	30.0%
	No idea/wrong idea	100	37.0%
	Total	270	100%
Which factor would you consider in choosing whom to marry?	Religion/Spirituality	103	38.2%
	Character	102	38.0%
	HIV	64	24.0%
	Beauty	53	20.0%
	Genotype	47	18.0%
	Family background	41	15.0%
	Education	39	14.5%
	Wealth	14	5.2%
	Health	14	5.2%
	Age	7	3.0%
Employment	9	3.3%	
Would you marry someone you loved even if both of you were sickle cell carriers?	Would marry	56	29.2%
	Would not marry	86	44.8%
	Undecided yet	50	26.0%
	Total	192	100%

The knowledge of behavior relating to SCD was also poor. We asked our unmarried respondents to state the factors they would consider before choosing a marriage partner. About 38.2 per cent would consider the intending spouse's religion and spirituality, 24 per cent would consider HIV status; but only 18 per cent would consider the genotype. In fact, beauty was considered more important than genotype. Not only this, 29 per cent of unmarried respondents would marry someone whom they loved even if both of them were sickle cell carriers. Fifty-six per cent of our married respondents did not check their genotype before marriage, and 63 per cent of unmarried respondents would not check their genotype before marriage.

Radio was the most important source of health information for 73.2 per cent of our respondents but 65.4 per cent could not remember ever hearing any SCD information on radio. Most (66.8 per cent) listen to radio daily, and 85.5 per cent had control over at least a radio set.

The health workers we interviewed confirmed the sickle cell ignorance in Nigeria, and some blamed the media, the government and health advocacy groups for it. A doctor said:

Awareness is really low especially in the rural areas. People are ignorant of SCD...The urban dwellers who get information about SCD are the ones influenced by the information...they are the ones that might go to carry out blood tests.

According to him, urban dwellers receive information through such other means as public health campaigns in schools, and IEC materials distributed in cities. These materials do not get to the rural areas. Another respondent put the task squarely on radio, which, according to her, is the only way of reaching rural and non-literate people. Health workers claimed that people with higher levels of education knew more about SCD. Said a nurse:

Most of the people who come here for ante-natal do not know their genotype. But those who are privileged to have education go for their genotype tests even before marriage.

We felt this was to be expected. After all, educated people could access information on SCD from other sources such as magazines and books. Of the 89 respondents (33 per cent) who gave correct information on SCD, 71 (80 per cent of the correct answers) had secondary school education and above. Health workers had educated

or enlightened their patients on SCD when such patients, especially women, attend ante-natal clinics. Health workers claimed that they did not use radio to educate people about SCD because the stations did not invite them to give SCD talk or interviews.

Our analysis of AKBC radio health talks and jingles showed that the station did not give any talk or air any jingle on SCD in the one-year period that we examined. Seventeen (73.9 per cent) of the health pieces were on HIV/AIDS; 4 (17.3 per cent) were on tuberculosis while 2 (8.7 per cent) were on malaria. Why did AKBC have nothing on SCD? All our interviewees at AKBC Radio believed that it was the emphasis on HIV/AIDS that dwarfed attention to other conditions including SCD. One of them said:

Everyone, everywhere is talking about HIV/AIDS. Wherever you turn to it is AIDS. So we think of HIV more than we think of SCD. That informs the kind of counsel and education we give our listeners. I don't think we ever talked about SCD in this station; I'm not sure.

Another reason advanced for the absence of sickle cell information on radio was lack of sponsorship. Interviewees informed us that there are several groups which sponsored health talks on HIV/AIDS, tuberculosis and malaria. These groups paid some money to the stations and some of them bring recorded messages which the radio simply aired. There was no such support for SCD. An interviewee ventured the argument that "because SCD is an African problem, Western donors do not see the need to support its eradication". Another but more implicating reason given was that the staff and management of the station were not aware of SCD as a major health challenge, and the State Ministry of Health has not alerted them. Or otherwise, there would have been more SCD information on radio.

I know there is SCD but I did not know its prevalence. We in the media do not know everything. Someone has to alert us, maybe the Ministry [of Health] or the management or an NGO. If someone told us that one quarter of Nigerians have SCD, we too would have been alarmed and would have cried out to the young [unmarried] ones.

The government lacks commitment to people's welfare, and the station tends to emphasize programs that will generate revenue. A radio worker put it in more damning terms:

We lack the technical skills to give enlightenment and education on this matter. But that is a minor problem. We lack initiative. We don't do things unless someone else is doing it (sic) or someone asks us to do it (sic). We are not, I'm sorry to say, we are not smart. Our management lacks commitment. We have all these programs on AIDS because they bring money to the station. AIDS is a money-spinning machine. And our government is not interested in people's welfare. All they do is politics to make them richer and keep them in power.

Another one said that being government employees, they are meant to please government. "It doesn't matter if you do not serve the people or enlighten them. Just be sure you do not say what offends government and you will be fine".

Discussion

Discussants of news selection criteria (Boyd, 1997; Folarin, 1998; Yopp and Haller, 2005) have suggested that when a problem is of a great magnitude and impact, it attracts media attention. Our study shows this not to be true in the case of SCD in Nigeria. It is true that the HIV/AIDS situation in Nigeria is severe, but it is also true that many more people are likely to suffer from SCD issues than from HIV. The sickle cell disorder threat is actually of greater magnitude and its potential impact has extremely serious consequences for the health of the nation. Despite this, the attention of radio workers is not sufficiently drawn to SCD to the point that they could begin to enlighten their listeners about it. Even if they lack the technical skills, they could invite health workers for informative interviews and talks.

The lack of commitment to the SCD cause by government is perhaps the strongest explanation for sickle cell ignorance in Nigeria. If government were committed, it would have mandated radio stations to mount a campaign with or without sponsorships. Adoption of neoliberal economic policies by government in Nigeria is taking a severe toll on the commitment of broadcast media to public service and development programming. Following the deregulation of broadcasting in Nigeria in 1992, state-owned broadcasting stations were asked to become fiscally self-sustaining. This gave ascendance to profit over social responsibility, and resulted in a continual drop in development and public service programs (Ojebode, 1998).

In media studies circles, the debate on whether or not the media have effects on people is no longer an issue. What is in question is how

much effect and under what conditions (Littlejohn, 1999). Our study does quite indirectly suggest that the media might have influence on their listeners, at least at the cognitive level (Hybels and Weaver, 2001). Lack of SCD information on radio seems to correlate with SCD ignorance among listeners and this seems to suggest, though not conclusively, that the presence of SCD information might correlate with reduction of SCD ignorance among listeners.

The question of who sets the media agenda has been engaged almost only in political communication circles (See Olorunnisola, 2006). Health communication researchers have not paid enough attention to this.

Recommendations

In many cases, the media do not just set agenda and prime an issue just because it is there. Often, some external subtle and implicit pressure brings the media searchlight to beam on an issue. Our study suggests that media must be primed in order for it to set the social agenda with health in its proper position on the agenda. It appears that the overwhelming attention given to HIV/AIDS is setting media agenda in a way not favorable for SCD and other health conditions that may be as critical as, if not more critical than, HIV/AIDS.

The question of who sets the media agenda has been engaged almost only in political communication circles (See Olorunnisola, 2006). Health communication researchers have not paid enough attention to this. In many cases, the media do not just set agenda and prime an issue, just as Atanda(1996, pp 3-34) has indicated.

A nexus of political and economic factors combine to make radio fail to contribute to sickle cell knowledge in Nigeria. Government is not committed to SCD education, SCD programs are not sponsored and so yield no profit for stations, radio workers are ill-prepared and station management puts money first. The place to begin is with a change of attitude by the ministries of health and information and station management.

SCD advocacy groups in Nigeria (such as the Sickle Cell Foundation) need to refocus their advocacy. Rather than simply providing care and support for those suffering from SCD, they should be more proactive and more focused on informing the public. They should make efforts to educate carriers on the need to choose their spouses wisely. They should also be more active in media advocacy. They are in a good position to prime the media pump. National and international donor agencies should support SCD education and

intervention. Nigeria government at various levels must create awareness about SCD, and make efforts to carefully discourage, and possibly outlaw cultural and other practices that provide a fertile ground for the spread of SCD or stigmatize those suffering from SCD. The blame for SCD ignorance is beyond radio.

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Ethnicity and doctor - patient communication in Kenya.

By Ann Neville Miller

Abstract

This study extended previous research indicating that a substantial minority of Kenyan patients interviewed prefer doctors from certain ethnic groups, at least when it comes to treatment of serious illnesses. This study examined the possibility that such preference may be, in part, due to different expectations regarding doctor communication styles. A total of 269 participants completed questionnaires on ethnicity in doctor-patient communication in which age, gender, and ethnicity of doctors were manipulated. Small to medium sized effects were found for the interaction of age and gender of doctor such that patients expressed different expectations for the communication of young Asian doctors in comparison to doctors of other ethnicities as well as older Asian doctors. Overall, however, the results of this study of patient preferences for doctors of certain ethnicities is not driven to a large extent by communication issues.

Key words: patient-provider communication, ethnicity, Kenya

Introduction:

Relatively little research has addressed the role of ethnicity in the medical interview outside of Northern Europe and North America (Mullin, Cooper, & Elemento, 1998). Even in the African AIDS epidemic, which has generated hundreds of studies regarding specific cultural values and behaviors that impact prevention and care efforts, virtually no attention has been paid to ethnicity as it impacts the patient-provider interaction itself. This is despite the fact that ethnic identity in Africa is a critical component of the modern African situation (Berman, Eyoh, & Kymlicka, 2004), as ethnically based conflicts in Uganda, Rwanda, Burundi, Sudan, and more recently Kenya, make all too clear. What studies have been published on the topic in the African context have primarily been situated in South Africa. Scholars there have noted language barriers between English and Afrikaans-speaking doctors and patients who speak African vernacular languages (Lesch, 2007), patient embarrassment with

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medical personnel whom they perceive to be highly educated and authoritative (Herselman, 1996; Mullin et al., 1998; Steyn, Borchers, & van der Merwe, 1999), and differences between patient magico-religious understanding of health and the biomedical approach of white physicians (Grant, 2006). These observations parallel findings in North American and European settings indicating that in comparison with intra-cultural medical interviews, intercultural interviews are characterized by more misunderstanding, less satisfaction, lower patient compliance (for recent reviews see Charles, Gafni, Whelan, & O'Brien, 2006; Harmsen, Meeuwesen, van Wieringen, Bernsen, Bruijnzeels, 2002; Meeuwesen, Tromp, Schouten, & Harmsen, 2007; Rosenberg, Richard, Lussier, Abdool, 2006; Schouten & Meeuwesen, 2006), and a range of negative patient outcomes of care (Beach, Keruly, & Moore, 2006; Cooper, Beach, Johnson, & Inui, 2006; Cohen, Rivara, Marcse, McPhillips, & Davis, 2005; Institute of Medicine, 2002; Laveist & Nuru-Jeter, 2002). Street (2003) has identified four major communication-related factors that might contribute to these negative outcomes. Ethnically discordant patients and providers may: a) speak different languages or dialects, or use different metaphors and idioms with the same language; b) have different preferred styles of communicating in medical encounters; and c) operate out of different explanatory models of health and illness. Finally, d) providers may hold racist or perceptual biases. These issues may not only affect patient outcomes directly, but also indirectly as they influence the level of trust that patients have in their providers (Epstein & Street, 2007).

South Africa is unique on the continent, however, and findings in that context are not necessarily relevant to the rest of sub-Saharan Africa. In other African nations, including Kenya where the present study was conducted, few doctors are white. African doctors are more likely to be aware of the worldview of their patients with respect to health and illness, and to operate with similar expectations regarding styles of communication in the medical encounter. It is true that they may still grapple with language difficulties. In Kenya, where the present study was conducted, over 40 languages are spoken (Central Intelligence Agency, 2009); providers may not speak a particular client's vernacular even if they share fluency in one of the two national languages, Swahili and English. It is also true that questions of interethnic bias came to the fore in nearly every aspect of Kenyan life as the ethnic conflict during post-election violence there in early 2008 indicates (CBS, 2008). It could be revealed in the doctor-patient

relationship. Nevertheless it appeared to us that previous research on patient-provider ethnic discordance had not addressed an important characteristic of multi-ethnic societies. In many sub-Saharan nations, certain ethnic groups are associated with particular occupational geniuses. Among these, some ethnic groups are recognized for expertise in medicine, and even for treatment of specific types of conditions. In Kenya the Luo are known for excelling in medicine, as are Kenyans of Indian origin (commonly called *Asians*). It could be, therefore, that rather than seeking out physicians who share their own ethnic background, some patients might prefer that their doctors come from another ethnic group, and that under those circumstances they might trust someone who did *not* speak their language more than someone who did. Although the particulars of this sort of preference would vary from country to country, the phenomenon is likely to be widespread.

We investigated this possibility in a previous study (Names withheld, nd) involving both survey and focus group research. Nearly all of our participants stated that when choosing a doctor, ethnicity was among the least of their concerns; it was a non-issue. They rated demographic factors in general as less important than factors related to the doctor's qualifications, communication skills, and cost of service. On the other hand, when asked about their preferences for treatment of specific medical conditions, a substantial minority did express partiality. For less serious medical conditions the inclination of these participants was in congruence with previous research: they preferred an ethnically concordant doctor. Reasons for this centered around communication issues. Interpersonal factors were apparently more important for a substantial proportion of our participants, however, in cases of serious illness. Those who did indicate a preference were more likely to prefer Indian doctors for eye problems and Europeans for major surgery, cancer, and heart problems.

Our previous research did not inquire into reasons for patient preferences for doctors of certain ethnicities. In particular, we did not explore differences in patient expectations about how doctors from different ethnic groups would communicate with their patients. Further, because we asked participants directly about their preferences regarding demographic characteristics of doctors, it is possible that participants who indicated that demographic factors were not important to them in the selection of a doctor were influenced by a social desirability bias, not only with respect to ethnicity but also in r

relation to other factors like doctor gender and age. In Kenya, culture and customary law place women in a subordinate status even in the face of dramatic social changes and constitutional guarantees of equal rights (Miller et al., 2009; Muturi, 2005; Rugalema, 2004). Such distinct differences in gender roles could lead patients to have different expectations about the communication of male versus female doctors. Certainly in Western contexts evidence indicates that physician communication style does vary by gender (Elderkin-Thompson, Wiatzkin, 1999).

In addition, provider age has been found to play a role in patient perception of health care providers in other contexts (McKinstry & Yang, 1994; Shah & Ogden, 2006). Given that age has traditionally been accorded great respect in African cultures (Moemeka, 1996), both of these provider attributes might influence patients' expectations of doctor-patient communication. Therefore we posed the following research question:

RQ1: What is the relationship of doctor (a) age, (b) gender, and (c) ethnicity with patient expectations of doctor communication?

Method

Students from classes at a private university in Nairobi were asked to each collect questionnaire data from two individuals over the age of 18 who had sought medical attention within the past year, only one of whom could be a family member. Students explained the purpose of the study and obtained informed consent from participants, then handed questionnaires to participants to fill out. Questionnaires were also distributed to classes of evening undergraduate and masters students at the same university. These classes were selected to represent a wider range of ages, professions, and income levels than traditional day classes. A total of 280 questionnaires were distributed in the same manner as study one, but to different classes. Of these 11 were completed by participants who indicated they had not been to a doctor within the previous 12 months and were therefore discarded. Of the remaining 269 participants, 30.1 per cent were male and 66.5 per cent were female. With respect to age, 60.6 per cent were aged 21-30; 22.3 per cent were 31-40; 9.3 per cent were 41-50; and 3 per cent were 51-60. With regard to marital status, 60.2 per cent of participants were single, 33.8 per cent married, 1.5 per cent separated, and 1.1 per cent widowed. With respect to highest level of education completed, 1.1 per

cent had completed primary school; 13.4 per cent secondary school; 21.6 per cent technical college; 50.9 per cent university; and 8.9 per cent graduate school. Participants were from eight different ethnic groups with the largest proportion being Kikuyu (31.6 per cent), Luhya (14.5 per cent), Luo (12.3 per cent), Kamba (9.7 per cent), and Kalenjin (7.8 per cent).

Respondents in the study were presented with a situation in which they were asked to indicate a combination of doctor preferences: gender of doctor: male or female; age of doctor: younger or older; ethnicity of doctor: Kikuyu, Luo, or Asian (see Shah & Ogden, 2006). Participants were randomly assigned to one of twelve combinations of these variables. Participants first answered questions regarding their age, sex, marital status, income level, and education. They then read one of twelve versions of a brief scenario. An example is given below:

Imagine you are sick and you need a doctor. You get to a clinic where the doctor on duty is Dr. Achieng Onyango. She is in her early 30s. Dr. Onyango is a graduate of Nairobi University. She has been practicing medicine for the last five years. (young female Luo)

Ethnicity of doctor was conveyed by names that would be clearly identified with a specific Kenyan ethnic group. Participants were asked to indicate their expectations of communication with the doctor described in the vignette by means of Likert-type scales ranging from 1 = "not at all" to 5 = "extremely" in terms of six functions of medical communication developed in the light of Street's four communication factors in ethnically discordant patient-relationships and de Haes and Bensing's (2009) six functions of patient-provider communication: fostering the relationship, gathering information, providing information, making decisions, enabling disease- and treatment-related behavior, and responding to emotions (see also Epstein & Street, 2007). Participants responded to a series of 38 statements on a five-point Likert-type scale, from "strongly disagree" to "strongly agree." These questions were divided into two sections. The first was prefaced with the statement: "A doctor from my ethnic group would be more likely than other doctors to," followed by a list of physician behaviors. The second was prefaced with the statement "If I was seeing a doctor from my own ethnic group as compared to others, I would be more likely to" and followed by a list of patient behaviors. Questionnaires were

pretested with 10 undergraduate students. Students found the original vignettes confusing. Vignettes were rewritten and tested with 14 graduate students. No difficulties were expressed about the new vignettes.

Results

Data were analyzed using two three-way MANOVAs as an omnibus test, with gender, age, and ethnicity of physician as independent variables and the individual items of anticipated behavior of doctor and participant as dependent variables. Box's M test for equality of covariance matrices was significant. However, because F scores were low (both 1.18) and the test is conservative, we deemed it acceptable to assume homogeneity (Huberty & Lowman, 1998). Results regarding patients' expectations regarding their own behavior are presented in Table 1 below. As indicated, no significant multivariate effects were found.

