Health Literacy, Empowerment and HIV/AIDS: Striking a Balance on an Uneven Playing Field

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Abstract

A relatively new arena of public health practice, known as *health promotion*, attempts to address the underlying determinants of health, including social, cultural, economic and political factors, which contribute to global health inequities. The concept of *health literacy*, though still in the process of gaining universal recognition and utilization, has developed from this perspective and is a key outcome of health promotion, as well as conventional information, education and communication (IEC) initiatives. Within the context of the HIV/AIDS epidemic in sub-Saharan Africa, the following paper discusses the need to develop health literacy programs and goals based on empowerment and human rights education models designed to facilitate societal level changes. Lessons learned from past HIV/AIDS prevention approaches and characteristics of successful empowerment strategies are presented. Examples of potential best practices in health literacy using traditional media and popular entertainment tools, including promising Internet-based initiatives, are given. Lastly, several policy and practice recommendations are made relative to the advancement of health literacy in sub-Saharan Africa as a weapon against the further progression of the HIV/AIDS epidemic.

1. INTRODUCTION: A NEW PUBLIC HEALTH PERSPECTIVE

The overall health status of most populations can be directly linked to levels of economic and human development (UNDP, 2002). Despite the technological advances and related improvements in health and quality of life that occurred during the second half of the 20th century, a great divide persists between people living in high-income, developed countries and the remaining majority living in low- and middle-income, developing countries. Disparities in average life expectancies, infant and maternal mortality rates, and measures of infectious diseases are often dramatic. Women, those living in poverty, and racial and ethnic minorities are disproportionately affected within both developed and developing countries (Evans, Whitehead, Diderichsen, Bhuiya & Wirth, 2001).

The recognition of global health inequities in the field of public health has led to the development of a relatively new arena of practice known as *health promotion,* which aims to address the underlying determinants of health, such as socioeconomic status, gender equality, and political voice (MacDonald, 1998). Though sometimes mistakenly equated with or placed under the umbrella of disease prevention or health education, health promotion is increasingly seen as an overlapping, yet distinct field of public health practice. Health promotion was most clearly and broadly defined by the World Health Organization (WHO) in The Ottawa Charter for Health Promotion as "the process of enabling people to increase control over, and to improve, their health" (WHO, 1986, p. 1). Rather than viewing health as simply a lack of illness, health is framed in more positive terms and considered a resource that contributes to physical, mental and social well being and allows people to achieve their life goals (Breslow, 1999). This unique approach encompasses five areas of activity—multidisciplinary and multilevel collaboration for healthy public policies, creating supportive environments, strengthening community action, developing personal skills, and reorienting health services. Health promotion involves the transformation of societal norms and the creation of political and social environments that are likely to benefit population health (Syme, 1986). Ultimately, health promotion contributes to the fulfillment of human rights, such as dignity, justice and equity – basic prerequisites for the health of any society (WHO, 1986).

The term *health literacy* has arisen from the field of health promotion and can be considered a close cousin of information literacy, which arose from the field of library science and has been well defined elsewhere (Grant, 2002; Rader, 2002). Initially adopted primarily in the United States, the term was used to refer to an individual's ability to understand basic printed information related to health care, such as appointment reminders, educational pamphlets, or prescription instructions. Numerous definitions of health literacy have been proposed and debated in recent years. While a universally accepted definition has not been established, for the purposes of this discussion, the following definition is used:

> Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals and communities to gain access to, understand, and use information in ways which promote and maintain good health.

This definition expands upon the WHO definition (Nutbeam, 1996), moving beyond the individual to include a community focus. Nutbeam (2000) has further dissected the term, proposing three different types of health literacy. The basic skills as described above are considered *functional* health literacy. The next level, *interactive* health literacy, focuses on personal and social skills development, such as self-confidence, negotiation, and assertiveness, and the resulting individual health-related behaviors associated with these attributes (Hubley, 2002; Nutbeam, 2000). Lastly, *critical* health literacy refers to the development of specific higher level cognitive and communication skills, such as accurately interpreting and evaluating media reports, navigating health care systems, and the capacity to effectively access and use health information (Kerka, 2000; Nutbeam, 2000). Critical health literacy may be reflected in social and political actions that benefit the health of an entire community (Nutbeam, 2000), such as environmental movements or changes in state health insurance policies. Hubley (2002) recently proposed that health literacy in combination with self-efficacy results in *health empowerment*, a process that incorporates affective, communicative and cognitive skills relative to health development. Fundamental to health literacy, therefore, is an element of empowerment, subsequently linking it to economic and social development in both developed and developing regions of the world (Kickbusch, 2001).

