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HIV/AIDS Information Seeking and Healthcare Communications in Sub-Saharan Africa

Kendra Albright, Ph.D.

University of Sheffield, Department of Information Studies, Regent Court, 211 Portobello Street, Sheffield S1 4DP, UK.

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ABSTRACT

Sub-Saharan Africa is the hardest hit region in the world where AIDS threatens to decimate entire populations. Although the region has 10% of the world's population, it accounts for 63% of people living with HIV/AIDS. Of the estimated 2.1 million AIDS-related deaths in 2006, 72% of them were in Africa (UNAIDS/WHO, 2006). Although the epidemic has stabilized in the region, this means that the numbers of people who are newly affected with HIV are still roughly equivalent to the number of people who are dying from AIDS.

Twenty-five years into the epidemic, there is still no cure for AIDS. Information remains our most crucial weapon in the war against the AIDS virus. But is the provision of information successful in combating this terrible disease? The results are mixed. There have been some successes, most notably in Uganda, where the prevalence of HIV/AIDS has dropped from estimates as high as 30% in some areas to as low as 5%. While a few other countries show some small gain in the fight against the disease, most continue to report increasing rates of new infections and deaths, despite the targeted efforts of information and communication campaigns.

This paper provides an overview of the status of HIV/AIDS in Sub-Saharan Africa. Health Behaviour Theories (HBTs) are examined and compared with information-seeking behaviour theories. The potential benefits and limitations of information and communications are examined in the fight against AIDS, focusing on the specific complexities of Sub-Saharan Africa. Considerations are proposed for HIV/AIDS information and communication campaigns in the region.

INTRODUCTION: SUB-SAHARAN AFRICA AND AIDS

Africa is the world's second largest continent, encompassing about 22% of the total land area in the world, nearly 12 million square miles (Figure 1). The Sub-Saharan region covers the entire continent with the exception of the northernmost countries of Algeria, Egypt, Libya, Morocco, Tunisia, Western Sahara and, arguably, Mauritania

(The Canadian International Development Agency). Sub-Saharan Africa is faced with numerous challenges and is characterized by high population growth, an increasing HIV/AIDS health crisis, limited financial resources, negative growth in agricultural and economic output, drought and political instability.



Figure 1. Sub-Saharan Africa (Source: The Canadian International Development Agency)

Sub-Saharan Africa has significantly greater prevalence of People Living with HIV/AIDS (PLWHA) than anywhere else in the world (UNAIDS, 2006). Although it accounts for only 10% of the world's population, it has 63% of the PLWHA (Figure 2). Seventy-two percent of the estimated 2.1 million AIDS-related deaths in 2006 were in Sub-Saharan Africa (UNAIDS/WHO, 2006). Of the 380,000 children who died in 2006 of AIDS, 87% (330,000) were in Sub-Saharan Africa. Although the epidemic has stabilized in the region, this means that the numbers of people who are newly affected with HIV are still roughly equivalent to the number of people who are dying from AIDS.