Table 1. *Multivariate Effects of Age, Gender, and Ethnicity of Doctor on Patient Expectations Regarding Their Own Behavior in the Medical Interview*

	Wilk's Λ	df	F	p	η^2
Gender	.93	12, 202	1.19	.29	.07
Age	.95	12, 202	.92	.53	.05
Ethnicity	.91	24, 404	.91	.72	.05
Ethnicity*Age	.88	24, 404	1.17	.27	.06
Ethnicity*Gender	.93	24, 404	.61	.93	.04
Gender*Age	.95	12, 202	.91	.54	.05
Ethnicity*Gender*Age	.88	24, 404	1.07	.22	.07

With respect to doctor anticipated behavior, no main effects were found. However, a two-way interaction emerged between ethnicity and gender of doctor (see Table 2).

Table 2. Multivariate Effects of Age, Gender, and Ethnicity of Doctor on Patient Expectations Regarding Doctor Behavior in the Medical Interview

	Wald's chi-square	df	p-value
Gender	15.192	1	.000
Age	1.02	1	.314
Ethnicity	30.384	1	.000
Ethnicity*Age	1.92	1	.165
Ethnicity*Gender	30.384	1	.000
Gender*Age	15.192	1	.000
Ethnicity*Gender*Age	30.384	1	.000

In order to interpret the interaction we first examined the univariate tests of between subjects effects on the individual dependent variables. Results are presented in Table 3. Only items on which significant results obtained are included, in order to save space. Most effects were small according to Cohen's (1965) guidelines, one was medium sized. For each of the significant dependent variables, we ran a simple effect with age at each level of ethnicity. Simple effects attempt to maintain the essential structure or nature of the interaction effect by breaking the interaction effect into component parts and testing each part for significance. We applied the Bonferroni adjustment for multiple comparisons. Results are presented in Table 3. As indicated, all of the effects resided in either the Luo or Asian condition of ethnicity. When we examined pairwise comparisons it was evident that participants expected less of what has been labeled in Western contexts as patient-centered communication—97% as physician competence—from young as opposed to older Asian physicians. Conversely they expected more of the same behaviors in young versus older Luo physicians. As a double-check we also ran simple effects in the other direction; that is, we looked at ethnicity at both levels of age. As might be expected, for several of these same variables patients were more inclined to expect patient-centered communication from young Luo doctors (and in one case young Kikuyu doctors as well) than young Asian doctors; they were more likely to state that they expected patient-centered communication from older Asian doctors than older Luo doctors.

Table 3. *Interaction Effect of Age and Ethnicity on Expectations of Doctor Behaviors with Simple Effects for Age at Each Level of Ethnicity*

Expected Doctor Behavior	F	p	η^2
Check everything when examining me	8.56	.000	.08
Kikuyu	2.69	.10	.01
Luo	3.06	.08	.01
Asian	11.37	.001	.05
Suggest more than one alternative for treatment.	6.99	.001	.06
Kikuyu	.87	.35	.04
Luo	11.17	.001	.05
Asian	2.42	.12	.01
Check to be sure I understand what I am supposed to do for treatment.	6.36	.002	.06
Kikuyu	.72	.396	.00
Luo	.26	.609	.00
Asian	16.52	.000	.07
Explain to me the possible outcome if I do not Get treatment.	5.50	.005	.05
Kikuyu	2.14	.145	.01
Luo	7.06	.009	.03
Asian	1.81	.18	.01
Listen carefully to my explanations of what I think might be the cause of my problems	4.97	.008	.05
Kikuyu	.13	.714	.00
Luo	5.54	.020	.03
Asian	4.27	.04	.02
Engage me in small talk to help me relax	4.30	.015	.05
Kikuyu	1.75	.187	.01
Luo	.66	.419	.00
Asian	.43	.510	.00
Not rush through the appointment	4.32	.014	.04
Kikuyu	.19	.660	.00
Luo	7.89	.005	.04
Asian	1.96	.160	.01
Prescribe the best medication	4.16	.017	.04
Kikuyu	.75	.387	.00
Luo	1.71	.193	.01
Asian	5.86	.016	.03
Make the right recommendation for my Treatment	4.12	.018	.04
Kikuyu	3.35	.069	.02
Luo	2.01	.158	.01
Asian	4.63	.033	.02
Explain to me the likely causes of my symptoms	3.90	.022	.04
Kikuyu	.08	.782	.00
Luo	3.74	.054	.02
Asian	3.99	.047	.02

Discussion

Research on ethnicity and doctor-patient communication has typically viewed doctor-patient relationships as those in which both parties hail from the same ethnic background as preferable to ethnically discordant relationships (Charles et al., 2006; Meeuwesen et al., 2007; Rosenberg et al., 2006). Communication problems such as speaking different languages or dialects; having different preferred styles of communicating in medical encounters; referencing different explanatory models of health and illness; and holding of racist or perceptual biases on the part of physicians have been cited as leading to a range of negative outcomes in terms of both patient satisfaction and quality of care (Street, 2003). These issues may not only affect patient outcomes directly, but also indirectly as they influence the level of trust that patients have in their providers (Epstein & Street, 2007).

However, in multi-ethnic societies like Kenya, some patients may actually prefer to have ethnically discordant health care providers, in part because of privacy issues that arise when seeing doctors from their own ethnic group, but also because certain groups are believed to exhibit a sort of genius for particular medical conditions (Names withheld, nd). In this study we attempted to extend aspects of previous research and to determine to what extent differences in communication styles might bear some relation to those preferences.

We also compared patient expectations about doctor-patient communication as it relates to ethnicity with the additional predictors of physician age and gender. We obtained only one effect for the three variables on patient expectations about how their doctors might communicate with them: an interaction between physician age and ethnicity. That effect turned out to be located in different expectations of young versus older Luo and Asian physicians. No differences emerged between expectations of Kikuyu doctors of different ages. However, our participants expected more of what has been labeled as "patient centered" communication from young as compared to older Luo doctors. That is, they were more likely to expect young Luo doctors to do such things as suggest several options for treatment, explain what would happen if the patient did not get treatment, and listen carefully to their descriptions of their symptoms. In contrast, our participants ascribed more patient-centered communication and even diagnostic competence to older Asian doctors than to young Asian doctors. That is, they were more likely to indicate that older Asians

would check to be sure they understood what they were supposed to do for treatment, check everything when examining them, and prescribe the appropriate medication.

From a practical standpoint both young Asian and older Luo physicians might benefit from taking extra care to listen to patients and explain thoroughly aspects of diagnosis and treatment so that possible patient expectations to the contrary will not negatively impact the treatment process. However, these effects were mostly small. Our findings suggest that issues other than communicative competence may explain the strong preference for a minority of Kenyan patients in our previous study for Asian and European doctors in cases of serious illness.

Finally, it is also worth noting that we did not find any main effects for doctor gender. In Western settings, female doctors have been found to use more positive talk, partnership building, information giving, and emotional support than male doctors (see Elderkin-Thompson & Waitzkin, 1999, for a brief review). We did not examine actual doctor-patient communication in Kenya, but at least in terms of what they expect to experience when they talk to their doctor, our participants evidenced no difference. Given evidence regarding the subordinate role that Kenyan women play in many aspects of society, the fact that patients expect the same behaviors from both genders is encouraging (Miller et al., 2009; Muturi, 2005; Rugalema, 2004).

Two limitations of this research should be mentioned. First, our sample was highly educated. It is possible that in a less educated sample more ethnic bias would have been evident. Furthermore, as an initial exploratory study, this research measured only patient responses not hypothetical situations and not patient outcomes from actual doctor-patient interactions.

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How participatory is “participatory communication” for HIV/AIDS awareness in South Africa

By E.M. Govender, E. Durden and S. Reddy,

Abstract

This article includes a theoretical discussion of the field of development communication, the paradigm of development support communication (DSC) and the concept of participation. The article explores varying levels of participation that can be identified in interventions, including participation in the planning, implementation and reception phases of such projects. It goes on to provide an overview of current practices in South Africa, based on a survey of HIV and AIDS projects. This small survey of 16 organizations from across the country elicited information about the range and scope of the projects, specific information about participation, the rationale behind the projects, and the selection and involvement of participants in the projects. Through responses to the questionnaire, we are provided with a broad overview of how organizations working in the field of HIV and AIDS involve the target or beneficiary community in their programmes.

Key words: Participation, development, HIV and AIDS.

Introduction:

Development communication refers to “the planned use of strategies and processes of using communication aimed at achieving development” (Bessette, 2005, p. 12). There are four recognized distinct paradigms of development communication, which can be categorized as modernization theory, dependency theory, development support communication and “another development” or participation (Tomaselli, 2001; Servaes, 1995; 1999). This chapter explores why participation is the currently preferred paradigm for communicating about development, and what some of the challenges to implementing

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participatory projects might be. It also analyzes some of the contrasting approaches to mitigating HIV and AIDS in South Africa through examining levels of participation. Participation is an action-oriented practice, involving people physically, mentally and emotionally in a particular project or program. It is important to remember that communication is one of the vital components of participation, as involving people in an initiative would not be possible without free speech and open dialogue.

To better understand the complexities of participation and the varying levels at which community members can be involved in participation, we have turned to the *Ladder of Participation* designed by Sherry Arnstein in the 1960s. We apply this understanding of participation to a selection of participatory HIV and AIDS projects in South Africa, to explore how participation is practiced in the field. This is through a survey of a range of different purportedly participatory projects that work in HIV and AIDS prevention, care and support.

Defining participation

Tufte and Mefalopulos define participation as “the involvement of ordinary people in a development process leading to change” (2009, p. 4). In this process, the community members themselves become the agents of change, rather than being led by outside agents (Servaes, 1995). Participation is seen as “the opening of dialogue, where the source and receiver interact continuously, thinking constructively about the situation, identifying developmental needs and problems, deciding what is needed to improve the situation, and acting upon it” (Nair and White, 1993, p. 51). It is clear then that communication plays an important role in the process of participation as people become included and involved through continuous dialogue about the challenges that they face with regards to development. Participation necessitates a move away from the top-down, one-way flow of communication of the modernization paradigm of development communication, towards a communication process that facilitates interactive dialogue and discussion amongst members of the target community. Feedback is a fundamental aspect of this model, as the people involved have the ability to discuss, negotiate and make collective decisions. The focus on dialogue in the participatory paradigm is influenced by the pedagogy of Paulo Freire (1969, 1989, 2002). Freire calls for individual participation of learners in the learning process in order to empower them through the development

of critical thinking. His pedagogy centres around the notion of critical consciousness, which he asserts can be developed by democratic participation.

The principle of participation requires the involvement of people who are directly affected by an issue to define the problem, and to identify steps toward resolving that problem (Thompson and Kinne, 1990). The principle of ownership is closely related to participation, as ownership is about people taking responsibility for and control over the process of change. Thompson and Kinne suggest that these two principles follow the same premise: "Change is more likely to be successful and permanent when the people it affects are involved in initiating and promoting it" (1990, p. 46). This notion of people-centeredness is at the core of participation, and raises other issues such as ownership, appropriateness and commitment. At the heart of participation is the idea of empowerment; as communities are, ideally, provided with the opportunities and resources to actively address their own needs and advocate for their own social change (Waisbord, 2001).

Concepts of development and support

While participation is defined as a distinct paradigm of development communication, it is important to recognize its synergies with the development support communication paradigm (DSC). This paradigm revolves around the sharing of information and knowledge and the creation of links between different parties involved in the development process (FAO, 2002). While development planners and implementers play a role in the process, the emphasis is on the beneficiary community participating actively in their own development.

DSC is a process whereby the donor or partner aids the process of development through mediums of finance and expertise. Melkote (2000) emphasizes that although professionals may have a part to play in terms of designing interventions, the key players are the people handling their problems in local settings. DSC calls for the review of power and control, and focuses on the revision of the levels of power maintained by experts and those which can be awarded to the communities. While recognizing the importance of community participation in development processes, DSC also recognizes the role of other stakeholders and partners in the process. Ideally, communities address their problems with aid from donors and funders as opposed to control and power being exercised by those donors (Govender, 2010).

In addressing public health crises, such as HIV and AIDS, it is recognized that outside experts have a role to play (Waisbord, 2001). These financial, technical, scientific or general development experts are referred to as the DSC professional, whose responsibility it is “to work with the individuals and communities at the grassroots so that they eventually may enter and participate meaningfully in the political and economic processes in their societies” (Melkote and Steeves, 2001, p. 356). DSC therefore envisions development as beginning with supportive partnerships between external experts and a beneficiary community, until such time that the community can take complete responsibility and ownership for its own development. While the DSC professional represents a vital component in the development process, the community should retain the locus of control if they are to experience empowerment, especially as the DSC professionals eventually withdraw from the community after their services “become redundant”, meaning that the community needs to be prepared to assume total control of itself (Melkote and Steeves, 2001, p. 363). The question of community participation remains vital within such programs, to ensure that the community is empowered to assume this control during and after an intervention.

Participation: A means to an end or an end in itself?

In order to better understand how empowerment functions, it is useful to draw on the ideas outlined by Melkote and Steeves (2001) relating to the *participation-as-an-end* approach, as opposed to the *participation-as-a-means* approach. The latter perceives participation simply as a means to achieve certain development objectives. The focus is on the end-goal or results that are to be achieved and participation is valued only as a means which can contribute to achieving specific goals or results. The participation-as-a-means approach is primarily concerned with how efficiently and how effectively a particular development goal can be reached (Cleaver, 2001).

In the context of DSC, the problem arises when this goal is defined and pursued by the donors, rather than the beneficiary community. There is the potential for participation to be used as a means to exploit the community in order to fulfil the donor’s agenda. There are often cases where the donors, rather than the beneficiaries, direct the planning and implementation of the initiative. In these cases, the donor dictates how their funds are to be used, limiting the input and opinions of the local community (Garrett, 2007; Hanson, 2003). Most donor

funding tends to determine specific outcomes, and there is the possibility that "expert" western knowledge and solutions may be seen by the donors as more valuable and appropriate than traditional cultural beliefs and practices. Local community needs and plans of action may be re-defined or re-shaped to suit the funder's agenda, and "in this way local knowledge becomes compatible with bureaucratic planning" (Mosse, 2001, p. 32).

While participatory projects strive for empowerment, the issue of power may be the very reason why they sometimes fail to fulfill their participatory ideals. Despite the fact that work within the DSC and participatory paradigms claim to be an egalitarian approach to development, the reality is that it is difficult to completely avoid an unequal distribution of power. It is particularly difficult when the participation-as-a-means approach is used, as this often limits the community's involvement in an initiative to token participation, where local people are "fitted" into the agenda and plans imposed by the external donors (Melkote and Steeves, 2001). Limiting participation is often justified as being quicker and more efficient than employing a fully participatory approach, particularly in cases of crises such as epidemics where the transmission of facts and knowledge becomes paramount. However, a failure to consult with the local community and to understand their needs can lead to inefficient use of funds (Bolton, 2007; Collier, 2007; Radelet, 2006). This is becoming increasingly clear in the context of HIV and AIDS:

With AIDS becoming increasingly mainstream within policy discourse, Northern policy agendas can often overshadow local needs and priorities. Funding is crucial, and still far from adequate. Yet the amounts now being made available may lead to conflict, inefficiency or rushed decision-making unless these allocations are more strategic and consultative. In addition, donors increasingly have to prove impact, showing how money distributed is used to optimum effect. This results in an over emphasis on simple indicators and short term results, at the cost of long-term change.

Scalway's reference to "long-term change" is important when considering the participation-as-an-end approach. This approach strives to encourage full community participation, rather than simply token involvement. While there is still an overall goal in place, it is the actual *process* of participation which is valued (Melkote & Steeves, 2001). - Participation-as-an-end is an empowering approach as it

addresses “the need to think, express oneself, belong to a group, be recognized as a person, be appreciated and respected, and have some say in crucial decisions affecting one’s life” (Melkote and Steeves, 2001, p. 337). As an end in itself, participation is seen as a process that “enhances the capacity of individuals to improve or change their own lives” (Cleaver, 2001, p. 786). This process of participation and empowerment generally occurs over a sustained period of time, so that substantial changes in the short-term are not expected.

The *ends* approach is more concerned with the basic human rights of people whilst participation as a *means* is more goal-oriented, usually fulfilling the requirements of donor obligations. Being participatory for the sake of being participatory is not the important issue, but the rationale behind it is. Involving the people in a community can build feelings of ownership and allow them to address their needs from their own perspective, ensuring that they are committed to the initiative until it is completed (Cadiz, 2005).

Although the participation-as-an-ends approach strives for participation and empowerment, there is always the potential for conflict in such initiatives. Conflict between different parties may arise as one of the consequences of trying to reconcile participation and hierarchical power relations. Participatory approaches call for equal access, dialogue and power-sharing, and as such may challenge customary beliefs and power structures, creating unrest and conflict between the ‘expert’ professionals and the local community. Ideally, such initiatives strive for genuine participation, which means that everybody involved must be “open, flexible and continually willing to learn” (Boon and Plastow, 2004, p. 3). This type of openness, however, challenges conventional power relations, which can undermine the status of experts and authority figures. Therefore, while participation is to be valued, there should always be an awareness of the existence of unequal power relations and the potential for conflict arising through these relations.

An application of the ladder of participation

In order to analyse the levels of participation and the influence of donor agencies in local HIV and AIDS mitigation projects, Arnstein’s ladder of participation (1969) was used to analyse the data collected. While there may be those that caution against the simplification of participatory processes into a coded model, Arnstein’s ladder proposes a structure against which one can objectively measure participatory

practices. Arnstein herself cautions that this ladder is a simplified typology that does not cover all of the nuances of participation, and that "in the real world of people and programs, there might be 150 rungs with less sharp and "pure" distinctions among them" (1969, p. 216).

Levels of participation

One of the key debates in the development field is around who participates, how, and to what extent. Arnstein devises eight discernible levels of participation:

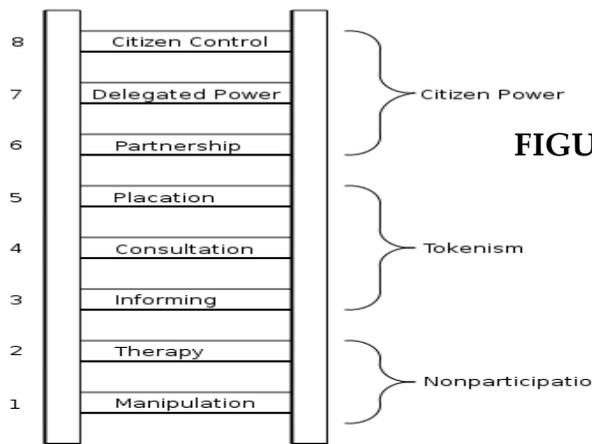


FIGURE 1: Sherry Arnstein's Ladder of Participation (Arnstein, 1969)

Non-participation

At the lowest rungs of the ladder and the least participatory levels sit what Arnstein terms *manipulation* and *therapy*. There is no value in these for the project participants and their real objective is "not to enable people to participate in planning or conducting programs, but to enable power-holders to 'educate' or 'cure' the participants" (Arnstein, 1969: 218). Participants do or say what the development agents suggest that they should, but do not have any understanding of the issue that affects them (Hart, 1997). For manipulation to be avoided, all facts regarding the project and its potential must be made available for the community so that they can make informed decisions (Chin, 2006).