2. THE GROWTH OF A GLOBAL EPIDEMIC

The topic of health literacy is critical to the discussion of one of the modern world's most urgent health priorities, the epidemic of HIV/AIDS that continues to spread through many developing countries. According to the most recent estimates by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the WHO (2002), of the 40 million people in the world living with HIV/AIDS at the end of 2001, approximately 95% lived in the developing regions. Although highly variable across countries, Sub-Saharan Africa has been the most seriously affected, with 28.5 million people in the region living with HIV or AIDS at the end of 2001. There were an estimated 3.5 million newly infected persons and 2.2 million deaths from AIDS in the region in 2001. Young adult populations, typically considered the most productive members of society, have shouldered the greatest burden, leaving behind tremendous hardship and suffering (Berkman, 2001). An estimated 13.4 million children, some of whom are HIV-positive themselves, have lost one or both parents to AIDS (UNAIDS/WHO, 2002). Grandparents or other relatives are often left to provide for orphaned children, requiring already constrained resources to be stretched even further (Williams & Tumwekwase, 2002). Economically, many developing countries in the region are regressing, having lost a significant portion of their labor and agricultural forces to AIDS (Monico, Tanga & Nuwagaba, 2001).

3. FACTORS CONTRIBUTING TO THE SPREAD OF HIV/AIDS

3.1. Gender Matters

The epidemic's continued growth has been attributed to a number of underlying social, cultural, political, and economic factors. Of the societal factors, gender inequality and oppression are often considered the most important. Women are frequently powerless in sexual relations and reproductive decisions, potentially becoming the victims of gender-based violence if they attempt to negotiate with their partners (Ankrah, 1996; UNESCO, 2001). Among adolescents in South Africa, for example, violence by boys as a means of controlling their girlfriends is common in sexual relationships. In addition, social status and masculinity are largely defined by numbers of sexual partners, and femininity by desirability as a girlfriend. The process can be intensely competitive, making it socially taboo on one hand not to have a girlfriend, or on the other, to reject sexual advances (Wood & Jewkes, 2001). The lower social status of women and girls sometimes results in insufficient access to accurate information about HIV transmission and prevention, as well as diagnosis and treatment services (Human Rights Watch, 2002). However, even in cases where women have the knowledge, for example, that condom usage decreases the risk of HIV transmission, some men may be offended by the suggestion or take it as a sign of unfaithfulness. In many of these societies, early marriage and polygamy are still practiced, further increasing health risks for women. Under such oppressive conditions, lack of awareness of and respect for human rights may be accepted as the way of life, especially by women (Ankrah, 1996).

Women also lack economic power in most countries of sub-Saharan Africa (Ankrah, 1996). They are still viewed as property in many places and have limited economic rights, such as land ownership or access to credit. The practice of wife inheritance continues to be common in Kenya, Swaziland and Zimbabwe, contributing to the spread of HIV/AIDS. In this practice, when a man dies his brother automatically gains possession of his house, land, livestock, wife and children (UNESCO, 2001). Many poor, young women, often from rural areas, resort to sex work as a means to support their families (Ankrah, 1996). It is also not uncommon for sexual favors by young girls to be solicited in exchange for expensive material goods, such as cell phones and clothes (UNESCO, 2001). Given this economic dependence and the traditional attitudes toward women, it is perhaps not surprising that a larger proportion of people living with HIV/AIDS in the region are female (UNAIDS/WHO, 2002). In some places, teen-aged girls are four to seven times more likely to become infected than their male counterparts. Of the 26 million affected adults aged 15 to 49 years old in sub-Saharan Africa, 15 million are women (UNAIDS/WHO, 2002). Yet, in the presence of the social stigmatization and discrimination often associated with HIV/AIDS, women may also face other more immediate social and economic costs, including a real risk of abandonment, physical injury, or starvation if thought or known to be infected (UNAIDS, 2001).