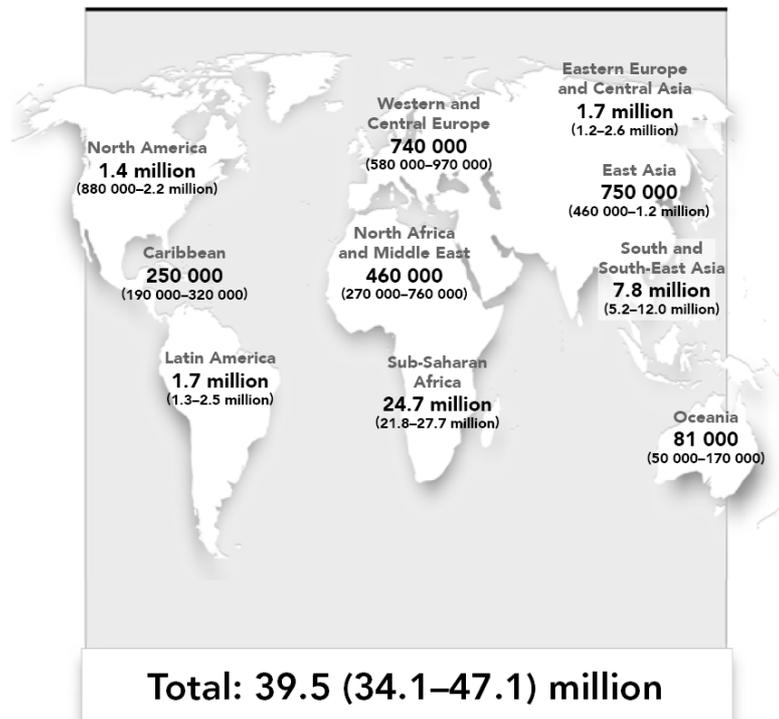


Figure 2. Adults and Children Estimated to be Living with HIV/AIDS (Source: UNAIDS/WHO, 2006)

There are regional variations of AIDS patterns within Sub-Saharan Africa. AIDS can be considered as multiple, regional epidemics (UNAIDS, 2004b). In East Africa, Uganda has had the greatest gradual decline in prevalence rates, combating the problem through information and communication campaigns aimed at prevention. Infection rates for HIV/AIDS in Uganda have dropped from estimates of 18.5% in 1995 (Uganda AIDS Commission Secretariat, 2001) to 6.7% in 2005 (UNAIDS, 2006). These declines, however, may be deceiving; they may be the result of mortality statistics rather than a real drop in incidence. UNAIDS (2004b) suggest, “Adult HIV prevalence has been roughly stable in recent years. But stabilization does not necessarily mean the epidemic is slowing. On the contrary, it can disguise the worst phases of an epidemic when roughly equally large numbers of people are being newly infected with HIV and are dying of AIDS.”

Statistics about HIV/AIDS prevalence often come from prevalence statistics among pregnant women in urban antenatal clinics as representative of the entire population. The same pattern of gradual decline is seen in other East African countries as well as Uganda. Despite the decline, however, HIV/AIDS remains a serious epidemic with the numbers of deaths from AIDS rising dramatically each year.

In West and Central Africa, prevalence rates appear to have changed very little, stabilizing around 5% or below with the exception of Cameroon and Cote d’Ivoire whose rates are upwards of 10% among pregnant women at the antenatal sites. This is similar to the rates found in most countries of Southern Africa, with the exception of Angola, where the rate remains steady at around 5% (UNAIDS, 2004a).

Women are disproportionately affected by HIV, accounting for more than half of the people living with HIV/AIDS in Sub-Saharan Africa (UNAIDS, 2004c). In most Sub-Saharan countries, the age of sexual debut for women is earlier than for men

(Green, 2003). This suggests that women are likely to be infected at earlier ages and more frequently than men, particularly among those aged 15-24 years (UNAIDS, 2004c).

HEALTH INFORMATION AND COMMUNICATION

Because there is no vaccine or cure for HIV or AIDS, information is crucial for preventing the spread of the virus. Through widespread information about HIV/AIDS, the people of Sub-Saharan Africa can gain the knowledge needed to change their behavioural response to the AIDS epidemic.

The study of the relationship between information and behaviour change is complex and is of concern to many disciplines, notably Information Science and Communications (Dervin, 2005). Information Science is concerned with studying the phenomena of information, including the behaviours of people who seek and use information. These studies provide an understanding of the process that people use to locate information that is relevant to their information need. Communications is concerned with the transmission of information, particularly in educational campaigns. In combination, they offer a powerful complement to our understanding of the ways in which information can affect behaviour change as well as its limitations. Information Science and Communications, however, are two separate disciplines and have only recently begun to work together in approaching the role of information in behaviour change.

Information science investigates the relationship between users and information in terms of information behaviour and information seeking behaviour. Wilson (2000) defines the two terms:

Information Behavior is the totality of human behavior in relation to sources and channels of information, including both active and passive information seeking, and information use. Thus, it includes face-to-face communication with others, as well as the passive reception of information as in, for example, watching TV advertisements, without any intention to act on the information given.