At the second level of Arnstein's ladder is the concept of *therapy*. NGOs and other catalyst organisations may use this approach because they feel it is in the best interests of the community and that it is "for

their own good". This is reminiscent of the arrogant, patronising aspects of the modernization paradigm of development where outside experts "know better".

Tokenism

Tokenism involves a symbolic gesture of power-sharing, but is essentially a substitute for the real thing. *Informing* at level three of the ladder, is indicative of tokenism, where information is offered to the supposedly participating community. While information is a vital step of any development project, at this level, information often takes the form of one-way communication from the development agent to the recipient. This is clearly contrary to Freirean notions of dialogue and development. At level four, Arnstein cites *consultation* as another form of tokenism. Although she recognises the importance of consultation and dialogue in the participation process, she states that unless this is coupled with other forms of participation, there is no guarantee that the opinions of the participants will be taken into account. At the fifth level of *placation*, there is hand-picking of selected individuals to be involved in decision-making processes. Community participants are informed about the project but are assigned particular roles that they have not chosen (Hart, 1997).

Larry Kincaid and Maria Elena Figueroa (2009) present a critique of this type of false dialogue, and call for a new model of communication for participatory development that is based on genuine dialogue, information sharing, mutual understanding and agreement, and collective action. This calls for greater co-operation between groups, and takes us to a higher rung on the ladder, where *partnership* is more indicative of genuine participation.

Citizen power

At the sixth level *partnership* on Arnstein's ladder, both the development agent and the target community share responsibilities for decision-making, planning, implementing and evaluating the participatory project. Arnstein suggests that "power is in fact redistributed through negotiation between citizens and power-holders" (1969, p. 212). However, this power can be handed over only if there is an organized power-base in the community with access to resources. In extremely under-developed areas, these resources may not exist, and this is where there is potential for the development of undemocratic structures that mimic the bureaucracy of the government and

development agents. This is the "institutionalism" that Cleaver (2001) suggests can in fact hamper development. At level seven, *delegated power* is less often witnessed than the power-sharing of partnership. At the eighth and highest rung of the ladder, and therefore the most desirable outcome of participation, is *citizen control*, where citizens "can govern a program or an institution, be in full charge of policy and managerial aspects, and be able to negotiate the conditions under which "outsiders" may change them" (1969, p. 214). She suggests that the most important step to achieving this is removing any intermediaries between the community group and the source of funds. At this level, Hart (1997) suggests that the community then has the space and resources to generate their own ideas for a project, to set these up and then to invite the catalyst agent, if necessary, to be part of the project.

This chapter explores the levels of participation proposed by Arnstein in relation to a survey conducted with participatory NGOs in South Africa. The discussion and analysis of the survey ensures better understanding of how such projects are encouraging the participation of their target communities in their projects.

Approaching the survey: the sample

The study took the form of a survey of Non-Governmental Organisations (NGOs) working in the field of HIV and AIDS in South Africa in 2009/ 2010. The Centre for HIV and AIDS Networking (HIVAN) provided access to their database through their HIV-911 programme which is a compiled database of organizations involved in HIV and AIDS interventions in South Africa. The directory lists over 13 000 organisations which is an indication of the enormity of the problem and the varied responses to HIV and AIDS.

A detailed review of the directory suggested that the organizations working in the field could be broadly categorized into those that work with prevention, treatment, care and support. The focus of this study was to elicit organizations offering participatory approaches to addressing issues of HIV and AIDS. We have examined how local communities participate in communication about their own development, exploring participation in dialogue and discussion about the projects. Projects were purposively selected across areas of prevention, treatment, care and support, providing a shortlist of the following nine thematic categories: a) prevention messages, behavior change and support, b) arts-based methodologies for healing , c)

community development, d) bereavement counselling, e) preventing mother to child transmission (PMTCT), f) provision of anti-retroviral drugs (ARVs), g) adherence to anti-retroviral drugs (ARVs), h) provision of voluntary HIV testing and counselling services (VCT) and j) faith-based interventions.

These categories were selected as they offered localized and community-based approaches to HIV awareness and prevention. The other categories predominantly included clinics, hospitals and workplace activities, which were eliminated for the purpose of this study. Three organizations were purposively selected from each of the nine categories to constitute a representative sample of organizations across the nine different provinces of South Africa, with different types of projects. The selection criteria were based on organizations' own descriptions of the nature of their work in the HIV-911 database. Organizations that identified their work as participatory were eligible for selection, and later randomly selected within each category to make up a total sample of 27 organizations.

The 27 groups were contacted by telephone, and 16 were willing to participate in the survey. The questionnaire was forwarded to these 16 organizations but only eleven were returned to the research team. While eleven organizations may seem a small sample, this research should not be seen as a quantitative study, but rather one that provides an overview of the wide variety of organizations working in South Africa.

An overview of participatory HIV and AIDS projects in South Africa

What follows is an overview of the selected organizations, arranged according to the nine thematic categories explained above.

Prevention messages and support

The three organizations selected in this category were all community-based initiatives. One group provides community members with advice on a range of issues including HIV and AIDS, and offers home-based care in the community. The second group is a youth movement using peer education strategies for HIV prevention and behavior change. The third organization offers home-based care services and a program for orphans and vulnerable children. This sample shows that projects in this area target all ages with both

prevention and care projects, providing education to those who are not infected, and support to those that are.

Using arts-based methodologies for healing

One of the selected arts-based groups was a non-profit organization that focuses on capacity-building, and runs a pre-school sewing and clothing project. The second organization provides care and guidance for young people through a music performance program. The third group is an arts center that uses art as a way for young people to express themselves and also provides support and social welfare services. The arts are used for healing, expression and income-generating for those affected by the epidemic.

Community development

The three selected community development projects were all focused on providing support and assistance rather than capacity-building. The first was a non-profit organization providing financial assistance and other forms of direct services to those unable to maintain a livelihood because of illness. The second was a community-focused organization offering social development and upliftment programs. The third organization focused on both community and individual upliftment, within a network of churches. All three groups focused on *helping* people in need rather than empowerment in the social or political sense.

Bereavement counselling

Of the three interventions selected in this category, most catered for the needs of children who were bereaved or orphaned. One was a private, non-profit welfare organization focusing on the needs of children affected by HIV and AIDS and poverty. The second group focuses on alleviating poverty and HIV and AIDS within the community. The third cares for vulnerable children in townships by building and supporting community development activities. All three groups in this category focus on bereaved or vulnerable children within the context of community rather than assistance to them as individuals. This is typical of the African approach to family, where children are seen as part of a wider community.

Preventing mother to child transmission (PMTCT)

Most of the organizations that are listed under PMTCT offer support to mothers and their children, as well as to others who need assistance. Predominantly run by nurses, these organizations provide physical treatment for terminally ill patients and their families. Of the three selected groups, one was a care home, one a comprehensive primary health care facility, and one a community centre. Again, there is a tendency here to focus on the individual within the community context rather than as individuals alone.

Provision of anti-retroviral drugs (ARVs)

Under this category, organizations offer a wider range of services than just the provision of drugs. Of the three selected groups, one was a primary healthcare facility offering HIV and AIDS-related services for employees of a mining company, one an advocacy organization that builds capacity in the public and private sector to deliver safe effective and affordable anti-retroviral therapy, and the third a residential facility for HIV-infected and children.

Adherence to anti-retroviral drugs (ARVs)

ARV adherence is also addressed by a wide range of organizations, many with a link between the private and public sectors. Of the three selected groups, one is a private group offering specialist medical HIV and AIDS comprehensive care including adherence counselling and monitoring, one is a church-based group that is an ARV provision site, and the third a NGO that functions as a hospital offering support and ARV therapy.

Provision of voluntary HIV testing and counselling services (VCT)

Of the three organizations sampled that fall into the provision of VCT category, one is a comprehensive education program that combines home visits with counselling and referral to a testing site, one is a university-based clinic offering VCT and education to students and staff, and one is a primary health care facility offering VCT and other HIV and AIDS related services.

Faith-based interventions and organisations (FBOs)

Of the three organizations selected, one focuses on peer education on HIV and AIDS and sexuality in secondary schools, one a mission and development agency committed to serving and addressing the needs of children and youth, and the third a foundation that offers

support for the destitute. Although we had singled FBOs as a separate category, it is interesting to note that many of the other organizations sampled noted that they work within a faith-based framework, and the churches and other religious bodies were very active in all forms of support and intervention, particularly prevention and care program.

The survey questionnaire

The questionnaire that was used for the survey was an adaptation of a survey used in a study of participatory theatre for development projects (Durden, 2009) and was developed on the basis of Arnstein's Ladder of Participation. The survey was divided into four sections that deal with general information about the projects, specific information about participation, the rationale behind the project, and the selection and involvement of participants in the project.

Limitations of the survey

One of the limitations of the survey was that it did not allow organizations to state the frequency of approaches. While some organizations may sometimes use different strategies, there was no place to note this. The instruction on the questionnaire tool was for respondents to apply the questions to their most recent or most relevant projects. The study could have also eliminated other interesting participatory projects due to the limited sample size. However, the data collected was for qualitative interpretation, making a small sample more useful.

Although the survey allowed a space for further comments and information from the participants, few used this opportunity, and there is no additional data available on the projects. The study did not allow for follow-up interviews with the participating projects, and therefore lacks a detailed understanding of the justification for the projects' choices regarding their participation strategies.

Survey results and discussion

General information

Of the eleven completed questionnaires, there were representatives from all of South Africa's nine provinces, except for the North-West. An organization from the North-West had been chosen for the survey, but had not responded. Under the key areas of work, it was apparent that the majority of the organizations worked broadly in more than one

of the demarcated fields. This suggests that there is scope and indeed a need for organizations to provide more than one service in the HIV and AIDS sector. The majority of these organizations (55 per cent) defined their focus as community development, and went on to specify other areas that they worked in, such as preventing mother to child transmission, providing ARVs, and working with orphaned and vulnerable children. This suggests that these organizations see themselves as centers of development, over and above providing services. Half of the surveyed groups do prevention work, suggesting that the need for prevention messages and encouraging behavior change remains a priority for many organizations in the field.

All of the projects were described as ongoing projects, suggesting the potential for long-term and sustainable interventions in the field. Although one of the key problems noted in the participatory paradigm is encouraging sustainability, all of these projects manage to run themselves long-term. This could be because they have established themselves with an organizational infrastructure and funding sources that allow for longevity.

Below is a presentation and discussion of the findings with regards to the participation of the local community at different levels in the eleven surveyed projects.

Participation in setting goals for the projects

The findings from the sample organizations suggested that in some communities, local people maintained a certain level of ownership over the projects. In terms of development theory, for a project to be both successful and appropriate, the target community should be part of the process of setting goals for projects. All of the eleven organizations stated that they determined their own goals for projects. Three of the organizations went on to qualify that their funders also had a say in the determination of these goals, and a further three noted that other experts had input into this. This shared responsibility for goal-setting suggests that the DSC principle of establishing partnerships is realized in these projects. Donor interference and agenda setting were not mentioned as barriers to the project objectives in the cases where donors were involved.

None of the organizations mentioned that community gate-keepers had a hand in setting the project's goals. This is a good sign that local power-holders are not determining the outcomes of such projects. Only four organizations suggested that the community participants

themselves determined the goals for projects. This suggests that participation of the target community members in determining what they will benefit from, and how, is still limited. This may result in community members feeling that they are simply the beneficiaries of outside projects, rather than full partners in such projects.

Determining involvement in the projects

The survey results suggest that there are a variety of strategies used for identifying and selecting participants for these HIV and AIDS projects. All of the organizations stated that they themselves determined who participated in the projects. Just over half of them (six) stated that funders and other experts had input into whom the target beneficiaries should be, again reinforcing the concept of partnerships and shared responsibility between the local organization and donors. Four organizations reported that they hand-select individuals from the target community group to work on the project. This method is indicative of the diffusion of innovations approach, which is otherwise not wide-spread amongst these organizations.

Eight of the organizations reported that their projects involve working with individuals selected by the target community group themselves. This is the majority of the groups surveyed, and is a promising sign for genuine participation. Where the community is making these decisions for themselves, then it is more likely that the participating individuals will take on roles of responsibility within the projects, as they feel the importance of the community mandate in their participation.

This communal selection of participants is evidence of the projects being inclusive and avoiding the pitfalls of manipulation that Arnstein (1969) refers to. However, the participatory selection of participants must be accompanied by their participation in other processes to ensure that they do have power within the project.

Participation in project management

Half of the survey projects stated that they included individuals from the target community group in managing the project. What exactly this management entailed was not specified. More than half stated that their work involved creating partnerships with target community groups where the community group decides on policy and management issues. This is a positive sign, as involving local people in this management process builds local skills and capacity, and bodes

well for the future sustainability of such projects. This inclusion of local people in management issues suggests that there is a more dialogical approach to the work, and that there is potential for partnership, and the delegation of power, leading ultimately towards the power-sharing that Arnstein suggests is indicative of true participation.

Determining content for the projects

The survey results suggest that the content and the messages of the projects were predominantly determined by the organizations themselves. There were six projects which responded that funders and other experts had a hand in this, and four which stated that community participants were instrumental in these decisions. One organization did not complete this section of the questionnaire, and so only ten answers are recorded here. Just four of the organizations report consulting with community groups about their issues of concern. Although this involves some consultation with the community, Arnstein's model suggests that it is indicative of tokenism. This echoes the earlier finding that very few organizations fully include the community in decision-making about the projects. If this is indicative of the general trend, then these self-proclaimed participatory projects are using participation as a means to an end rather than the more empowering approach, where participation is seen as an end in itself. There is the potential, therefore, that the participatory aspect of these projects may become insincere, unsustainable and generally ineffective. For participation to be truly successful, it needs to be championed for its own sake, not only as a pathway to achieving a particular end-goal. Six of the ten organizations reported that local people participate in pre-determined projects. This is an example of Arnstein's levels of manipulation and therapy, where the funders and catalyst organizations presume that they know what is best for the target community. This phenomenon is common amongst health-related projects, where bio-medical information is in the hands of a few. Participation can then become simply a form of rubber-stamping by the local community, and used as means to the ends specified by the development agent. In terms of Arnstein's level of participation, the collected data suggest that the first aspect of *non participation* is evident in issues of content selection.

In addition to this, eight of the groups said that their work involves passing pre-determined information to the community via specific

in-groups. This is again indicative of the top-down monological communication that characterizes modernization, suggesting a tokenistic approach to participation. In this selection of in-groups, there are parallels to the *diffusion of innovations* approach proposed by Everett Rogers in the 1960s and refined over a number of decades. Diffusion is primarily concerned with the communication of ideas within a social system (Ascroft and Agunga, 1994). These ideas are generated from outside the community and then dialogue is encouraged within the community to spread these imported ideas. These three tokenistic levels of informing, consulting and placating potential participants from a community may encourage a certain amount of dialogue, but participatory decision-making is not part of these processes. The impulse for the development still comes from outside the community, and the control still rests in the hands of the external change agency. This cannot result in the social and structural change necessary for development to come about.

Participation in creating and facilitating projects

Four organizations reported that participants make recommendations about projects which are run by their organization, suggesting that the community has some input into the content of the projects, but no control. Again, we see a certain level of participation in these cases, however, the level of power-sharing and citizen-power promoted by Arnstein is not achieved through this consultative process. Half of the surveyed organizations said that their projects were created together by their organisation sharing decisions with community participants. This would suggest a greater level of participation than has been reflected earlier. This act of co-creation gives rise to the potential for more meaningful partnerships between organizations and the local community.

Four of the organizations reported that participants are selected and trained to run their own projects. This strategy is more empowering than the previous options, and involves a greater level of participation. Seven of the groups, which is a significantly high percentage, stated that the target community or group and their own organizations were in full partnership regarding all aspects of the project. Although this is stated, again this is contradictory to earlier findings. This would suggest that the concept of partnership held by these organizations is significantly different from what Arnstein and other theorists suggest are the components of genuine participation.

Only one organization reported that their projects were initiated and created by the community participants and all decisions were made by the group on their own. This is an example of the kind of citizen-power that Arnstein suggests is true participation. That only one of the surveyed organizations reflected this as their practice suggests that handing-over control is still uncommon in HIV and AIDS projects. Partnerships and power transfer may be seen to be the ideal in participatory projects, however they are not easy to implement and come with their own set of problems. Arnstein suggests that altruistic development is not a common practice, as “those who have power normally want to hang onto it; historically it has had to be wrested by the powerless rather than proffered by the powerful” (1969, p. 213). This then gives rise to some of the debates mentioned earlier regarding the non-democratic and exclusionary nature of local structures.

Training and building capacity in the projects

Although seven of the groups responded that they themselves did some training of community participants, for the most part this responsibility fell to funders and other experts (ten of the eleven organizations). In only one instance did the community participants themselves become involved in training others from their community. A realistic view of the context of South African NGOs is that many organizations do not have the capacity to conduct training, either because of a shortage of skills on the part of the organization, or a shortage of time. Either way, this suggests that outsiders are taking on this role in the surveyed organizations. This phenomenon may be indicative of Arnstein’s concept of *therapy*, where outside experts are perceived to know best and feel they must impose this knowledge on the local community. Where local communities are characterized in the most part by slow development, poverty and a lack of skills, there is the danger that outside agencies will not take the time and effort to develop local capacities for decision making and organizational efforts.

Participation in research about the projects

Research for projects was mostly done by the organizations themselves. Significantly, none of the organizations mentioned that funders were involved in this. Although this question was designed to enquire into the research that informs the programs, respondents may have interpreted this as research into how the programs are received. As more than half of the programs are determined by funders and

outside experts, we must assume that their research informs the project. However, it would seem that the organizations are otherwise self-sufficient in this regard. Only one organization included members of the target community in this process. Again, this may be a reflection of the lack of skills in these communities in general. All eleven of the organizations report that they themselves are responsible for monitoring and evaluation of their projects. This is often a stipulation of the funding, and there appears to be high capacity in this area amongst HIV and AIDS organizations. In addition to this, ten of the surveyed projects report that funders and other outside experts are involved in this process, which may be indicative of the current trend to find external and supposedly unbiased evaluations of projects that can motivate for future funding.