3.2. Politics and Limited Resources

Although a majority of national governments in sub-Saharan Africa have come out with strong positions regarding HIV/AIDS, for the most part the political will to address HIV/AIDS came late, with silence and denial initially being the norm, rather than open discussion and aggressive national responses (Human Rights Watch, 2002). In many

cases, national responses paralleled the late commitment of financial resources coming from donor countries in the North. The health care services needed to identify and treat those with HIV/AIDS have been limited in many countries, attributable in part to the lack of financial, technical and human resources. Discrimination, stigma and denial have helped perpetuate the epidemic's spread as people who think they might be HIV-positive do not get tested even where the necessary services and technology are available, or they test positive and hide their status (Monico, Tanga & Nuwagaba, 2001). To add another layer of complexity, during the past decade a number of countries in the region have been involved in civil conflicts. In addition to major losses of life, these conflicts have resulted in loss of income, destruction of infrastructures, and mass migration of millions of people (UNHCR, 2000). Given these factors, in addition to the psychological stress inherent to such situations, refugees and internally displaced persons are at even greater risk of becoming infected with HIV (McGinn, Purdin, Krause & Jones, 2001). Even in the more peaceful countries, such as Kenya, human rights violations and corruption of government officials have been, and continue to be, commonplace (Nowrojee, 2000; Phillips, 2002). Under these circumstances, marginalized and poor people—those most vulnerable to HIV/AIDS—rarely have a political voice.

Although growing sums of money are being dedicated to the global fight against AIDS, competition for funding remains intense. Donor institutions are under increasing pressure to minimize costs and maximize impacts, often requiring them to sacrifice potential long-term benefits for more tangible outputs, such as posters, pamphlets and publicity-generating events (Scalway, 2002). Most projects are based on relatively short funding cycles, making it difficult to demonstrate significant positive outcomes (Lafond, 1995). In addition, agendas are often set outside of the receiving country and frequently do not involve the people who are affected. While local partners may be recruited to allocate resources and evaluate impacts, they are not always adequately equipped with the skills or technology to do so effectively and efficiently (Scalway, 2002).

3.3. Social and Cultural Factors

Many past efforts to prevent the spread of HIV/AIDS in sub-Saharan Africa have failed to consider the entire social and cultural context. In an environment of poverty and violence, there may be a number of threats to one's life and health on any given day. Perhaps from the perspective of those living in the region, HIV/AIDS is just another one of those threats, albeit one that will not result in immediate death. Indeed, the concept of living beyond 60 years is relatively new in many places, with emphasis historically being placed on mere survival, rather than length or quality of life. Malnutrition, which presents a more immediate danger, continues to be a major problem in the region (Schroeder, 2001). Complications associated with childbirth are common, with a high risk of infant mortality from other infectious diseases, such as malaria and tuberculosis after birth (Ostlin, George & Sen, 2001). Deaths from AIDS are often blamed on poisoning or witchcraft, or euphemisms such as 'lengthy illness' are used (UNESCO, 2001). In addition, a number of misconceptions and false beliefs have developed relative to HIV/AIDS transmission. In some areas, for example, people believe that clean and well-

dressed individuals cannot become infected or that having sexual intercourse with a virgin will cure AIDS (UNESCO, 2001).

3.4. The Limits of Past Theoretical Approaches and Strategies

Efforts by outside institutions and non-governmental organizations to address the HIV/AIDS epidemic in developing countries, while certainly having some merits and positive results, have, for the most part, been inadequate. A number of reasons have been proposed for the limited success in reversing the epidemic's upward trend, including the use of inappropriate theoretical frameworks (Scalway, 2002; UNAIDS, 2001). Western models, such as the health belief model (Janz & Becker, 1984), the theory of reasoned action (Fishbein, Middlestadt & Hitchcock, 1994), and the stages of change model (Prochaska & Diclimente, 1983), have focused on influencing individual attitudes, perceptions of risk, health decisions, and behavior changes through information giving and logical persuasion (Airhihenbuwa & Obregon, 2000; UNAIDS, 2001). Traditional 'behavior change communications' (BCC) and 'information, education and communication' (IEC) strategies for HIV/AIDS prevention may not be applicable in some contexts because they assume that people take health decisions rationally and of their own free will. Some of these approaches have failed to consider the roles of emotions, culture and environment and the lack of choice that characterizes the lives of many sub-Saharan Africans, placing them on an uneven playing field relative to their ability to protect themselves against HIV/AIDS (UNAIDS, 2001). Much would be gained from the integration of a human rights perspective and a focus on empowerment, both of which can contribute positively to the fulfillment of health literacy.