Information Seeking Behaviour is the purposive seeking for information as a consequence of a need to satisfy some goal. In the course of seeking, the individual may interact with manual information systems (such as a newspaper or a library), or with computer-based systems (such as the World Wide Web) (49).

The field of Information Science spent many years focused on the role of systems in information behaviour (Wilson, 2000). It has broadened its research approaches over the last twenty years, moving from an *information-as-thing* perspective (Buckland, 1991), to the view that information as a theoretical object is at once both physical and cognitive (Raber, 2003). As we move towards a perspective that focuses increasingly on the user, questions are raised about the world of the user, the cognitive processes involved in information-seeking, and the processes the user goes through in order to find relevant information. Kuhlthau (1994), Ellis, Cox, et al. (1993), and Dervin

(1983), among many others, have contributed to our understanding of the characteristics of users and user behaviour. More recently, the work in LIS has moved to include issues of affect that also influence information behaviour (Nahl, 2005).

While information seeking research has focused on the characteristics of users, the impact of retrieved information has received a surprising lack of investigation. The problem is that research on information seeking behaviour is inadequate unless it takes into consideration the use of that information. Without understanding the effects of information on users and their behaviour, we have an incomplete picture of how information changes behaviour, which is of primary concern in healthcare information in general, and for HIV/AIDS specifically. The more we understand about the relationship between information and use, the more we can increase the likelihood of providing better information that is more carefully targeted to decrease the likelihood of spreading HIV/AIDS. Therefore, it is important to not only understand the specific characteristics of the user but also understand how it could possibly affect their behaviour. The answers to these questions will affect the way in which information is selected and presented and the possible affect it will have on users and their behaviour.

Information Science, however, can draw from a range of other disciplines and theories, most notably psychology and communications, in order to address these questions. By converging multidisciplinary theories it is possible to generate new ideas and theoretical collaborations that will illuminate our understanding of the relationship between health information and communications and behaviour change.

HEALTH BEHAVIOUR THEORIES

There are many health behaviour theories (HBTs) arising from the field of Communications that have been designed to investigate the relationship between health information/communication and behaviour change. Noar and Zimmerman (2005) reported the identification of over 2900 citations for HBTs, of which only 178 (6%) “unique citations contained two or more theories in the search record” (282). The implication is that many of the remaining articles reported single theories.

HBTs can be divided into categories including explanatory theories and change theories. Explanatory theories are those theories that address *why* a certain problem exists, and investigates the underlying variables that contribute to the problem (National Cancer Institute, 2005). Examples of explanatory behaviour change theories include the Health Belief Model, the Theory of Planned Behaviour, and the Precaution Adoption Process Model.

Change theories advance the development of health interventions by identifying important concepts that can be incorporated into information and communication messages and strategies (e.g., IEC). Change theories also provide a framework for evaluation of interventions. A benefit of change theories is that they inherently require an identification and analysis of assumptions prior to the design and implementation of any intervention programs. Diffusion of Innovations and Community Organization are two examples of change theories.

HBTs can also be grouped according to their characteristics. Message-based theories are those that investigate how individuals or audiences respond to messages. Fear based models, for example, are designed to elicit change through invoking fear responses. Belief-based theories are those that examine the sets of beliefs and perceptions of individuals about health. If an individual perceives that changing their behaviour will result in an improvement in health, then they are more likely to make that change. Intervention-based theories focus on behaviour change by way of prevention.

Because there is such a wide range of health communication theories, there is an equal variety of problems, cultures, and contexts that they target. Some centre on the individual as the program target, where others take a more holistic, social and cultural approach. Some of the theories can be utilized across cultures, but most have only been examined within a narrow context or culture (Airhihenbuwa and Obregon, 2000; Noar and Zimmerman, 2005). Researchers must take into consideration the characteristics of their target population including demographics as well as the specific social and cultural context, in order to advance our understanding. It may be necessary and/or desirable to utilize more than a single theory in order to account for the wide variations in target populations.