Nine of the eleven organizations report that their funders receive copies of the documentary evidence of the projects, such as videos, photos and reports. In only four cases do reports and evidence reach the target community and the participants themselves. This is indicative of an approach that perhaps does not give credence to the target community, and to the benefits of the community receiving information about the projects that affect and involve them. This withholding of information is typical of paternalistic programs that provide information to the target community only on a "need-to-know" basis. The resultant imbalance in knowledge about the project prevents community participants from becoming full partners in it.

Conclusions

The results of this survey suggest that participation is not across the board for these HIV and AIDS organizations and their projects. The target community is involved in open communication and dialogue about their own development in varying degrees. While consultation is common amongst all of the surveyed groups, this may remain at the level of tokenism in many instances. Only four of the selected eleven groups note significant participation by the target beneficiaries in determining who participates in the projects and what the goals for these projects should be. These are perhaps two of the most significant stages in participation.

Best practice examples argue that community members must be included in determining the outcomes for a local project for the project to be meaningful and sustainable. However, this inclusion of local people in the initial decision-making processes is not common in the

surveyed projects. If a project's goals are solely determined by catalyst organizations and their funders, the community cannot take full responsibility for their own development, and unequal power relationships between donors, development agencies and local people will continue.

Participation in the management and running of local organizations is reportedly high. Although this participation is not specified, most of the projects confidently report that the partnerships that develop between the local people and the organization are well-developed. However, as these organizations then fail to meet specific criteria regarding participation in typical management activities such as project goal-setting, reporting and evaluation, one must treat the reported instances of partnership in project management with some scepticism. There may be a number of barriers to ensuring participation at these managerial levels of such projects. However, the argument that local people may not have the skills and time to effectively be part of these decision-making processes must be countered, to ensure that participation does not become tokenistic.

Many strategic communication campaigns in the development field fall into this category of tokenistic participation; however the sample organizations did not identify themselves as such, and all purport to be participatory. That they are participatory to a certain degree must be accepted, but these degrees differ. It is apparent that much of the participation encouraged by these organizations is as a means to the end of providing health information, health care and other support and services. Community members participate in pre-determined projects through pre-determined strategies. While this is not indicative of a fully participatory approach to communicating about development, the participation-as-a-means approach should not be rejected out of hand, as it does have some benefits for both the individuals and the local community.

This kind of participation in communication processes and projects can build a sense of connection with and ownership of the projects, and can be expected to bring about some change in the lives of the participating individuals. However, it cannot be expected that such participation in projects and interventions but not in decisions and planning, will bring about any substantial shift in social power. Without this shift, it is likely that when donor funding runs dry or the managing organization moves to another area, the project will come to an end. In this case, the long-term benefits of such projects to the

community as a whole may be questioned. Only when ownership of a project is assumed by the community, can local people work together to safe-guard their own long-term interests.

If we view HIV and AIDS as a development issue, then we must recognize that people must be empowered to make decisions and take control over how they respond to the epidemic. This means that they must be involved more fully in all processes of communicating about their own development, and dialogue about local programs should include both outside experts and the local community from the start. Empowerment and the resultant freedom of choice that it brings can only be encouraged through genuine participation at all levels of local projects.

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The effectiveness of interpersonal communication for HIV/AIDS

By Noel Joram

Abstract

The present article reports a study of the communication processes in four rural communities in Tanzania which have led to a high rate of testing for HIV/AIDS infection and then, for infected persons, effective provision of medical attention, dietary support and especially counseling to develop positive life attitudes in the face of infection. The study was carried out in the Iringa region which has one of the highest rates of HIV/AIDS infection in Tanzania. The major factors leading to a high rate of testing were (1) the “caring” interpersonal communication of paraprofessionals living in the community such as a village nurse who could overcome fear of stigma by personal concern, (2) the use of consciousness-raising group and interpersonal communication, (3) the interpersonal communication within organized networks of HIV/AIDS positive persons who linked regional, national and international health service providers with infected persons in remote villages, and (4) the use of indigenous forms of folk media produced by HIV/AIDS positive groups. Although print media was useful, there is no evidence that radio or television was effective. In communities with low rates of testing, it was found that political or religious leaders tended to inhibit or discourage such interpersonal networks of HIV/AIDS positive persons.

Key words: communication and HIV/AIDS, interpersonal communication and HIV/AIDS, community-based organizations of HIV/AIDS positive persons, indigenous media and HIV/AIDS

Introduction:

Tanzania has the highest rate of HIV/AIDS infections in East Africa and ranks fourth worldwide in the number of people dying each year of HIV/AIDS (www.globalhealthfacts.org). What is most worrisome is that, in spite of the enormous efforts to communicate the lethal danger of HIV/AIDS, the number of those infected and the rate of infections continues to increase. The rates of infection are now increasing especially among lower-status women who are targets of sexual exploitation, and in the rural areas where mass media do not

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reach and interpersonal oral communication is a major source of information. The access to medical services tends to be lower in rural and lower-status urban areas. There is often an authority-dominated communication system centered around elders which has relatively little communication contact with the high-risk age groups. In these contexts, those in the high-risk age groups tend to be more fatalistic, even more hesitant to admit infections and more reluctant to take measures to adopt the regime of retroviral drugs and diet that would enable them to live with their infections.

Part of the problem is that many people in the high-risk category or who are infected do not have adequate information as to how to defend themselves from infection or what to do if they think they are infected. Many people, however, do have varying degrees of information. The more serious problem is that many who may be infected and need treatment, are afraid of the stigma, social rejection and social pressures for radical changes in their lives if their positive status is made public. Just one of the consequences is that if they are known to be infected, then they should, in honesty, change their sexual relations in order to not infect others. Sexually active groups also need to change their sexual activities which imply changes in their social behavior. In this context the need is not just information about HIV/AIDS but a social context in which it is possible to re-arrange one's social interaction and re-arrange one's life habits, especially one's sexual habits.

As the review article of Eiza Govender in this issue of *African Communication Research* indicates, there is now broad consensus that the social reorganization of lives to respond to the infection or danger of infection requires a reorganization of the local community context (Govender, 2010, pp. 217-219). The communication for social change approach implies that development must start from the initiatives of the local community, with involvement of local catalyst persons, leadership in community-based organizations and with community organization as the links for bringing national and international services to the people in the community (Bessette, 2006; Quebral, 2006; Uphoff, Esman, Krishna, 1998). All of the stakeholders, including national planning offices, will be involved, but the local community leadership has the major responsibility (Melkote and Steeves, 2001; Tarawalie, 2008; Rodriguez, 2001, p. 19; Servaes, 2001, p. 20). Efforts in HIV/AIDS communication has shifted away from emphasis on the initiatives of the state and technical experts to emphasis on initiatives of community organizations, including local initiatives in planning and

evaluation (Obregon and Mosquera, 2005, pp. 237-244). There has been a move away from the mass media campaign approach aiming to persuade high risk or infected individuals to change behavior toward a process of local communication by community-based organizations (CBO) which obtain services and insure that these services reach HIV/AIDS affected people in the local context in the most effective and equitable manner (Malikhao, 2008, p 309). The most significant impact of mass media messages about HIV/AIDS is often its stimulation of users to form CBOs (Tufte, Corrigan, Ekstrom, Fuglesang, Rweyemamu, 2009, p. 166).

The mass media are found to be less communicative than alternative media produced by local people in the local community such as drama, singing groups and locally produced video (Lie, 2008, p. 281). Local paraprofessionals and group discussion facilitators are often the catalysts in a process of local communication process (Bessette, 2006; Uphoff, Esman, Krishna, 1998, pp. 52-56). The mass media may be important in raising a general awareness, but are less effective in actually bringing about behavioral change (Lie, 2008, p. 282). It is the interpersonal action or mass media combined with discussion that sets the stage for rethinking one's life. Often behavior change depends on the CBO activity which creates the *conditions* for change such as making medication and more nutritious food available.

Rather than simply mass media, forms of interpersonal interaction are the seen as the most effective means of creating preventive consciousness or in helping infected persons to reorganize their lives (Buhler and Kohler, 2002; Lie, 2008, p. 281; Roy and McCain, 2001, p. 425). By interpersonal is meant not only one-on-one personal conversation and counseling, but small group discussion, the consciousness raising group discussion of facilitators, forms of community organization in multiple meetings, interpersonal contacts with agencies providing information, medical supplies and equipment, and working with community development agents (Singhal and Rogers, 2002; Singhal, 2006, p. 726). The sense of trust, commitment, responsibility, compassion and concern is the "glue" which holds together a complex network of stakeholders in a response to a very complex epidemiological phenomenon dominated by fear of revealing one's infection and adapting to a fairly demanding regime of reorganization of one's personal life (Roy and McCain, 2001).

Particularly important has been the development of interpersonal networks among AIDS-infected persons (Lie, 2008, p. 281; Roy and

McCain, 2001). Information about HIV/AIDS as a health issue is needed—for example, what medicinal and dietary routine one must adopt, but even more important is sympathetic interpersonal and small group communication what enables the person to reorganize one's life values, one's social status in one's family and community, and one's life routines. The current research stresses that the key factors are community organizational initiatives, participation of the people in the community, building on the indigenous health practices and indigenous knowledge and the support of the stake holders from local medical officers to health agencies to overseas donors (Thomas, 2008, p. 43; Lie, 2008; White, 2008; Govender, 2010). Especially important is the use of the Freirian consciousness-raising dialogue to encourage people suffering from the stigma of HIV/AIDS to develop a sense of their own worth and their ability to manage all of their own services (Cadiz, 2005; Obregon and Mosquera, 2005, p. 241; Singhal, 2006, p. 726).

The most effective CBOs are those which are initiated and led by HIV/AIDS positive and high risk persons because they understand the trauma of infection, are motivated to reach out to infected persons and understand how to communicate with others who are undergoing the experience (Chillag et al, 2002). The CBOs made up of HIV/AIDS positive persons are especially effective as linkages between public medical services and those who are infected or high risk because they can, through interpersonal networks, search out and reach people fearful of revealing their infection (Chillag et al, 2002).

All of this emphasis on the local action implies a process of socio-political change in which local actors are empowered and encouraged to take initiatives that respond to local needs.

This cumulative research indicates what factors should be involved, but what is still not too clear is just how all of these factors fit together to provide strong support for the necessary action. If a community is going to introduce a program based on local organization, what is the first step and how does interpersonal communication form the basis of all aspects of the strategy. This is the focus of the present study.

The research methodology

To get a clearer idea of how communities can reorganize themselves to respond to high rates of HIV/AIDS infection and highly exposed high risk groups, case studies of eight communities in the Iringa region of Tanzania were carried out from June to August in 2007. The area of

research in the Iringa region has a particularly high rate of HIV/AIDS infection. All hospitals in Tanzania are required to report AIDS cases to the health ministry using clinical AIDS surveillance forms (Kapiga, 2005, p. 122). In the 2003-2004 reports, the Mbeya region had the largest percentage of cases followed closely by the Iringa region. Iringa appears to be affected by the HIV/AIDS pandemic because there is a high rate of out migration of the men in search of seasonal work and exposure to multiple sexual partners during this period outside the community. Upon return they tend to infect spouses and other women in the local Iringa communities.

The Iringa region is also the site of very significant community reorganization experiences in response to the HIV/AIDS pandemic. The author of this article had worked in the Iringa area with youth organizations and was familiar with the region and its HIV/AIDS responses. All of this led to the choice of the Iringa region as a site for the study. Since rural areas of Tanzania are rated the most resistant to control efforts and communication strategies, the study chose to focus on rural communities in the Iringa region.

The first step in the research design was to do a broad survey with key informants who knew the communities well to discover four communities where there had been a high rate of cooperation with testing for HIV/AIDS and relatively large numbers of HIV/AIDS positive persons who had successfully reorganized their lives to be able to live "positively" with their health conditions. The study then attempted to discover the communication processes that led to success in dealing with the HIV/AIDS infected persons. "Success" meant that those testing positive were faithful in taking the retroviral medicines and in maintaining the right diet. In their sexual and other relations they were respectful of others and, in general, were living a very active and productive life in spite of their infection. A list of some eight communities was drawn up and visits to the communities were made to inquire about their willingness to cooperate in the study. Four communities were identified in which there had been significant development of community organizations and often quite innovative communication strategies in these communities. People in all of these communities were very willing to tell the story of how they had developed their responses to the HIV/AIDS epidemic in their midst.

It was evident in the initial survey that some communities with indications of a relatively high rate of infection had not responded with community organization and internal communication strategies. The

study was also interested in knowing what were the inhibiting factors in these communities that were often close to the high response communities. Thus, communities with low rates of testing and low rates of remedial practices were identified and from these four “low response” communities, comparable to the high response communities, were selected for analysis. Contact people were identified and agreement to cooperate in the study was obtained.

A visit of four to five days was carried out in each of the communities so that it was possible not only to have extensive group and individual interviews with all of the major actors in the community but also to observe meetings and other activities. Efforts were made to visit with all important stakeholders such as local hospitals, medical personnel and representatives of the agencies working with HIV/AIDS to get many different perspectives. The visits to the low response communities tended to be shorter, in part because there were fewer actors and activities.

The histories of how the community had created its response were obtained in focus groups and individual interviews in a three-stage approach. The first stage was a very open invitation to “tell the story” as they remembered it in order to allow them to structure the salient points of the account according to their indigenous world view. In the second stage, the respondents were asked to enlarge upon those aspects of central interest in the study such as how community organizations were formed, but still within the structure of perception and concern of the local people. Only in the third stage was an interview guide introduced to insure complete information on the following points:

- The community organizational structure administering the consciousness-raising activities among HIV/AIDS positive persons and high-risk groups and the remedial care among positive persons.
- The catalysts who set in motion community organizations and those offering continuing leadership.
- The degree of participation of people in the community in the decision making and the various organizational activities.
- The communication strategies used to gradually bring HIV/AIDS positive persons to testing and to reorganize life activities.
- How the organization worked with resource institutions and obtained the medical and other assistance needed to deal effectively with the HIV/AIDS positive persons.

One limitation of the present study is that it tends to focus more on the communication strategies for responding to the needs of those who are infected by HIV/AIDS than on the ways to prevent the high risk groups from getting infected. Both aspects are included in all the case studies presented, but the former tends to come through more strongly.

The Results - The high organization communities.

The Piuma Community

The organization of 171 people living with HIV/AIDS in the Piuma community is remarkable because it is providing most of the services needed by HIV/AIDS positive persons to carry on a quite normal active life. Since its organization in 2001, the group has built its own dispensary and office in the Bulongwa Ward serving people from 11 surrounding villages. The organization provides reliable testing for positive status, the necessary ARVs and nutritional dietary supplements, the equipment to test for liver and kidney functioning and counseling services to help those who discover their HIV/AIDS positive status. The association has been able to mount income-generating projects to create an emergency fund for HIV/AIDS positive persons. The counseling service is especially effective because it is carried out by people who are HIV/AIDS positive and can show by their own lives and experience that it is possible to live a relatively happy life in spite of the positive status. Not the least important, is the example of the remarkable leadership and services to the community that the members of the organization are providing. They are now among the most active and respected people in the community.

Although there is a government-run hospital in the Bulongwa village the HIV/AIDS positive members of the association have lost their confidence in the personnel there, in part, because the hospital was blamed for misappropriation of money allocated for people living with HIV/AIDS. The personnel in the hospital are seen as simply "employees", and members have little confidence in their testing or other services. In general the people in the hospital were not friendly and did not attempt to understand the problems of HIV/AIDS positive persons. The hospital does provide care for persons in an advanced stage of HIV/AIDS, but the counseling and human care is seen as not as good as that of the association.

A big step forward was getting the funding to build their own dispensary. It is located in the house of a former member of parliament near the market area where the people come from the surrounding villages regularly for food and other basic necessities. Although the village does not have electricity, the building had wiring and they were able to buy a generator to operate the testing equipment and get access to Internet. In general, the equipment of the dispensary is better than that of the hospital and kept in better condition by the careful attention of the association leaders.

The association carries on a very active educational program and, in the year 2006, a total of 306 persons came to their dispensary from the ward area to be tested. Some of these who were very sick but afraid to reveal their status were referred to the hospital. One of major successes of the group is the reduction of the stigma, rejection and isolation of the people with HIV/AIDS. The group is very active in raising the consciousness of the danger of HIV/AIDS among the young, "high risk", sexually active young people, and the leaders in the association feel that they have had an impact among these young people.

How did the group get started?

The catalyst person was a nurse who lives in the community, knows the local people very well and is much loved by the people in the community. She had some training in medical services and had worked with CARE so that she had some experience in community development. She had four years of experience working with HIV/AIDS patients in a clinic, but especially important has been her training in counseling. In her early period as a nurse in the community she was keeping a record of the people who started and then dropped the medication. She was concerned with the poor nutrition of the positive people.

She began by speaking quietly and privately with some individuals about the importance of steady use of the medication and being careful about their diet, but then she encouraged them to come together for group discussions. Most were very reluctant to reveal their status, but she managed to convince them that in the long-run it was to their advantage. Many were fatalistic with no hope, and in the focus group interviews they jokingly recalled that they referred to themselves as "dead man walking", "expected dead person", "eating alone" – referring to their segregation from the family meals. She was able, however, to recruit a group of seven over a period of three months in

2001. The group discovered that they enjoyed the discussions and decided to give themselves the name, "People Living with Hope" (People Living With Hope Association, PLWHA).

As the group revived their hopes, they began to invite their friends to join them. Since the nurse is a government employee with many responsibilities, she suggested that they might help by moving around the villages and encourage others to get tested and then, if they proved positive, to join the discussions of the group. She helped the group make contact with a hospital in Njombe, about 100 kms away, and get a few videos which explained the problems of stigma and how to live with HIV/AIDS. They finally got a mobile video projector and a VCT and, with their own testimonials, they were encouraged by the number of people who agreed to get tested. Some joined the group the same day after hearing about the benefits they would have. In the focus group interviews they said that since they started their talks to the community, stigma has been reduced a lot, influenced mainly by their own example.

As the group grew, it has strengthened its organizational structure and has drafted a constitution, which gives all group members equal participation in decisions and equal voice. Each member is a member of a committee responsible for a specific activity. For example the construction committee was responsible for building a small dispensary with nine rooms which the group is currently using for voluntary counseling and testing. In committee meetings members are learning to be accountable to the organization and towards each other. In the focus group interview, members rather proudly told the interviewer, "It was just minutes before you arrived that we have suspended our secretary general for money embezzlement". The group commented that their committee system and the participatory way of running meetings has been a learning experience not only for members but for all the people in the community on how to be involved in decision making processes.