4. THE EMPOWERMENT MODEL

The term *empowerment* has been used extensively in psychology, sociology, education and public health literature, with wide variations in meaning depending on the context in which it is used. In general, empowerment can occur at multiple levels from the individual to the larger society and can be considered a process, as well as an outcome (Minkler & Wallerstein, 2002; Raeburn & Rootman, 1998). Most often it is used to refer to a social action process in which individuals and communities gain control over their own lives and facilitate desired changes. At the personal level, *psychological empowerment* has been used to describe an increase in confidence or self-esteem, perhaps stimulated by a crisis or unexpected life event. Individuals may then be inspired to become involved in a larger social cause.

Community empowerment can lead to advocacy, political action, policy changes or legislation in favor of disenfranchised groups (Laverack & Wallerstein, 2001; Raeburn & Rootman, 1998). This level of empowerment may be strengthened by the development of 'critical consciousness,' a term coined by Brazilian educator and philosopher Paulo Freire in his book *Pedagogy of the Oppressed* originally published in 1970 (Freire, 2001; Minkler & Wallerstein, 2002). Freire began his career by teaching illiterate people in the *favelas* of Recife to read and write, and later developed a teaching methodology that has

been used throughout the world (Shaull, 2001). The central premise of critical consciousness is that education should result in transformation and liberation. According to Freire, people can be inspired to take action through reflection, analysis, and dialogue. Using this approach, the underlying causes of a societal problem, the interconnectedness of these conditions, and strategies to bring about change can be linked together. Based on his experiences and observations, Freire believed that by improving language skills and increasing awareness of human rights, ordinary citizens can become instruments in the creation of social equity by stimulating changes in the policies that affect their lives (Freire, 2001).

The World Bank (2002) recently proposed an empowerment model for poverty reduction designed to increase freedom of choice and action in poor populations. In this model, empowerment, while an intrinsically desirable goal, can produce other instrumental benefits by building on the positive characteristics and capabilities of the poor. According to the authors, empowerment requires four main elements – information, inclusion, accountability and organizational capacity. The flow of information between marginalized groups and the public and private sectors regarding institutional performance must be open and accurate. To overcome lack of political power and voice, representatives of those living in poverty should be included in budget negotiations, policy debates and decision-making. In addition, political, administrative, and social institutions should be accountable to the public for their actions. Local organizational capacity needs to be developed so that community members learn how to work cooperatively and mobilize resources to address common concerns. Within this empowerment framework, people must be seen as partners, not problems, which will require a change in mindset for donors, professionals, and the communities they serve. Formal, as well as informal, institutions must become more aware of and responsive to the needs of poor people and the reality of their daily lives (The World Bank, 2002).

In this model empowerment is not viewed as an independent and sufficient strategy, but is considered an essential component of development. The World Bank (2002) proposed five areas of action necessary to improve the effectiveness of development efforts. First, basic services must be easily and equally accessible. Implementation of services and distribution of resources should be conducted in a decentralized manner; therefore, local governance mechanisms must be established. National level governance must also be strong and organized. Pro-poor market development strategies must be expanded, including investments in education for women, micro-economic loan systems, and incentives for small business owners. Lastly, access to legal aid and social justice must be offered to everyone regardless of social status to discourage human rights violations.

As the health of a society has a direct impact on its potential for human, social and economic development, efforts to improve development would be enhanced by including programs aimed at increasing health literacy levels, moving toward the ultimate goals of poverty reduction and health equity. The remainder of this paper will emphasize the need to incorporate elements of the empowerment model described above, specifically information and inclusion, into HIV/AIDS prevention and treatment programs for the purpose of enhancing health literacy. In addition, the need to place health literacy

development within the realm of basic institutional services in sub-Saharan Africa and other developing regions will be discussed.

5. EDUCATION, LITERACY AND HEALTH—A PARADOX

The most general definition of literacy refers to the ability to perform basic reading, writing and calculation tasks—skills generally learned in a primary school setting. Literacy level usually reflects the educational attainment, but must be considered in relation to its interaction with other societal attributes, such as equity and justice (Sen, 1999). An estimated 40% of all children in Africa were not enrolled in school in 1995 (Kelly, 1999). In sub-Saharan Africa, boys are more likely to attend school than girls, especially beyond the primary grades, and literacy rates are almost uniformly higher for males compared to females (UNDP, 2002). In Niger and Burkina Faso, for example, the illiteracy rate among women is close to 90% (Save the Children, 2000). Indeed, a majority of the illiterate population in sub-Saharan Africa is made up of women—women who know may they are at risk for HIV/AIDS, but who are poor and powerless.