Critics of behaviour change models identify several problems with the models. First, we have not matched our research design to clearly investigate the theories and models that have been proposed (Noar, 2006). Second, the models do not take into adequate account the role of the cultural context within which studies are conducted, with cultural factors often cited as the overriding factor that is missing from many health promotion programmes (Airhihenbuwa and Obregon, 2000; Singhal and Rogers, 2003; Kalipeni et al., 2004). In Sub-Saharan Africa, for example, issues of power imbalances in sexual choices are overlooked and not addressed by such theories. Women are sometimes coerced into sexual situations through violence, fear, or economic necessity. To say that a woman *chooses* to engage in sexual activity with a partner may not reflect the entire scope of that decision. Related issues such as poverty, sexual inequality, and migration are related issues that must be addressed in order to examine behaviour change regarding HIV/AIDS information and communications in Sub-Saharan Africa. Behaviour change theories typically assume that decisions regarding sexual activity are based in rational thought. This assumption fails to realize and consider the complexities of sexual interactions and choices that are made by the partners involved. Third, behaviour change theories do not address the full scope of complexities involved in human behaviour and contribute to the limited effectiveness of information-based healthcare campaigns. Dervin (2005) suggests that healthcare campaigns “yield behaviour change rates of about 7% to 10%” (p. S75).

INADEQUACIES OF EXISTING APPROACHES

Despite the usefulness of behaviour change models and theories, information and communication campaigns that are designed to promote healthcare have not been adequately researched and evaluated for their effectiveness (Noar and Zimmerman, 2005). The sheer number of behaviour change theories reflects the need for consolidation and assessment to determine the degree of overlap and adequacy of

existing theories. The purpose of theory is to develop an existing framework that accounts for collective observations until new observations conflict with the framework, at which point, either new theories supplant the old theory or existing theory is modified. Such is not the case with behaviour change theories, thus limiting the advancement of the field (Noar and Zimmerman, 2005).

The effectiveness of behaviour change theories is also not clear because results are often interpreted within the framework of one of the dominant theories, forcing the results to fit the theory. Airhihenbuwa and Obregon (2000) suggest:

Stated differently, commonly used communication strategies often attempt to fit implementation processes into the rules of a dominant theory or model in social psychology rather than allowing the field experience to shape its own framework. Moreover, the role of cultural contexts in successful implementation of programs often is omitted, even though evidence abounds that culture is a central feature in health behaviors and decisions particularly in the context of behaviors that may predispose people to HIV/AIDS (6).

The role of culture in the information campaign is an important component of AIDS information campaigns. Many of the healthcare campaigns are designed within a given population and are not tested outside of that group. Further, Airhihenbuwa and Obregon (2000) claim that “classical” models of health communication are “based on social psychology that emphasizes individualism”(5). They are thus inadequate to address the specific needs of a more collective culture, such as those found in much of Sub-Saharan Africa. The needs of the individual (i.e., the *self*) are addressed by such approaches but with Sub-Saharan cultures the context within which the individual defines their health status, it is the “state of well-being of family and community that regulates how individuals measure their state of health” (Airhihenbuwa and Obregon, 2000, 9).

A mass media approach designed to change behaviour is inadequate to provide incentive for all members of society. Because of the range of individual information needs and the processes through which individuals *make sense* of their worlds and their realities, AIDS messages need to be targeted to smaller groups or individuals (Airhihenbuwa and Obregon, 2000). Information seeking behaviour contributes to our understanding of the ways in which individuals pursue their search for and understanding of information to solve their needs. It provides research on ways to remove or reduce barriers to needed information, whether it is through an improved design of information interfaces or through the availability of information in a wide range of formats that can be customized to meet the needs of either individuals or small groups.

Despite the problems that have been identified with behaviour change theories and models, they offer the best prevention for HIV/AIDS since there is no cure. Information campaigns based on behaviour change theories build on previous research and advance our understanding of the ways in which the information changes the individuals who are exposed to the prevention messages. This is a useful element that has been scant in Information Science research on users and information.