One of the major advantages of having a strong local organizational base with their own decision-making structure and accountability system, especially the financial accountability, is that the group can make direct contacts with NGOs, government services, and other grassroots HIV/AIDS organizations for training courses, medicines, equipment, financial help, loans to start income-generating projects, and many other support services. Since most of the members have only a primary school education at best, at the outset they did not

know how to make these contacts. But with the help of the local nurse the association has been able to contact both local agencies and has made direct contact with international support groups, most notably with an agency in Austria, to obtain high quality equipment for testing and other services to HIV/AIDS positive persons in the area. These initiatives to making contacts is one of the reasons why the services are looked upon as being superior to the bureaucratic services of the government.

Health education activities of the group

One of the most significant activities of the group is to make contact with various agencies to come to the community for training workshops for their own members and others in the community. The following is a list of some of the more important training programs they have arranged.

This training has been a major factor in the self-sufficiency and strong organization that that the association has built up. All of the

work of the members of the association is voluntary, without remuneration, except for reimbursement for expenses.

The communication strategies of the association

To get their message across to the people of the villages in the surrounding area, the association had no resources for media equipment and so used the traditional communication forms of villagers in the harvest festivals, funerals and other community celebrations: choirs, popular music groups, poetry and traditional forms of dancing. One of the most effective means of communication has been folk drama, with skits and plays composed by the members of the association themselves. Through this publicity the association has about seven to ten people coming to their dispensary every day for health information or other services. Although the members listen to a regional radio station, they were not aware of any radio programs dealing with HIV/AIDS or other health issues.

The association has been successful in recruitment of new members who are now on the ARV medication and nutritional program because from the beginning they were able to tour around all villages in Bulongwa ward and talk to all village leaders about their plans. The local leaders are part of the group's success because the leaders have given the group access to village meetings where they can provide their testimonials and provisions of education materials for their communities. Before, people living with HIV/AIDS were not recognized as a group and were shunned by village leaders. With an organization and their sensitization program, the group came to be recognized in their locale and invited to participate in any local community development activities and appropriate tasks that local leaders propose to them.

Once their dispensary was established and they had electricity, they established Internet services with a website, www.piuma-simba.org and an email address, office@piuma-simba.org. With the help of the nurse, who does translations for them, they are able to have regular communication with many national and international agencies.

Economic empowerment

The group has received funds from different organizations including TACAIDS, Firelight Foundation, and the friends from Austria. TACAIDS funded the project of a fish pond for the group members. The association has also established various gardening projects to

guarantee the proper nutritional standards for positive persons. The group has also been able to sell the products to help in other transportation and medical bills for PLWHA.

The Makete Support People Having AIDS (MASUPHA)

The MASUPHA organization is in a semi-urban area of the town of Makete and, like the PLWHA association in the Piuma community, is an association of 392 HIV/AIDS positive persons. It is, more accurately, a federation of many groups in different surrounding villages. Although the federation started only in the year 2004 it has been able to initiate a number of income generating projects in different villages. In 2007 this included two hectares of vegetable gardens, three hectares of maize, two hectares of wheat, two hectares of sweet potatoes, one hectare of peas and one and a half hectares of pyrethrum. These projects supplement the nutritional needs of the members. The group has also been able to start three pig raising projects, six guinea pig projects and seven poultry projects. The group has also been able to plant four hectares of trees and they expect to plant more trees for environmental purposes and for lumbering activities.

The federation has also been able to start their own savings and loan association (SACCOS) from their monthly contribution of 500 Tsh in every meeting they attend. From the ten per cent profit they have been able to raise Tsh 1,971,000 (about US\$ 1300) and the fund is still revolving. From all these activities the group is currently paying for school fees, uniforms and exercise books for 34 orphans. All the above activities provide nutrition which is necessary for people living with HIV/AIDS.

How the MASUPHA federation got started

The catalyst person in this case was a social worker who was hired by Medicines Sans Frontier (MSF) which had a two-year contract to provide assistance to HIV/AIDS positive persons in the Makete region, one of the areas of Tanzania especially hard hit by the pandemic. The MSF established their own care and treatment clinic in Iwawa hospital because, at the time, there was no hospital that was providing ARVs in the Makete district. The role of the social worker, hired because she had training in participatory animation methods, was to go around the villages to encourage them to get tested for HIV/AIDS infection and, if positive, to begin the process of medication, dietary support and regular physical checkups. The social worker felt overwhelmed with

the task because it was a relatively large, semi-urban, more densely populated area. Some 50 per cent of the people did not come to collect their medicines on their prescribed day, and it can be lethal to start ARV's and cut it short because it is a lifetime commitment. Stopping it might lead to death. She also knew that many in the area were positive, but they had no one to help them go to the hospital when they were sick. Given the high degree of stigma in the area, the social worker could see the need for mutual psychological support. Finally, she knew that the MSF contract for services in the area was for only two years and she was worried about what would happen to the people after that.

The social worker began to talk with some of the more regular persons coming for treatment explaining that there was a great need for help in reaching the HIV/AIDS positive persons and that the MSF would soon be leaving. Like the nurse in Piuma she began to encourage them to form a group of mutual support. It was not easy in the beginning because people were skeptical about persons working with NGOs. As those interviewed in the focus group said, "in the beginning we weren't sure of the intentions of Aida (the social worker) because there were a lot of people who wanted to use people living with HIV/AIDS for their own financial gains. In time we realized that she had good intentions and she was going to be discharged from the organization (MSF)." One thing that helped the social worker relate to the people was that she was of the same Kinga tribe and could speak to them in their own language.

In the beginning there were only 14 in the group, but they were influential in persuading others to join them in taking the ARVs regularly. As one of the focus group interviewees said, "In the beginning we heard in our villages that if we started to use ARV it would make our situation much worse, but after seeing the first members of the group we were convinced that it was just a misconception, because their situation was much better than they were before enrolling in the program". In the focus group one of them reiterated this "It took me a while to go and get tested because I knew that I would be stigmatized if I was HIV/ positive".

The group was particularly successful in reaching more people and recruiting them for their organization because of the support which they received from MSF in the beginning. For example, the group members were given a public address system and mobile video projectors. The fact that the promotion was done by HIV/AIDS

positive persons who could testify to the improvement in their own lives was convincing. Also, the fact that the members are volunteers, without remuneration, is also convincing. As the MUSUPHA group grew and they contacted villages further out in the hinterlands, they discovered that many of the people did not have the financial resources to travel to the hospital in Makete so they obtained a mobile VCT to take out to more remote villages to provide testing services.

As the group grew they decided to establish a formal organization with a constitution that guaranteed the right of all members to participate in the decisions and demand accountability of the elected leaders. The social worker helped them formulate the constitution but they also got help from a local businessman who guided them in how to elect leaders with the participation of all and how to make these leaders accountable to the members. Like the Piuma association they are organized in committees with specific responsibilities and regular meetings of committee members. Members of MUSUPHA are scattered some as far as 50 kms from Makete, so they decided to establish village units of the organization linked together as a federation. This enabled members in a particular village to work with their community leaders and to get the leaders to take more responsibility in supporting the activities of MUSUPHA. The fact that there is fairly autonomous leadership in each village has explained why the federation has grown rapidly to almost 400 members. The central office of the federation is located in Makete so that they could have easy access to the Makete hospital and the various NGOs that provide some assistance. Although the federation office and dispensary is located some 10 kms from the District Commissioner's office, they still are able to have fairly easy access to the District office for the support that they find there.

Capacity building training

When the federation was first established the MSF helped the members set up a series of training workshops to assist them and others get skills for carrying on after the departure of MSF. The chart below indicates the kinds of training which proved especially helpful to them in their work. The training has helped the group to be self-sufficient and not depend on MSF as the main source of support for their activities.

Organization	Capacity building	Outcome
TANOPHA	Home Based Care	Home Based Care
TACAIDS	Planning and financial procedures	They have clear plan, written reports, and account for the money they got from the donors.
TACOSODEA	How action groups can start their own income generating projects and be self sustaining	Projects as mentioned and provide food and nutrition for 362 people
MSF	ARV, nutrition, fundraising	All those enrolled in the group (362), adhere to ARV. They also got funds from Fi relight Foundation, and TACAIDS to support the ARV medicines and the nutritional supplement

The communication strategies of MUSUPHA

The MUSUPHA federation places great emphasis on meetings of members with local village leaders, and they have incorporated the traditional village communication forms such as choirs, popular music groups, folk dramas, dances and traditional *ngomas*. As noted above they have used loud speaker systems and video projectors, but the most effective communication is interpersonal contact. The group does person to person and small-group education in the district hospital in Makete twice a week on Tuesday and Thursday. From early 2006 to June 2007 (the date of the interviews) they have been able to talk with 2449 men and 4652 women in the hospital. The group has also been using other small media such as leaflets and brochures that have information about the activities of the group and the benefits that people will have if they test and join the group. It is not every one that attends meetings so others respond after reading the materials handed to them. The MSF helped the MUSUPHA federation make contact with many agencies and NGOs to get the resources needed to carry on their work after the departure of MSF. This was the source of the help to set up agricultural projects to supplement diet and to initiate income generating projects for the extra financial resources the group needed.

The TAHEA Nyamihuu Association

The TAHEA Nyamihuu group, named after their village Nyamihuu, is now responsible for providing HIV/AIDS prevention services in their ward. The group has been particularly successful in the promotion of

both male and female condoms according to the statistics they have from their centre.

This group originally started as a group of only eight women in Nyamihuu village in 1992. They gathered together to help each other find a way out of poverty with simple income-generating projects. But, as one woman said in the focus group interview, "As time went by we saw that some of our members were dying with HIV/AIDS and we decided that it is better to do something about it". The group of eight women shared their idea with the ward executive officer asking how the group could respond to the problem of HIV/AIDS in their community. After several consultations it was agreed that they should start a program of HIV/AIDS education in their community, and that it would be prudent to have a mixture of men and women to be able to reach all groups. Later the ward executive officer decided to take the idea to village meetings to get volunteers who were willing to join the group, and in a month the group had 26 people. One of the activities that they particularly enjoy doing together are the performing arts, especially their original compositions of singing and dancing. This is also one of the principle ways they carry on their educational activities in the community. They have scheduled meetings every Monday to plan for their weekly tasks, but they also meet on Thursdays for rehearsals of their arts performance. They saw that their work in the community as very important to the point that they decided to invite a guest from the Tanzania art commission (BASATA and COSOTA) to tell them how to get a commission for artistic copyright so that they can register their work and not allow it to be replicated by other people.

The group also has a constitution and bye-laws that guarantee the rights of all members and guide their activities. According to the focus group interview, they try hard to get the participation of all the members in meetings so that everybody feels he/she is part of the group. One of the bye-laws is that every member is supposed to adhere to is testing for HIV/AIDS. In the interview one of them said, "*We are the mirror of our society. Everybody looks at us for guidance and we have done just that*". They feel that this makes what the group talks about in community meetings more trusted because they actually do it themselves. Also, like other active groups they have committees for specific activities with committee meetings for discussing their action plans. There is participatory communication within the groups. The group also has received training for their HIV/AIDS educational and service activities as the following indicates.

Organization	Capacity building training	Outcome
AMREF	Home based care and support	Home visitation for people critically ill
PSI	Facts about condoms	Condom distribution
BASATA	Interactive performing arts	Use of participatory art in HIV/AIDS Prevention education
TAHEA	Financial procedures, fundraising, budgeting and report writing	Reports of activities, weekly budgets
CARE INTERNATIONAL	Making fliers, brochures, leaflets	Leaflets, fliers and brochures
DR. ATTA (UDSM)	Making short films	Production of short films on HIV/AIDS

The training aims to give the group the capacity to perform their activities without depending on help from outsiders. They can write their own proposals, plan their own activities and make their own small media for their community. Having this capacity has helped the group develop and expand their activities from their village to the entire Nzihi ward.

The group has benefited a great deal from a paraprofessional advisor living in the community that the group calls a "director". This person works in an NGO with more network connection than any other group member, and she has been responsible in finding organizations that will respond to the group's need for development. She is responsible in finding Dr. Atta from the University of Dar-es-Salaam who taught the group how to make short films. She is also responsible for persuading the village leader to give the group a piece of land for income-generating projects so that they can be more involved in the educational work rather than continually worrying about economic needs. From her own NGO the group has received some of the capacity building training listed above. In general this advisor serves as a kind of public relations officer helping the group make contact with the many agencies and NGOs that are providing some help.

The communication strategies of the group

The group has set up a mini library which makes available reading materials useful in the community. The group has a regular delivery of free magazines from FEMA in Dar es Salaam which produces *Fema, Si*

Mchezo and other publications about sexual reproductive health. The contact with this publishing company was made by the para-professional advisor after she met the well-known manager of Fema, Minou Fuglesang, in a forum in Dar-es-Salaam. The group has also been able to utilize local community meetings in the ward to reach the people of the community. Most helpful has been the support from the ward executive officer who has introduced the group to all the leaders in the ward so that HIV/AIDS has been part of the agenda in every meeting that the villages are holding.

Much of the education of the community regarding the reorganization of one's life in the pandemic of HIV/AIDS is done by this group with their singing and dancing performances which are also a celebration of the talents of the community. In addition the members of the group are doing a great deal of quiet interpersonal counseling in the villages where they live.

Health services to the community

The group is about 50 kms from the nearest town and there is no hospital or NGO providing health services anywhere near the ward. In order for people to get health services or information the group is the only means. One of the major services is the distribution of condoms out of the office of the mini-library where they have other educational materials. The condoms are also made available in the villages at the times of their singing and dancing performances. The following statistics kept in the mini-library by the committee in charge shows the effectiveness of the group.

Year	Female condoms	Male condoms
1994	50	100
1995	130	100
1996	1,900	1,700
1997	5,900	1,900
1998	12,000	9,100
1999	15,000	14,000
2000	21,500	16,000
2001	21,800	25,611
2002	22,500	27,000
2003	24,000	23,000
2004	27,000	25,200

2005	28,000	28,000
2006	29,000	27,000
2007		

The group originally came together to organize income-generating projects, and this continues to be one of the major objectives of the group.

The Kamasai group

This is the first HIV/AIDS group in the Ilula ward, an area heavily infected by HIV/AIDS because it is located on the main highway where trucks stop for fueling and food. This has attracted many poor local women and has brought a wave of HIV/AIDS to the surrounding villages. Since 2004 when they were organized, the Kamasai group has been carrying on an educational campaign regarding HIV/AIDS in the ward. Before that time, there was virtually no attempts at HIV/AIDS awareness in the area. They have used the library of the local secondary school as a distribution point of materials on HIV/AIDS. They claim that more ten people visit this centre every day. They have also attempted to establish a federation of HIV/AIDS groups in the villages of the surrounding Mazombe district. They claim that since the group got started in the year 2004, they have been instrumental in bringing more than 2000 to be tested for HIV/AIDS.

How the Kamasai group got started

The person responsible for raising the awareness of HIV/AIDS in the area is originally from Kamasai village but was living in Dar-es-salaam for business reasons. When he decided to come back to his village he saw that a lot of young people did not have work which led them to engaging in risky behavior. He has a certificate of social work so he knew something of the art of facilitating community organization. He saw that there was a need to find a solution to the problems. He knew that he must utilize people's motivation as a way of communicating with them, so he offered to provide footballs if people would join together and prepare a football pitch. Because of people's love for the sport they joined together and made a football pitch.

Once the young people began to come to the football pitch regularly, he began to discuss the issues of HIV/AIDS with them. Then

he made a practice of regularly gathering the young people at the football pitch. Before any match and after the match they have informal seminars to discuss the problems facing young people and solutions. After about six months they became convinced that HIV/AIDS education should go beyond football and beyond their village, so they decided to form their group to work in the entire ward. The group got a good response from many young people because they speak the same young people's language and they share the same interests. They found it was easy for young people to understand what they were talking about. The response for testing was strong because they identified with the people who were talking to them.

Training for community education

Once the group had formed, the person with some social work training who had brought them together also helped them get in contact with many NGOs and agencies working in HIV/AIDS awareness and action. This training, listed below, proved to be of great importance in setting up their organization, learning how to carry on HIV/AIDS education and setting up their testing services.

The organization	Capacity building training	Outcome
TACAIDS	Financial procedures, planning and budgeting	Planning, reports on financial spending
CARE international	Making small media	They distribute brochures and fliers
SIDA	Entrepreneurship	Income generation projects poultry, tomato farms, pig keepings projects
AMREF	Home based care	Visitation for people living with HIV/AIDS
BASATA	Using performing arts for HIV/AIDS education	Use of performing arts for HIV/AIDS education

Forming an organization to provide services

The Kamasai group, with the help of outside training workshops, eventually formulated a constitution which set up committees, defined election procedures and responsibilities, guaranteed membership participation and made accountability clear. With the constitution, every member is involved in some activities and every member could be a leader. Initially, the group was totally dependent on outside support, but since this was uncertain, often their

visits to villages were stopped. The income-generating activities have provided some income for the organization to pay for travel and given the members more time to engage in consciousness-raising and educational activities.

The Kamasai village where the centre of the group is located is about 10 kms from the main road and they are about 50 kms from a town where there is a dispensary. There is no reliable transportation from the village to the main road, so most of the time the people have to walk 10 kms to reach the main road. Fortunately, the Kamasai group was able to get a mobile VCT from AMREF to take out to the villages for testing. The group is also making the ARV drugs available in the villages.

The communication strategies of the Kamasai group

This group has much simpler communication approaches than other associations, mainly going out to the villages, talking with the people and offering them the services that are needed. Communication between the group and the community members is largely through the village community meetings and also through ward and district festivals. These events bring the people together and guarantees an audience. As noted above, the local secondary school provides a central access point to get information and services.

Communities where HIV/AIDS education and services did not take hold: What were the factors in the lack of success?

The research design selected for case studies the communities where there had been a high rate of testing and adoption of life practices suitable for a positive status and then gathered data on the communication factors which made these communities relatively successful. The research design also selected communities where there had been much less success in testing and life reorganization of positive persons to see what were the communication factors - the lack of good communication - inhibiting a good response to the pandemic. Here are presented the case studies of these communities where there was low levels of testing for HIV/AIDS and low levels of care for infected persons. In general, the case study descriptions tend to be more sparse precisely because there was less organization, fewer responsive contact persons and not too much to report.