PREVENTION STRATEGY

The general approach that is taken for prevention campaigns is dependent upon a number of factors. First, the circumstances of the particular set of individuals or target audience must be clearly understood in order to design an information strategy. It is useful to consider investigating why people are not engaging in healthy behaviour. Another way of looking at this is to consider why they engage in risky behaviour. Asking individuals why they engage in risky behaviour can be accomplished through a needs analysis. This analysis will identify attitudes, norms beliefs, and perceptions regarding desirable behaviour (e.g., safe sex practices) and will help to shape the design of the implementation.

Second, once there is an understanding of why people behave as they do, looking at how behaviour can be changed within the specific context can be explored; what needs to be considered in understanding how to address the explanatory variables of the existing and the target behaviours. Strategies that are designed to target the identified variables will likely be more successful. For example, people in their late teens are not as likely to respond to fear messages because developmentally at that age they are more likely to be in denial of their mortality. Designing information strategies that involve interpersonal, peer-to-peer information about positive behaviour is likely to be more successful than fearful information (e.g., mortality rates of young people with AIDS).

Third, once the strategy has been implemented, it is useful to conduct an evaluation review. It is helpful to identify the information and formats that appeared to be more salient and have more affect than others. The programmatic effects also need to be considered as to whether they were the catalyst for change or if there was something else that was responsible. Evaluation should identify the information strategies that were most effective that should be considered in future contexts of future studies.

HIV/AIDS INFORMATION IN SUB-SAHARAN AFRICA: THE CASE OF UGANDA

The case of Uganda offers a powerful example of the synergy between Information Science and Communications for HIV/AIDS prevention programmes. The dissemination pathways for HIV/AIDS information in Sub-Saharan Africa are often based upon a formal Information, Education, and Communication (IEC) strategy. These strategies provide goals for the dissemination of information from numerous partners within society (i.e., multisectoral organizations) and can include government at all levels, non-governmental organizations (NGOs), faith-based organizations (FBOs), community-based organizations (CBOs), bilateral and multilateral agencies, and private companies, although this is not very common. IEC strategies within the Sub-Saharan regions are often developed taking their specific cultural considerations into account (Albright, 2004). While these strategies provide the necessary political and civil support from within the country, they do not guarantee that AIDS information campaigns and messages will be targeted to the specific culture, particularly among organizations that come from outside the region.

In Uganda, the Ministry of Health credits that country's decline in HIV/AIDS to mass communication and condom promotion campaigns, that seek to increase the levels of knowledge of at least two methods of protection from HIV/AIDS and increase

condom use (Uganda Ministry of Health, 2003). Bessingera, Katendeb, and Gupta (2004) attributed the knowledge and use of condoms for both men and women to behaviour change messages in the media (i.e., radio, television, poster, or other print material). The greater the number of mass media channels through which people are exposed to HIV/AIDS messages, the greater the increased knowledge of condoms and how to use them (Bessingera, Katendeb, and Gupta, 2004).

The Ugandan approach is based on communication, behavior, and care. Organizations involved in providing information and communication about AIDS focus on three main topics: (1) information about AIDS the disease; (2) reducing the number of sexual partners, referred to as *zero grazing*; and (3) caring for people with AIDS, which includes not assigning blame or passing judgment. Testing and counselling is offered at the local level, to promote rapid and definitive diagnosis. Counselling is offered not only to those who are diagnosed with HIV or AIDS, but also for family, community members, and health personnel. The multisectoral approach emphasizes the caring of others throughout the establishment of care networks (e.g., The AIDS Support Network (TASO) and other faith-based organizations).

Uganda's drop in prevalence has included a combination of multisectoral approach coupled with unprecedented openness by prominent political, cultural, and community figures who have promoted the cultural integration of the AIDS message in Uganda. Rather than ignoring the problem, it has been openly discussed in the media and embraced as a national problem. This message has been repeated by official government sources as well as by non-governmental organizations (e.g., Human Rights Watch), faith-based organizations (e.g., World Vision), and other organizations who care for those who are infected.