The Igingilanyi community group

The group came together in 2003 because they were alarmed at the number of people in their community dying of HIV/AIDS. The main purpose of the group was to provide HIV/AIDS prevention education in their village. The group did not have a catalyst, facilitating person with some experience in health education or community organization and did not see the need for this. They only joined together because they saw that there was a problem in their village and wanted to do something about it. "We decided that the only thing we have is our passion for drama and choir *ngoma*. We went to our village leader several times but the only thing he does is agree with us...but with no action. He had no suggestions on what we might do". The group has tried several times to get support from their ward executive office but this never produced any results. The only thing that kept them together is their love for performing arts.

The group is in a very rural area, about 60 kilometers from the main town. This means that they are quite isolated from any NGOs or agencies working with HIV/AIDS.

The group is seen by village and ward leaders as mainly a performing arts group for community celebrations. The group has been involved in the activities that the community leaders seem to think will work in their advantage. For example the group is typically asked to prepare performances in events like world AIDS day, women's day or any other official activities that their leaders would benefit from. They were not given an opportunity to present to village and ward leaders their interest in HIV/AIDS education and prevention. Nor has the group tried to get the support of local leadership in any forceful way.

When explaining their plight in the focus group, they said, "We are very frustrated since the beginning. We have asked help from our leaders so that we can rescue the situation. We have seen our friends die, but the leaders only look for us when they need our help".

The group has been in contact with some NGOs that are interested in health and family planning issues, but they received no help in setting up an HIV/AIDS project in their community. For example the group received two weeks of training from Marie Stopes on family planning. But the purpose was not to develop the capacity of the group for its own intended work, but because the family planning group wanted to use them to set up and promote their own talks. It was cheaper to use the group than doing it themselves. After the

campaign the group ceased to do any further awareness raising on family planning. Instead of raising the capacity of the group, the group has only been used as a means to fulfill other NGO's plans...

The group members explained that they also do not meet in a regular fashion because most of them are farmers and must spend a lot of their time in their farming activities. Since the group started in 2003 they have not changed their leadership. There is no clear constitution that could help the group in their decision making. The group only meets when they are asked by their village or ward leader to prepare a performance or a message for that event.

Here we find a group with considerable good will and considerable communicative ability in drama and singing, but with no encouragement, guidance or support. As a result they have done virtually nothing in HIV/AIDS awareness and prevention.

The "Eden Garden" project in Lupalilo Ward

Lupalilo is one of those wards in the Iringa region that is particularly hard hit by the HIV/AIDS Pandemic. In 2004 an American nun visited the Eden Garden village and was able to see for herself the situation of people living with HIV/AIDS and orphans. She was touched by the situation and decided that it would be good to have a group that would help people living with HIV/AIDS. But instead of talking to the people living with HIV/AIDS and encouraging them to organize themselves she talked to the church leaders asking them to do something for the HIV/AIDS victims. She promised that she will provide help where needed, but she was not able to stay and work with the community or send persons capable of working in the community.

When the idea of the organization was proposed none of the people living with HIV/AIDS was consulted or involved from the beginning. Instead, what the church did was to select eight persons from the church who they thought could lead the group. The group of eight were supposedly the decision makers but in reality all the decisions were made by the top leaders of the church. The people with HIV/AIDS were indignant that they were completely ignored and they decided to boycott the project because they were not involved in the group. They complained that many of the decisions were not made in their favor.

When the money for the project was sent to the church it included a provision for vocational activities such as carpentry and tailoring and in fact some of these facilities were installed. But since there was so little promotion among the HIV/AIDS positive persons, these facilities

remained idle. The HIV/AIDS positive persons complained that the church received considerable money, but this was not made available to the people who needed it. In the end the money and the project was carried out by the church people for a small group of orphans

The group is about 20 kms from Makete, which is the center of the district, and about 12 kilometers from the nearby hospital. It might have been possible to form a group linked with the hospital to get testing done and provide the support that HIV/AIDS positive people need. But the church leaders did not see the need to consult with anyone who was familiar with HIV/AIDS, convinced that they knew it all.

In the end, the group did nothing to help the HIV/AIDS positive persons get the support they needed and did little to stop the spread of HIV/AIDS in the community. The Church group did nothing to contact agencies to help the group or give training. Currently the group only deals with the orphans with little or no participation of people living with HIV/AIDS.

The Magubike group

This is a group of young people meant for providing HIV/AIDS education in Magubike village in the Kidamali ward. The area has a considerable number of migrant workers because it is a region of tomato production. This has increased the prevalence of HIV/AIDS, and this has increased the risk for the young people in the area. This group started out with considerable concern for the problem, but for several reasons it never reached the stage of providing HIV/AIDS education and support.

In the year 2003 Magubike had a village meeting and one of the agenda items was HIV/AIDS. According to the focus group interview, what inspired them to think of starting the group was seeing the group from the nearby village who came in the meeting to provide HIV/AIDS education. The young people of Magubike village were thinking of inviting the people from the neighboring village to help them get their own group started. Instead, immediately after the meeting the ward executive officer sat down with young people and told them that it was a shame that people coming from another village would come and do the job that young people of the same village could do. He said, "There is no point of people to keep on dying. It is essential that we stop sleeping and do something about the situation".

It took three months for the group members to join up and register the group in the district office but in that time the ward executive leader was able to link the group with TACAIDS and other external agents. TACAIDS supported the group with finances that were able to pay the transportation costs for the group to travel around their village and also to finance uniforms for orphans. During this time the ward executive leader made most of the decisions, and the group of young people did not develop their own strong leadership. It was only after finishing the funds for TACAIDS that their ward executive officer was shifted to another area. The group said that the new ward executive officer does not have any interest in the issues of HIV/AIDS. "We have been left orphans", they said.

Lack of capacity building training and economic empowerment

Apart from training in specific work related to HIV/AIDS like home based care from AMREF the group did not receive the training that was responsible for handling organizational development, neither has the group been empowered economically. This has decreased member's participation because of involvement of people in their own income generating activities.

This group does have their own constitution but the main problem is that they meet only when there is a big event in their communities. Instead of responding to community problems the group responds to the will of their ward leaders. Unfortunately the group has not seen any reason for selection of leaders since few decisions have been left to the group, a situation that makes leadership very difficult in the group.

In spite of the concern among the young people and the willingness to do something, there is little or nothing being done in the ward to raise awareness and provide better services for those who are infected with HIV/AIDS.

A still-born group in the Nzihi village

The group of the young people of Nzihi community was organized by a international volunteer organization who invited the local youth to join them in efforts toward HIV/AIDS education and prevention. The volunteers came for a six-month experience in the community with their own action plan and prescribed methodology. The leaders in the volunteer organization did not consult local leaders and did not invite the young people to participate in the planning. According to the young people interviewed, the involvement of the local youth came as

an afterthought when it became apparent to the volunteer organization that they could not have a significant impact in six months and it was obvious that they had to get the cooperation of the local people to achieve anything at all. Although the young people of Nzihi recognized the problem of HIV/AIDS in the village and could see the need for organized action, the idea of forming an organization did not arise out of a sense of concern of the young people. The volunteer organization wanted to get quick cooperation from the young people and offered to pay them money if they would cooperate. The motivation of the local youth for getting involved was the promise of payment.

From the beginning the youth of the community were not involved in the planning. The volunteers did all the planning. The group was not formally registered with the government office nor was it recognized as an autonomous entity that would be sustained for a long period. The meetings were only through the direction of the volunteers. The only activity that the young people were invited to do was to stage some performing arts on the topic prepared by the volunteers. All the expenses of the group were paid for by the volunteer organization. There was virtually no effort of the volunteer agency to train the youth in the management of organizations or other activities that the youth were involved in. The volunteer agency never encouraged the group to establish links with agencies such as TACAIDS or AMREF.

The volunteers used to invite community leaders to different workshops, and the youth were asked to entertain the leaders. Of course, the leaders saw through all this, and as soon as the volunteers left, the leaders made no efforts to keep the group going. Nor did the community leaders develop any significant interest in HIV/AIDS education and prevention. Some of the youth did see the need to continue the organization after the volunteers left, but they got no encouragement from the community leadership. The frustration of the youth with the volunteers and with the community leaders was summarized well by one of the young people, Daudi Mbina in the focus group interview:

The main problem with our community is our leadership. In the beginning we tried to ask for permission to continue with providing HIV/AIDS education. Some of us who wanted to be involved with this education should be given a chance to do so. It

is our right, because when God asks us why we didn't do anything we will tell him that it was their fault (the leaders), not us.

Unfortunately, the experience of the young people in the Nzihi community is repeated by many other volunteer organizations and NGOs who are only concerned with their own plans and financing. The losers in all of this are the victims of HIV/AIDS living in those communities.

The Kidamali community group

The group in Kidamali, made up of women, was organized in 2003 to carry out HIV/AIDS education and prevention, but, for various reasons, collapsed in 2005. The interview was only with Miss Jemana Mhapa, the former chairman of the group.

The group did not emerge primarily because the women had a deep concern about HIV/AIDS, but because the Women's Day celebrations of the area were to be held in their village and the focus of the celebration was on women and HIV/AIDS. The women of Kidamali community were embarrassed by the fact that the celebration was going to be held in their village and they could report nothing because they had no activities on HIV/AIDS. So the women rushed to get a group organized, registered and with a plan of some activities, at least on paper.

The group could have worked with a nearby dispensary to assist the dispensary in its HIV/AIDS activities, but they had never cultivated relations with the personnel in the dispensary and could not get immediate help from the dispensary in setting up some programs. In fact, they could get no immediate support from any local officials except the district cultural officer with whom they had never worked. There was no NGO or paraprofessional nurses working in the community who might have put them in contact with TACAIDS or other similar organizations for guidance and support. They had had no training in running an organization and little orientation on how to work with HIV/AIDS positive persons. So they had only their own limited experience to draw on.

Salvation for the group seemed to come from with the establishment of a cigarette company called Nyati. The owner of the industry did not want to lose his employees because of HIV/AIDS so he started paying the group members to provide HIV/AIDS education to the

personnel of his cigarette factory. So the group became dependent on him for operation and even gained new members because of that. Unfortunately, the cigarette factory closed after one year and, without this support, the group quickly collapsed.

The former chairwoman noted in the interview that the group had little solidarity and could not have lasted. There was no proper free election of leaders which led to much jealousy. The main motive was the financial gain. When that was gone the group dissolved.

The story of this group is quite common. Many agencies, especially government and international agencies pay people "sitting fees" to come to meetings and participate. When there is no pay, there is no organizational activity.

The Nduli community group

Like so many village groups this group started not because of the interest of the local people but because a political officer wanted to start something and control its activities. Often the motivation is that higher officials are asking local government representatives if there are any HIV/AIDS education and prevention activities. There is nothing that local government officers can report, so, out of embarrassment, the officer unilaterally starts something.

In the case of the Nduli community there was, indeed, a severe problem of HIV/AIDS infection with all of the attendant problems. So the officer chose the people he wanted in the organization and the officers he wanted. Unfortunately, these were largely loyal political followers, but not people interested in doing something about HIV/AIDS. This researcher set up an interview with the group, but when he arrived he found almost all of them drunk with *ulanzi*. It was necessary to find others in the community to provide some information on the Nduli community group.

Summarizing

Although there is now a broad consensus that the best communication strategy for dealing with HIV/AIDS is through a participatory, community-based organization, strongly sensitive to the cultural and psychological conditions of the infected and high-risk groups, the present study has sought to see how all these factors fit together and interact.

1. The most important factor seems to be that the communicative action be taken by a local, community-based organization of people who are deeply empathetic with the problems faced by those involved, especially those who face the social isolation when their positive status becomes public. The key characteristics of this organization seem to be:
 - That it be very democratic and participatory with no evidence of trying to exploit the condition of victims of HIV/AIDS for personal gain.
 - That all actions and services start with the well-thought through and committed initiatives of the local organizations. Services are a response to the request of the local organizations which must exhibit at least some minimum capacities for good use of the services.
 - That the local organization has some type of formal “constitutions” which demands commitment, accountability and responsibility of the people who are involved.
 - That it be locally based rooted in the local culture reflecting the language, traditions, economic conditions and other local cultural aspects important to the local people.
 - It should also try to make sure that communication between the communities and the local paraprofessional does not create dependency. The paraprofessional support should aim to make the organization self reliant, focusing on the kind of communication that aims at building their economic and political capacity and linking with networks outside the community. Otherwise the initiative will collapse immediately after the catalyst leaves.
 - That those who are infected or high risk be the major decision makers because others cannot really understand and deal with the cultural and psychological problems.
 - That it be an autonomous organization free from manipulation by political and economic powerful groups.
 - That the major objective be to have a deep respect and loyal concern for those affected and attempt to create a spirit of hope and confidence that a reasonably happy and fruitful life can be led.

2. The guidance of a paraprofessional advisor who lives permanently in the community of the organization and has the following capacities:
 - Is familiar with participatory group animation methods which

raise the latent awareness of problems and need for action by non-directive forms of discussion and builds bonds of sympathetic listening and solidarity among those facing the problem.

- Capable of very quiet, patient interpersonal speaking to those affected, with much confidence and respect for their abilities, accompanying but respectful of freedom.
 - Has a discerning knowledge of resource agencies that can provide resources of economic help, medical training or political support and can help put often poorly educated people in contact with them.
 - Is conscious of the importance of the paraprofessional status that removes the distance that tends to separate the degree-holding, economically better off professional person from clients and fosters a deep, humble respect for the indigenous knowledge and indigenous forms of social relations of the people.
3. The presence and ready, generous support of agencies that can provide the medical, economic, educational and other services that are proved to be important for victims of the HIV/AIDS pandemic. These are organizations with the following characteristics:
- Having clear and demanding conditions for providing services, but also ready to take risks with amateurish local organizations.
 - Free of corruption, desire for personal gain, and callous exploitation of the unfortunate.
 - Free of political, religious or any other forms of favoritism.
 - Having genuine competence that gains and holds the confidence of the public.
 - Willing to make the services present even in remote areas and on the conditions of the local organizations.
4. The support of local political, religious, economic and other officials. This support is best when it has the following characteristics:
- Is non-partisan and free of the prejudices of social stigma.
 - Respectful of the autonomy of the local organizations and initiatives.
 - Tends to respond to the initiatives and freedom of the local people and their organizations.

5. Finally, actions which employ the following kinds of communication
- Rooted in the primacy of deeply sympathetic interpersonal communication that takes each person on his or her own individual characteristics and merits.
 - The most “persuasive” communication is the personal witness of those taking communicative initiatives, in a way that leaves the receiver free and contemplative.
 - Even when a mass medium is used such as radio (and radio would be preferable) the communicator relates to members of the audience as individual persons, speaking to them in a very personalized manner.
 - For public community-level communication, adopting a more poetic, narrative, performing arts, imaginative and open style of communication which frees communication from the more rational, calculating, means-end, high pressure persuasion style of classical “behavior change” objectives of communication.
 - As much as possible employing a listening, dialogical, communitarian, open discussion style of communication, where meaning is constructed by all those participating.
 - Giving a certain priority to communicating through local leaders who are respected by the local people and can support the communication of local organizations by their more official and “elderly” status.
 - The use of mass media would form part of a “multi-media” composite based on interpersonal, dialogical group discussion, print media, performative arts, mass media which essentially brings together the public in a dialogue to reach consensus on some issue.

Although the various components of this model are listed separately here, it is important to stress that all of these—the organization of the affected HIV/AIDS population, paraprofessionals, external support agencies, the official community leadership and the people organizing participatory communication—are simultaneously interdependent and mutually supportive. One cannot function properly without the support of the other.

Discussion and conclusions: the primacy of the interpersonal

All of the above elements of CBO initiatives to address the HIV/AIDS infection have been noted in other research on participatory approaches to the problem. What this research proposed was to

analyze how all these elements evolve, fit together, are mutually interactive and form a coherent whole.

What this research stresses is that the formation of CBO networks often begins with the action of a catalyst person such as a paraprofessional nurse, who lives in the community, has a strong personal commitment to the community, knows the high risk or positive persons personally and knows how to approach local people. The key capacity of these catalyst persons is their ability to introduce a culture of frank, open, trustworthy, and respectful interpersonal dialogue that enables both high risk and positive persons to talk about their status and reorganize their lives.

All of these catalyst persons had some training in community organization and often had some training in consciousness-raising facilitation. Given the low level of formal education of the leadership of the CBOs, they needed these catalyst persons to help them form an organization. Also, none of the CBOs could have been effective if there were not a series of government and private agencies providing equipment, medical supplies, training courses, funding for food production projects, published materials and a general readiness to respond to the needs of the local CBOs. And the CBOs often made contact only with the help of local paraprofessional health officers or other people who knew the availability of these services and could help the local leaders make bring these services to the community.

One of the key contributions of these CBOs of HIV/AIDS positive persons was the ability to establish an interpersonal dialogue with their peers to encourage them to be tested and, if positive, give them hope and the desire to adapt one's life to these circumstances. The interpersonal relation of friendship, respect and commitment was of crucial importance.

All of the successful CBOs were using local, traditional media such as choirs, drama, and other simple media that not only seemed to be ready at hand and an integral part of life in many communities, but brought the discourse of life adaptation to a personal, emotionally moving and motivational level. Although radio did not seem to be a significant factor, the publications such as those of Fema (Tufte, 2009) were available and used .

Such printed materials seemed to be employed more effectively because they were used as part of the educational, interpersonal testimony and consciousness raising programs of the organizations. Video, locally produced and circulated among communities, seemed to

be especially communicative. Embedding media in interpersonal relations made media much more effective. What this data suggests is that if edutainment approaches are used, they should be closely integrated with community-based organization activities and with the interpersonal communication processes (Tufte, 2006; Tufte, 2008).

As impressive as this data may be, for many of the readers this research may raise as many questions as it answers. Only a few successful CBOs were described. Were these fortuitous cases? How extensive are these interpersonal networks in Tanzania or in Africa in general? The leadership was very dedicated in giving time. Are the members of all such HIV/AIDS CBOs so generous? Given the problems of sustaining CBOs in Africa, how enduring are these organizations. Did the study catch them at their high point? The four successful CBO cases just "happened" to have very dedicated local paraprofessionals with quite remarkable community organization capacities. How extensive is this in Tanzania or in other countries of Africa? All of the CBOs found remarkable support in government and non-governmental medical and community organizational agencies. Is this typical of other regions of Tanzania or in Africa as a whole.

Clearly, the present research is only the starting point of a much longer research program.

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NOEL JORAM

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Applying health communication strategies to the classrooms in South Africa: A values-based entertainment education approach

By Amy Chesser

Abstract

The present article presents the results of an evaluation of the South African *Heartlines* program designed to develop health-related values, especially responsibility for the welfare of others, honesty, self control, forgiveness and interpersonal commitment, among 10th and 11th grade secondary school students through broadcast drama aimed at a general youth audience. The main behavior change mechanism promoted was identification with the youthful protagonists of TV drama program viewed in a home context. The evaluation included a pre-test survey, intervention (watching the TV programs) and a post-test survey asking students whether they felt greater commitment to the values promoted. In the post-test survey of 742 grade ten respondents in nine different schools and 595 grade 11 respondents in seven schools, more than 50 per cent of the respondents indicated that they identified with the protagonists in the films and felt a stronger commitment to the values promoted by the TV films. A significant aspect of the results of the program was to stimulate dialogue among youth about the values promoted in the films. An overall conclusion is that teenagers are interested in watching films promoting values of interpersonal relations and that such films do help to develop such values.

Key words: entertainment education, South Africa, education of teenagers in values of interpersonal commitment, promoting health-related values

Introduction:

South Africa has the highest prevalence of HIV and the most severe HIV pandemic in the world. An estimated 5.7 million people, or about 11 per cent, were living with HIV and AIDS in South Africa in 2009, which is more than in any other country (Department of Health, 2008; UNGASS, 2010). Additionally, South Africa has the largest number of HIV infections and the highest of people enrolled on antiretroviral

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therapy in the world (UNGASS, 2010). Recent reporting indicates a decline in HIV prevalence among young adults (ages 15-24) from 10.3 per cent in 2005 to 8.6 per cent in 2008. Currently, prevalence remains highest for females in South Africa (UNGASS, 2010; Department of Health, 2008).

A 1996 report highlighted the “interaction of behavioral, biologic, and socioeconomic pathways that increase adolescent vulnerability” for sexually transmitted diseases which includes HIV infections (Institute of Medicine, 1997). Several factors have been identified as contributing to the high rates of HIV and AIDS in the adolescent age group. Therefore, recent research has included investigation of these factors to better understand the pandemic affecting young adults worldwide (Barnighausen, Hosegood, Timaeus, & Newell, 2007; CDC, 2002; D’Angelo, Getson, Luban, & Gayle, 1991; Gillespie, Kadiyala, & Greener, 2007; Hargreaves, Bonell et al., 2008; Hargreaves et al., 2007; M. H. Katz et al., 1998; Morris R, Baker C, & S, 1992; Rotheram-Borus M, 1991).

This study was designed to assess the effects of the Values for Life curriculum and films designed by Heartlines as a part of the Life Orientation class for grade 10 and 11 learners in South African school settings. This is an exploratory study utilizing quantitative methods. Quantitative methodology in the form of self-report pre- and post-test survey questions is used to examine and describe relationships before and after exposure to the curriculum and films.

Background to intervention program

The Heartlines campaign (henceforth, Heartlines) was created in 2002 as an initiative of the Mass Media Project in South Africa. Heartlines addressed current social issues through value lessons with the intention of promoting reflection on daily lives and personal value structures. The overall purpose of the campaign was to contribute to the prevention and mitigation of South Africa’s HIV and AIDS pandemic and other social issues, such as crime, violence and the breakdown of family and social structures.

The initiative adopted values-based Entertainment Education (EE) strategies to promote both personal change and sustained societal change. An important aspect of the Heartlines approach was to use mass media as a catalyst for change in combination with individual, communal and institutional mobilization. The campaign films were

produced and aired as a cooperative agreement with the South African Broadcasting Corporation (SABC). The films included in the campaign, from 16 July – 10 September 2006, were promoted under the slogan “8 weeks-8-values: One National Conversation”. The films were complemented by a radio strategy across all 15 Public Broadcasting Stations (PBS), which hosted talk shows on the values each week. This was further complemented by a print media strategy which produced features for strategic placement across a broad spectrum of print titles, and built relationships with newsroom decision makers and reporters (Pauquet, 2006).

The first phase of Heartlines was a series of eight narrative films set as South African parables that focused on critical social issues, such as poverty, HIV and AIDS, inequality, racism and discrimination. The series aimed to speak to all South Africans by capturing the lives of ordinary South African characters, who represented a variety of personalities and cultures, and who were attempting to discover solutions to some of life’s biggest challenges. The values central to the film themes included: acceptance, perseverance, forgiveness, honesty, responsibility, self-control, compassion and second chances.

As part of the second phase of Heartlines, a 16-week module called the Life Orientation course was developed for grade 10 & 11 learners (approximately 15 to 16 years old). The materials were based on the eight Heartlines “values” films. To make the films more classroom friendly, each was reduced from 52 minutes to an average of 17 minutes. Additionally, an experiential learning workbook with 16 lessons (two lessons for each film dealing with the values of the film) was developed to compliment the film viewing. Grade 10 learners completed the first four modules which included: perseverance, acceptance, honesty and forgiveness. Eleventh grader learners completed a curriculum for the values: self control, compassion, responsibility, and second chances.

Planning included using Life Orientation materials in every school in every province in South Africa (about 7,000 schools) beginning January, 2008. To this end, 30,000 sets of Heartlines materials were duplicated and distributed in all nine provinces to district officials, whose job it was to distribute it to the schools in their districts. Additional training was supplied on demand. Some of the schools began to use this material in January, 2008. However, many schools in various provinces held back the material until they could receive

training on the use of them and plan to use the curriculum and films in 2009.

This research is a part of invited work conducted for Heartlines as a third-party, independent evaluation of the Life Orientation curriculum incorporated in the public schools in South Africa. Formative research was conducted through Soul City and Heartlines before the initiation of this project (Goldstein et al., 2005; Pauquet, 2006; Scheepers & Goldstein, 2007; Schierhout et al., 2007).

Findings suggest that risky behaviors impacting health, including the contraction of HIV and AIDS, may be imbedded in current youth cultural values and contradict more traditional values espoused by South Africans. Given current rates of HIV and AIDS for teens and young adults, as well as the cultural norms regarding sexual activity (Cooper et al., 2007; Hargreaves, Morison et al., 2008; Oyediji & Cassimjee, 2006; Zambuko & Mturi, 2005), young people aged 15 to 25 are at high risk for contracting HIV and AIDS. Because South Africa is interested in changing attitudes and providing knowledge and skills, research evaluating the impact of core cultural values is imperative for creating sustainable change.

Theoretical framework

There have been a multitude of research studies and interventions attempting to reduce HIV and AIDS rates in South Africa. The majority of published studies include the promotion and/or evaluation of condom usage (Cleland & Ali, 2006; Dinkelman, Lam, & Leibbrandt, 2007; James, Reddy, Ruiters, McCauley, & van den Borne, 2006; I. Katz, 2006; Mantell et al., 2006). There has been limited research, however, on the impact of entertainment education (EE) and other forms of communication on the relationship between perceived risk and actual risk behaviors in Sub-Saharan Africa (Anderson, Beutel, & Maughan-Brown, 2007). To date, no research has attempted to measure the impact of teen values on behavior in schools nationwide.

This research incorporates elements from two distinct behavioral theories including the Health Belief Model (Rosenstock, Strecher, & Becker, 1988), and Social Learning Theory (Bandura, 1969). The films incorporated in this research intervention were produced within the context of an EE communication strategy and guided by social learning theory (SLT) and the health belief model (HBM). Public health professionals and communication experts have utilized a number of

theoretical frameworks to support behavioral change efforts health behaviors include the individual level as seen in the Health Belief Model (Cummings, Jette, & Rosenstock, 1978; Rosenstock et al., 1988), at the community level (Pentz, Dwyer et al., 1989; Pentz, Johnson et al., 1989), at the population level (Hornik, 2004; Hornik & Kelly, 2007) and a combination of levels as utilized by the Social-ecological Model which integrated micro and macro levels as influences on behavior (Bronfenbrenner, 1979).

Numerous experts have debated the effects of public health communication upon health behavior. There have been several major controlled evaluations of programs (Southwell, Barmada, Hornik, & Maklan, 2002). Some examples of vague or no evidence of effects have been demonstrated through public health research (Farquhar et al., 1990; Jenks & Anderson, 1995; Luepker et al., 1994; Winkleby, Taylor, Jatulis, & Fortmann, 1996). However, other studies, including interventions targeted at youth with HIV and AIDS (Flicker et al., 2004; So, Wong, & DeLeon, 2005), have shown that behavior changes are associated with health communication in programs studied and through media coverage.

This study was designed and developed using the entertainment-education (EE) strategy for mass communication. EE is "used to disseminate ideas to bring about behavioral and social change" (Singhal & Rogers, 2002, p. 24). Social change is defined as the process in which an alteration occurs in the structure and function of a social system (Singhal & Rogers, 1999). Social change can happen at the level of an individual, a community, an organization, or a society. EE by itself sometimes brings about social change and, under certain conditions in combination with other influences, EE can create a climate for social change (Singhal & Obregon, 1999). Most predominantly, EE has been used to increase awareness of health values, including HIV and AIDS awareness and knowledge (Do & Kincaid, 2006), empowering women for sexual and reproductive health and rights (Pillsbury & Mayer, 2005), and to measure the effect of media in health education (Farr, Witte, Jarato, & Menard, 2005; Keating, Meekers, & Adewuyi, 2006).

Health Belief Model

The Health Belief Model was constructed by Rosenstock (1966), and included four constructs: (1) perceived susceptibility (which assesses an individual's acquiring the condition), (2) perceived severity, perceived

(3) barriers and perceived benefits, and (4) cues to action (also described within the context of this theory as potential external influences which promote the desired behavior). Social learning theory (a.k.a. Social Modeling Theory) emphasizes the importance of observing and modeling the behaviors, attitudes, and emotional reactions of others (Bandura, 1969). In his seminal book, *Self-Efficacy: The Essence of Control*, Albert Bandura introduced the concept of self-efficacy for cognitive behavior modification (1977). Bandura (1977, p. 22) stated:

Learning would be exceedingly laborious, not to mention hazardous, if people had to rely solely on the effects of their own actions to inform them what to do. Fortunately, most human behavior is learned observationally through modeling: from observing others. One forms an idea of how new behaviors are performed, and on later occasions this coded information serves as a guide for action.

Study Purpose

This study seeks to increase knowledge of the effectiveness of the values-based EE communication strategy within an educational system. There remains a gap in the literature regarding the impact of value-based campaign messages upon behavior change with youth. This exploratory research evaluated the pilot study intervention to research knowledge, attitudes, beliefs, and intended behaviors of learners age 15 to 17. The following research questions guided this study.

RQ1: What was the profile of the students participating in the study with respect to age, gender, living circumstances, and other key characteristics?

RQ2: What was the awareness level of the Heartlines campaign and are there any gender differences?

RQ3: Was the intervention effective in achieving its aim of increasing dialogue about values including perseverance, acceptance, honesty, and forgiveness for 10th grade learners and self-control, compassion, responsibility, and second chances for 11th grade learners in South Africa? If so, what kind of dialogue was achieved?

RQ4: Does viewing the films and curriculum increase awareness and knowledge about values including perseverance, acceptance, honesty, and forgiveness for 10th grade learners and self-control, compassion, responsibility, and second chances for 11th grade learners in South Africa.

RQ5: Was the Life Orientation curriculum effective in assessing self efficacy for the Learning Objectives included in the four modules for 10th & 11th grade learners that were promoted by the curriculum?

RQ6: Is there evidence of the 10th and 11th grade learners' intentions to adopt the values promoted by the curriculum?

METHODS

Participants

The Heartlines staff selected the schools based on geographic convenience and the school administration's willingness to participate in the study. The researcher requested that a variety of schools within the Johannesburg area be represented as a part of the sample for convenience purposes.

Locations

The sampling procedures attempted to show representation of the overall educational population for the same grade range in the Gauteng Province (Education Statistics in South Africa 2006, 2008; Hart, Chaparro, & Halcomb, 2008). The Heartlines team identified a convenience sample of 11 public schools in the Gauteng province of South Africa which confirmed their willingness to participate in the curriculum for January 2008.

Study Design

The research was an independent, external evaluation of the Values for Life curriculum for the Life Orientation course. The study includes data from pre- and post-test surveys. Quantitative methods are utilized to provide observations to inquiries predominantly through numerical terms and scaled responses. The data provided is used to explain communication behavior "by looking at processes that allow researchers to predict future behavior, frequently using models of

causal processes" (Reinard, 2001). Baseline surveys provided a measurement of relevant items to establish a reference point against which future research findings could be compared.

Procedures of survey development

A survey was constructed for grade 10 learners to assess the values associated with the films used for the curriculum including perseverance, acceptance, honesty, and forgiveness. There were 53 questions for the pre-test survey and 67 questions on the post-test survey. A second survey was constructed for grade 11 learners to assess the values utilized for their Life Orientation curriculum, values which included self control, compassion, responsibility, and second chances. There were 50 questions for the pre-test survey and 58 questions on the post-test survey.

Questions were related to four main contextual areas that are of particular importance to the Heartlines intervention team as they are comparative to the year-one Heartlines evaluation. However, some of the questions were amended for the youth population. These include: (a) the levels and patterns of media use, (b) religious affiliation and church participation, (c) and affective responses to religion, and (d) the extent to which respondents are affected by HIV and AIDS. Both pre-test survey instruments included demographic questions to capture the sex/gender, race, age, school attending, language used in the household, and religious denomination. In general, the variables were used for stratification purposes. The categories used for the variable "language most spoken in the home," were taken from the Heartlines year-one evaluation survey. The response choices included isiZulu, IsiXhosa, isiNdebele, isiSwati, English, Afrikaans, Sesotho sa borwa, Sepedi, Setswana, Tshivenda, Xitsonga, and Other. The race question responses include Black, Coloured, Indian, White, and Other.

The pre-test survey instrument captured the media usage by measuring recall of usage by asking one open-ended question, "How many hours a week do you do each of the following?" Six questions targeting faith-based or religious responses employed a five-point Likert-type scale. Response choices ranged from "1 = strongly agree" to "5 = strongly disagree". Both surveys included three questions related to knowing someone with AIDS, such as, "Do you know a child whose parents have died of an AIDS-related disease?"

The pre-test survey included questions assessing knowledge, beliefs, intentions, and self-efficacy for each of the Values for Life module

topics. There was one question for each value. The question stated, "In the past two weeks how many people, if any, have you spoken to about the importance of always doing <insert value>?" Respondents chose from five responses including zero, one or two, three to five, six to ten, or more than ten.

There were three phases to the study which included the following: (1) the pre-test survey (a baseline measure of pre-intervention responses), (2) the intervention (an eight-week curriculum administered during the Life Orientation class period), and (3) the post-test survey (designated for the session following the completion of the curriculum intervention).

The survey was administered by teachers prior to the start of the Life Orientation curriculum as a baseline of the curriculum and repeated immediately after the course sessions were completed. Surveys were distributed so that no data could be associated with a single participant response. Pre- and post-test surveys were administered to the same class session (i.e. 4th period, Wednesday class) and recorded by the school.

Prior to the collection of any surveys, an oral statement was read to learners to provide information regarding informed consent. All participant questions were answered. Any individual who, after hearing the informed consent/assent, elected not to participate in the study could stop taking the survey. No incentive to participate was offered. To ensure anonymity, participants placed completed surveys into a designated box located in the classroom, and school-appointed administrators or classroom instructor collected surveys for the Heartlines staff. The post-test surveys did not include demographic questions. Both (grade 10 and grade 11) post-test survey instruments included two questions to capture recall. The first question queried whether students took the pre-test survey and the second question asked them to choose their favorite film shown as a part of the curriculum. Nine questions were created to assess the Learning objectives for the Life Orientation curriculum as described in the Heartlines Educator's Guide. The AIDS questions and the media usage questions were not included for the post-test survey.

Statistical Analysis

Data was analysed at group level only. The data set was cleaned and analysed using SPSS 15.0 for Windows (Chicago). To describe the

participant population and outcomes, descriptive frequencies for each categorical variable were run, as well as the measures of central tendency for continuous variables. The effect of the EE intervention on participant outcomes (e.g., changes in knowledge, attitudes, beliefs, intentions and behaviors) were assessed using student's t test for independent samples (pre/post). To reduce the potential for Type I error, alpha was set at 0.05. The data was screened for missing data, outliers, normality, linearity, and homoscedasticity using methods and rules as described by Tabachnick and Fidell (2001). Following Tabachnick and Fidell's established criteria (2001), if more than 5 per cent of the data were missing from a participant's survey, the survey was removed from the data set. Therefore, reported totals for each data set were lower (20 per cent of cases removed).

RESULTS

Grade 10 participant demographics

After cleaning and screening the data, the grade 10 sample consisted of 742 participants. Nine schools were represented in the sample. Gender representation was 54 per cent (391/729) males and 46 per cent (338/729) females. The age in years of participants ranged from 13 to 19. However, the majority of the participants (72 per cent) were 15 or 16 years of age. Approximately 54 per cent percent of the participants were Black, and the remaining participants were Indian (16 per cent), White (23 per cent), and Other (6 per cent). The majority of participants reported speaking English (31 per cent) and isiZulu (23 per cent) language in the household, followed by Afrikaans (12 per cent), Multiple (8 per cent), Sesotho sa borwa (7 per cent), Sepedi (5 per cent), Other (5 per cent), isiXhosa (4.1 per cent), and Setswana (3 per cent). The Other category included isiNdebele, isiSwati, Tshivenda, and Xitsonga.

Grade 11 participant demographics

After cleaning and screening the data, the grade 11 sample consisted of 595 participants. Seven schools were represented in the sample. Gender representation was 56 per cent (330/595) males and 44 per cent (258/595) females. The age in years of participants ranged from 14 to 20. However, the majority of the participants (81.9 per cent) were 16 to 18 years of age. Approximately 60 per cent of the participants were Black, and the remaining participants were Indian (14 per cent), White (20 per cent), and Other (5 per cent). The majority of participants

reported speaking English and isiZulu language (25 per cent respectively) in the household, followed by Afrikaans (17 per cent), Sesotho sa borwa (9 per cent), isiXhosa (8 per cent), Sepedi (6 per cent), Setswana (4 per cent), Other (4 per cent), and Multiple (3 per cent). The Other category included isiNdebele, isiSwati, Tshivenda, and Xitsonga.

Frequencies and percentages associated with the religious affiliations were also collected. The majority of grade 10 (80 per cent) and 11 (87 per cent) learners reported belonging to a religious group. The most frequently occurring religious denomination was Christian for both grade 10 (41 per cent) and grade 11 (40 per cent). The Christian category was comprised of Roman Catholic, Protestant, and Christian responses. Finally, participants for grade 10 and 11 were asked three questions regarding relationships with people who died from or had HIV and AIDS to determine the relevance of HIV and AIDS issues in their personal lives.