The variety of organizations and partnerships involved in HIV/AIDS activities and information dissemination has contributed towards the behavioral change credited to Uganda. The behavioral changes have lead to a dramatic decrease in the number of non-regular partners and reduction in sexual networks (Low-Beer and Stoneburner, 2003). There has been a significant decrease in the number of non-regular sexual partners in Uganda compared with its neighbors; in 1995 there was a 60% decrease in the number of non-regular partners in Uganda compared with Kenya in 1998 and Zambia and Malawi in 1996 (Stoneburner and Carballo, 1997; Stoneburner & Low-Beer, 2000). Green et al. (2002) reported that adults in various African countries considered reductions in casual sex and abstinence to be the greatest response to AIDS; condoms were not considered to be as important. Condom use in Uganda has been reported to be similar to other countries in the region (Low-Beer & Stoneburner, 2003).

Personal channels are the main source for communicating information about HIV/AIDS in both the urban and rural areas of Uganda (Low-Beer & Stoneburner, 2003). Between 1989 and 1995 there was a shift from mass and institutional communication to personal communication channels in Uganda for communicating information about HIV/AIDS (Low-Beer & Stoneburner, 2003). Mass and institutional communication channels account for the majority of HIV/AIDS communication in all other countries reported by Low-Beer & Stoneburner (2003).

Albright, Kawooya, and Hoff (2006) surveyed over 300 AIDS organizations in Uganda and catalogued the types and formats of HIV/AIDS information disseminated by these organizations. These were matched with the type of organization. Faith-Based Organizations were more significantly more likely to disseminate information on abstinence, faithfulness, and orphans. The government was more likely to disseminate information on condoms and contraceptives. The most common channels for dissemination included radio and drama.

CONSIDERATIONS FOR SUB-SAHARAN AFRICA

Employing the appropriate types of information within a given context will account for not only the specific cultural considerations but will also result in a stronger ability to target specific audiences and individuals with specific needs. Phenomenological studies that investigate the situations of those infected with or affected by HIV/AIDS are needed to examine the results and the complexities of information and behaviour change. This approach is helpful to dig deeper into the underlying context of individual behaviour in order to locate the patterns of information seeking and use for HIV/AIDS information.

1. Materials should be designed specifically for the target audience within their particular culture. Much of Sub-Saharan Africa is based in oral tradition, so the use of non-print materials is likely to be more effective.
2. Materials need to be available in the language of the target population. For example, there are over 30 languages spoken in Uganda. Despite the fact that English is the official language, many people in Uganda do not understand English. Therefore, materials printed in English will be ineffective. Radio programs should also be available in the language of the target population.
3. Because much of the population in Sub-Saharan Africa is illiterate, materials need to be available in a variety of formats in addition to print. Some of the projects mentioned the use of audio in information delivery (e.g., audio books, radio), drama, story, and song, as a few of the methods used to deliver the HIV/AIDS message. Albright, Kawooya, and Hoff (2006) reported that radio and drama were the two most common formats for the dissemination of information. Additional formats for delivery that are culturally appropriate in the oral cultures of Sub-Saharan Africa also need to be considered.
4. Consider the collectivist culture of the target population. For example, information is commonly shared in community centres, youth centres, documentation centres, multipurpose telecentres, and centres. These centres serve as a community centre where local forums and meetings can be conducted, both formal and informal.
5. Regardless of other programmatic activities, peer education appeared to be the most common approach to spreading the HIV/AIDS message.
6. The use of fiction is useful for making HIV/AIDS information more interesting, particularly for children and youth.

CONCLUSION

The fields of Information Science and Communications both contribute to our understanding of the ways in which users seek and use healthcare information. Information Science brings an understanding of individuals, including their cultural context, that is complementary to Communications. Conversely, Communications brings a theoretical background that strengthens the approaches used in Information Science. There are, however, many theories about health information and behaviour change that are characterized by redundancies and superficial perspectives that do not advance our understanding of the relationship between health information and behaviour change. What is necessary is to evaluate behaviour change theories and identify similar concepts in Information Science and establish a common understanding of health behaviour constructs across the different bodies of research. Together, they bring a sharper, more targeted understanding and use of theories to guide the development, implementation, and evaluation of HIV/AIDS prevention programmes in Sub-Saharan Africa.

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