Campaign Recall

Learners were asked if they had previously heard of Heartlines and if they had ever seen the Heartlines film, *The Bet*. More than half of the respondents were aware of the Heartlines campaign for both grade 10 and grade 11 learners equaling 64 per cent and 71 per cent respectively. Recall of the most popular Heartlines movie, *The Bet*, which premiered on network television stations in 2006 and was re-issued in October 2007, was lower than overall campaign recall. Less than half of grade 10 (35 per cent) and grade 11 (43 per cent) participants reported having seen *The Bet* film. A Chi Square test of independence was conducted to evaluate whether there was a significant difference in awareness of the Heartlines campaign by gender for grade 10 learners. The two variables were gender and whether the student had ever heard of Heartlines. Males responding "yes" (59 per cent) were found to be significantly higher than females (41 per cent) responding "yes," Pearson $\chi^2(2, N=727) = 13.35, p < .001, \text{Cramer's } V = .13$.

A Chi Square test of independence analysis was also conducted to evaluate whether there was a significant difference in awareness of the Heartlines campaign by gender for grade 11 learners. Males responding "yes" (60 per cent) was found to be significantly higher than females (40 per cent), Pearson $\chi^2(2, N=582) = 6.67, p < .05, \text{Cramer's } V = .11$.

Increase Dialogue

An independent-samples *t* test was conducted for each dialogue question (higher frequency of discussion with other people). Two open-ended questions were included on grade 10 pre- and post-test surveys assessing learners' dialogue. The first question stated, "In the past two weeks how many people, if any, have you spoken with about not giving up/persevering?" Pre-test survey responses (N=742) ranged from 0 to 100 with a mean of 1.68 (SD = 5.33). Post-test survey responses (N=628) ranged from 0 to 200 with a mean of 2.33 (SD = 9.67). The second question asked, "In the past two weeks how many people, if any, have you spoken to about the importance of always doing the right thing." Pre-test survey responses (N=742) ranged from 0 to 300 with a mean of 2.77 (SD = 12.32). Post-test survey responses (N=628) ranged from 0 to 100 with a mean of 2.12 (SD = 5.33). There were no significant changes for any of the questions related to dialogue. The test was non-significant $t(1368) = -1.57, p = .12$ and $t(1368) = -1.23, p = .22$ respectively.

Three independent-samples *t* tests were conducted for the open-ended questions on grade 11 pre- and post-test surveys assessing learners' dialogue. The first question asked, "In the past two weeks how many people, if any, have you talked to about compassion?" Pre-test survey responses (N=587) ranged from 0 to 30 with a mean of 1.47 (SD = 2.64). Post-test survey responses (N=341) ranged from 0 to 34 with a mean of 1.88 (SD = 3.19). The second question posed, "In the past two weeks how many people, if any, have you talked to about being responsible?" Pre-test survey responses (N=580) ranged from 0 to 20 with a mean of 2.29 (SD = 3.07). Post-test survey responses (N=339) ranged from 0 to 23 with a mean of 2.26 (SD = 2.69). The third dialogue question asked, "In the past two weeks how many people, if any, have you talked to about getting/giving a second chance?" Pre-test survey responses (N=581) ranged from 0 to 40 with a mean of 1.68 (SD = 2.90). Post-test survey responses (N=341) ranged from 0 to 17 with a mean of 1.55 (SD = 2.14).

Again, an independent-samples *t* test was conducted to evaluate the hypothesis that students increased dialogue from pre-intervention to post-intervention for each of the corresponding questions. The hypothesis was only supported for one of three grade 11 dialogue questions. The test was significant $t(926) = -2.13, p = .03$ for Question 1 (compassion). However, the test was non-significant for questions 2 and 3 ($t(917) = -.94, p = .35$ and $t(920) = .73, p = .47$) respectively. The

95 per cent confidence interval for the difference in means ranged from -.79177 to -.03175. The mean difference was -.41.

Curriculum Evaluation

Twenty-five items were posed on the pre- and post-test surveys for grade 10 and grade 11 to assess the values promoted through the Values for Life curriculum. Several independent samples t-tests were conducted to measure the change from pre-test to post-test responses on 21 items from the grade 10 surveys. Direction was set for each question and 13 items were reverse coded. Fourteen of the 21 items had a significant change ($p < .05$). Nine items were significant in a favorable direction as shown in Table 1.

Table 1: Grade 10 Pre and Post Survey Independent Sample t-test Results

Pre Survey Item #	Question	Pre \bar{X}	Post \bar{X}	t	df	p
Q4(R)	I feel like quitting school.	4.31	4.11	3.34	1361	.001
Q5(R)	I am powerless to change my current circumstances, but I keep going anyway.	3.08	2.67	6.44	1349	.000
Q07	My spiritual beliefs help me continue through bad times.	3.85	4.11	-4.3	1365	.000
Q13(R)	It is a waste of money to educate someone who is HIV positive	4.44	4.30	2.42	1357	.016
Q16(R)	I admire power more than I admire honesty	3.48	3.33	2.43	1364	.015
Q22	I have been tempted to be dishonest, but have decided to be honest instead.	3.70	3.83	-2.38	1363	.018
Q23(R)	I have lied to get myself or someone else out of trouble	2.55	2.27	3.86	1361	.000
Q26(R)	If someone betrayed my trust, I would not trust him or her again.	2.45	3.49	-16.47	1362	.000
Q27(R)	It is okay to get back at someone when he/she deceives me.	3.18	2.96	3.36	1364	.001

Several independent samples t-test were also conducted to measure the change from pre-test to post-test responses on 19 items from the grade 11 surveys. Direction was set for each question and 6 items were reversed coded. Nine of the 19 items had a significant change ($p < .05$) in a favorable direction as shown in Table 2.

Table 2: Grade 11 Pre and Post Survey Independent Sample t-test Results

Pre Survey Item #	Question	Pre \bar{X}	Post \bar{X}	t	df	p
Q04(R)	I sometimes act before I think.	2.62	3.45	-11.07	963	.000
Q06(R)	When you learn that you have HIV, your life is over	4.24	1.66	36.22	954	.000
Q13(R)	It is ok for people to worry about themselves and not others	3.91	2.11	24.12	963	.000
Q14(R)	People who show empathy for others are weak.	3.96	1.47	34.68	953	.000
Q19	I help cook or clean	4.22	4.36	-2.32	963	.020
Q21	I have found a job or went to work to help out the family	2.92	3.10	-2.45	962	.014
Q24(R)	If a person is kicked out of school, he/she deserves to fall behind in studies.	3.68	2.30	16.62	964	.000
Q25	People in prison ought to have another chance to work when they get out.	3.44	3.80	-4.60	964	.000
Q26(R)	If my friend betrays me the friendship is over forever.	3.48	2.50	12.38	962	.000
Q27	Everyone makes mistakes in life that they have to overcome.	4.53	4.51	.27	955	ns

Learning Objectives

Table 3 (below) shows the percentages, mode and standard deviations for grade 10 and 11 responses to questions related to the learning objectives for the class. Mode for both grades ranged from 2.00 to 1.00. Positive group frequencies were calculated including mean scores from "Strongly Agree = 1" and "Agree = 2" responses. All responses for the 11 items for grade 10 and grade 11 intervention groups included a positive group frequency above 50 per cent.

Table 3: Grade 10(N=625) and 11 (N=341) Learning Objectives Frequencies

Survey Question	Grade	Strongly Agree (%)	Agree (%)	Neutral (%)	Disagree (%)	Strongly Disagree (%)	Positive Group %	Mode	SD
I am more confident to face my fears	10	31.3	41.4	21.4	3.8	1.9	72.7	2.00	.92
	11	28.8	46.2	21.2	2.1	1.8	75.0	2.00	.86
I am better at considering consequences to my choices	10	28.9	52.8	15.6	1.4	1.3	81.7	2.00	.78
	11	35.1	52.5	9.1	2.4	.9	87.6	2.00	.76
I often give others second chances	10	35.5	41.6	15.8	4.2	2.9	77.1	2.00	.97
	11	35.4	36.9	21.5	4.1	2.1	72.3	2.00	.96
I am better able to continue achieving my goals even through difficulties	10	40.4	41.2	15.3	4.2	2.9	81.5	2.00	.85
	11	36.2	45.3	16.2	2.1	.3	81.5	2.00	.78
I am better able to appreciate how values affect my world through acceptance of people different from me	10	40.4	41.2	15.3	1.8	1.4	73.4	2.00	.90
	11	24.3	44.1	24.9	4.7	2.1	68.3	2.00	.92
I am better able to act honestly to affect the world around me	10	31.4	42.0	21.7	3.1	1.8	77.8	2.00	.86
	11	31.5	43.8	20.9	3.2	.6	75.3	2.00	.84
I am better able to appreciate how my decisions to forgive others affects me and my world	10	28.6	49.3	16.9	3.9	1.4	71.0	2.00	1.00
	11	30.4	37.8	22.7	4.7	4.4	68.1	2.00	1.05
I am better able to attempt to increase the quantity of kindness and humanity in my world	10	31.6	39.5	20.1	5.8	3.1	81.6	2.00	.88
	11	49.9	38.1	8.6	2.4	1.2	87.9	1.00	.82
I have demonstrated self-knowledge and the ability to make informed decisions regarding further study, career fields, and career pathing	10	39.8	41.8	14.5	1.8	2.1	83.5	1.00	.90
	11	50.1	34.9	10.9	2.6	1.2	85.0	1.00	.99

Intent to Change

Participant intentions toward improved behaviors were measured through one qualitative question on the post-test survey instruments. The question, "Since the beginning of this class (Values for Life), what have you done differently to live out your values?" Two-hundred and sixty-eight responses were recorded from the grade 10 intervention group. The selection criterion for review of participant comments was decided during the review process and emergent coding procedures were established (Haney, Russell, Gulek, & Fierros, 1998). Two independent coders reviewed comments for the question responses.

The initial screen excluded missing comments and comments not relevant to the research questions. More than one coded term could be counted for each response. Researchers compared notes and reconciled any differences found during the initial coding checklist. The second screen determined the message content (changes attributed to the intervention) and information included in the comment which would be included in the systematic selection. Researchers used a consolidated checklist to independently apply coding for the second screen. Inter-rater reliability was .84 for grade 10 responses and .92 for grade 11.

Responses included some description of an intent for behavior change (26 per cent), honesty (20 per cent), forgiveness (16 per cent), respect (13 per cent), and acceptance (12 per cent). Additional terms were included in the content analysis were distributed below twelve percent (12 per cent) (i.e. faith, self control, responsibility, etc.).

Examples of grade 10 participant responses include the following:

- Since the film started I started to accept people and to forgive people and also to persevere and to be honest to everyone who talks to me and I learn that you must persevere if you want to reach your goals.
- I have learned that in life I must accept what I have and I have accepted what I am. I have learned that forgiveness is the key to survive or go on with your life and after doing this I did feel free because the burden I had in me has been lowered. I can continue to live my life with the person I forgave.

Two hundred and seventy-five (n= 275) responses were recorded from the grade 11 intervention group for the final question. Identical coding procedures used for grade 10 responses were applied. The term

used most frequently was compassion (20 per cent), followed by responsibility (17 per cent), self confidence (16 per cent), and values (16 per cent), intent for behavior change (13 per cent) and goal setting (12 per cent). Additional terms were included in the content analysis and were distributed below twelve percent (12 per cent) (i.e. respect, self control, acceptance, etc.).

Examples of grade 11 responses coded in the content analysis follow:

- I have started to value things that I have never valued, and I have learnt how to treat people who have HIV/AIDS. I have learnt to respect other people's values and responsibilities.
- I learned that you have to stay focused in your life and have self control .You have to have confidence to face your fears if want your future.
- In *The Bet* I learned that you should never try to hide who you are and let no one make you feel inferior, in spite of what people think and believe. I also learned that you should never let friends pressure you.
- I have been kind and paid more attention to other people's feelings and paid more attention to *ubuntu*.

LIMITATIONS

As the presentation below of the results of this evaluation indicate, there is evidence of positive effects of the Heartlines communication campaign both in its general educational objectives as well as the specific values promoted. However, before discussing the many positive aspects of the campaign revealed in this study, one must take into account limitations of this evaluation. The research was exploratory and did not include control group data.

The intervention was relatively short (eight weeks) and no follow up (i.e. three, six, twelve or eighteen month) post surveys were administered. Only teachers received printed materials. The Educator's Guide included assignment descriptions which could be written on a chalkboard for the students to copy into their class notebook. Some of the learners or instructors could have mistranslated the assignment, decided not to copy the information, or misunderstood the assignment

due to lack of copied material. All data responses were self reports. Social desirability for self report data is a concern for researchers (Piedmont, McCrae, Riemann, & Angleitner, 2000).

This study included an evaluation of data from a limited geographic location. The sample was collected from a convenience group of schools and results are only generalizable to the urban population of South Africa. As indicated by the post-test survey responses, grade 10 and grade 11 learners indicated strong self-efficacy (above 50 per cent) on all of the learning objectives included in the curriculum as presented in the instructors training guide. However, it should be mentioned that no pre-test assessment of the learning objectives was conducted. Therefore, there was no comparison analysis conducted to assess change related to the curriculum. The high responses could be attributed to social desirability and the learner's desire to please the instructors or Heartlines staff. Also, learners might overestimate their knowledge of the course curriculum (Kruger & Dunning, 1999).

There are several cultural considerations. Some of the limitations are specific to this particular study; others are cultural conditions which have to be acknowledged for behavioral studies in general. The researcher for this study was an American. Although a translator and guide were provided for the researcher, the contextual understanding was difficult. Unspoken nuances, idioms, the numerous (eleven) languages spoken, or the mere presence of an American during the training and pre-survey administration could have affected the interpretation and outcomes of the data.

During the pre-survey administration, there was a national power crisis. This affected work, transportation, etc. due to "load shedding" – where the power service discontinues electrical power in two hour time blocks for various sections throughout the day (Bearak & Dugger, 2008). Although a scheduled load shedding area was announced through the media and posted on the Internet, some days the schedule was not accurate. Additionally, during the time of the administration and collection of the post surveys, the culture and daily lives of the Johannesburg community was affected by xenophobic violence (Bloch, 2006; Handmaker & Parsley, 2002; Harris, 2001).

DISCUSSION

The sample size was appropriate for an exploratory study and demonstrated, through demographic responses, the data captured an adequate representative sample. Awareness of the Heartlines campaign

was high, particularly for males, and shows promise for the campaign creators. However, the number of students who had actually watched all of the films when they were shown on television (not as a part of the intervention in the school setting) was lower. This could be for a number of reasons: they do not own a television set, the time-slots were not convenient for them, or they do not have control over what is watched in the household. Therefore, the film and curriculum intervention proved a novel method for ensuring that the Heartlines values messages reach a broader population.

Overall, students reacted positively to the films during viewing and throughout the conclusion. The films and educational materials supported increased dialogue with family and friends regarding the values described. The results indicated the use of film as an EE platform to enhance learning and curriculum objectives works to communicate values to young people. Targeting a specific population group with an EE film (as a part of the overall curriculum materials) can increase the adoption of beneficial health behaviors (Snyder et al., 2004).

Through the use of films supported by curriculum components, young people's awareness of positive health behaviors increased. If the intervention strategy uses clear, simple messages, with characters that the audience can relate to, EE can increase awareness of values (such as self control, responsibility, etc.) and teach people better behaviors which can affect health status (Kirby et al., 1999). The EE approach is unique in providing a method for affecting audiences. The results of this research are consistent with Bandura's (1986) social cognitive theory, which posits that individuals can learn by observing and imitating or modeling others in real life or drama (television). These results support the use of Social Learning Theory (Bandura, 1977) within an educational setting using films. By allowing students to observe others (film characters) model positive behaviors, they are exposed to new guides for action.

The findings indicate that the Values for Life films and curriculum are effective in promoting awareness, discussion, and increased self-efficacy for values such as responsibility, self-control, forgiveness, etc. in teens as part of a comprehensive campaign in South Africa. The results suggest that by focusing on the attitudes and beliefs of student, increasing knowledge and awareness of personal responsibility and other core values, and seating the messages in self-efficacy research may be better equipped to predict health behaviors. This confirms the

use of HBM (Rosenstock, Strecher, & Becker, 1988) as a part of similar interventions. These findings also confirm the early works of Sabido, Rogers, and Rokeach indicating the importance of value-based health communication intervention strategies (Rogers, 1992; Rogers, Singhal, & Thombre, 2004; Rogers et al., 1999; Rokeach, 1973).

The values communicated through the film's characters were supported by the learning objectives in the assessment standards within the curriculum. As demonstrated in the results for the content analysis, learners in both grades provided evidence of recall of the terms and values promoted by utilizing them in their responses. More than half of the participants for both grades chose to write in a short answer for what they had done differently to live out their values since taking the 8-week class. The student responses indicated strong evidence of an intention to adopt the values promoted by the films. Students overtly communicated current changes in their behaviors or intent for behavior change based upon the values discussed. Therefore, this research indicates that, through the intervention, knowledge and awareness increased as did the student's intention to work toward changes in their behavior.

Finally, this study suggests that teens are interested in participating in learning environments which include entertainment (i.e. films). Through the engagement with the learners, the values-based approach was successful in increasing knowledge and awareness of the importance of behavioral change.

Directions for future research

This study presents many possibilities for future research. Because of the school locations chosen as a convenience sample, there is a need to include rural schools in future studies. Future studies could include an increased sample size by various demographics (i.e. ethnicity, language spoke in home, age, etc.) to further explore the role of these demographics in response to the films. Additional studies could include a broader age and grade level of students, for instance capturing learners age 12 to 18. Also, the same intervention should be tested among private school learners. The intervention could be presented and evaluated among students outside of South Africa to examine its level of effectiveness in other countries with similar cultural and demographic characteristics who are affected by the HIV and AIDS pandemic.

Future studies should also take into consideration various external variables which affect the social context of the intervention (i.e. social norms, economic factors, HIV and AIDS infection rates, etc.). These factors affect teen lives and may indicate which effects could be attributed to the intervention curriculum and which are related to broader socio-cultural factors. Future research should also include any of a variety of qualitative studies. Analysis of the intervention through in-depth interviews, focus groups, visual ethnography coupled with field observations could enrich future evaluations of this intervention. Additionally, future research could extend the understanding of Identification and Para-social Interaction between students by age and gender for specific film characters.

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