Nonetheless, given that there are other factors at work beyond literacy and knowledge, a paradox which is well known among health behavior experts has emerged in sub-Saharan Africa. Countries like Zimbabwe and South Africa with female literacy rates approaching 80% are also among the countries with the highest rates of HIV/AIDS (Save the Children, 2000). A recent study in the region indicated that the risk of becoming infected rises with level of education, perhaps associated with greater income and mobility, and hence, increased probability of having multiple sex partners (Kelly, 1999). Within many African countries, one of the occupational groups with the highest HIV/AIDS death rates has been teachers—again, most of whom were women (UNICEF, 2000). This example serves to illustrate that while education is obviously important, simply attending school, being able to read, and having access to information are not sufficient to prevent the spread of HIV/AIDS.

6. POTENTIAL ROLES FOR INFORMATION AND COMMUNICATIONS TECHNOLOGY IN HEALTH LITERACY DEVELOPMENT

Although health promotion is about more than the dissemination of information, public health practitioners have long recognized the value of information and communications technology (ICT) to enhance health-related knowledge. As in the case of education, ICTs, including traditional media, mass media, and digital technology can have a powerful influence, but are not sufficient to prevent HIV transmission. They can, however, be viewed as tools to facilitate empowerment and the realization of human rights by creating economic, educational, social and political opportunities (World Bank, 2002). Depending on the particular components and methods utilized, ICTs can contribute to the development of all three types of health literacy as put forth by Nutbeam (2000). In order to be of value, supportive policies and strategic project designs are needed to reach those at greatest risk. A number of variables should be considered in the development of ICTs

if they are to equally benefit all citizens and improve health literacy levels. Sustainability must be ensured through local ownership and operation, as well as low-cost production and maintenance (World Bank, 2002). In addition, ICTs must be appropriate relative to language, cultural content and social relevance and acceptable in quality, practicality and conciseness. If they are not based on the communication needs of the local people, investments of time and money will sadly be wasted.

In low literacy populations, print media in the form of visual representations and simple graphics can be effectively used to convey critical health concepts (Mensah, 2002). In addition, traditional media, including various forms of the arts and cultural entertainment, can be used to advance health literacy. For example, songs, dances, poems, plays and stories incorporating health-related messages may capture and sustain the attention of people who would otherwise have little time or interest in learning new information (Siegel & Doner, 1998). The use of traditional media is most effective when developed through the participation of local community members and representatives of target groups, contributing to a sense of ownership and empowerment (Baum, 1998). Such entertainment-education strategies, also known as *edutainment*, are rapidly gaining in popularity, facilitated by the use of mass media (Johns Hopkins University Center for Communication Programs, 2000).

Print and broadcast media, including newspapers, magazines, radio and television, are becoming less expensive and more accessible in underdeveloped areas. Mass media have the potential to reach those who are illiterate and for whom formal educational opportunities are limited, as well as more vulnerable and high-risk groups hidden within populations. Another reported advantage of such techniques relates to the stimulation of dialogue around HIV/AIDS, bringing it to the forefront of the public's consciousness and thus, inspiring community action and policy changes (Wellings & MacDowall, 2000) Media campaigns incorporating popular arts, entertainment and social marketing techniques have proven particularly useful in achieving some of the goals of health promotion, such as changing attitudes toward what is considered acceptable behavior (JHUCCP, 2002).

Lastly, new opportunities in digital media are presenting a number of potential contributions to health literacy development in sub-Saharan Africa. While some major donors remain skeptical (Bray, 2001) and a number of infrastructure challenges exist in the region, all nations of Africa now have email and Internet connectivity and can be considered officially online (The Communication Initiative, 2002a). While still limited at this time, access to telephones, fax machines and computers is gradually increasing in many urban areas through the establishment of local *telecentres*. Many centers offer technology skills training, leading to increased job opportunities and access to financial services. In addition, the Internet is opening a number of previously inaccessible doors to the general public, medical professionals and social activists. It is allowing people to feel more connected to the outside world and providing a safe place to get information they may not feel comfortable talking about with family or friends.

7. HUMAN RIGHTS EDUCATION – AN ALLY OF HEALTH LITERACY

Many believe that HIV/AIDS was born out of and exacerbated in many ways by human rights violations in which women, sex workers, injection drug users, and men who have sex with men have been subject to discrimination (Human Rights Watch, 2001a). The lower social status of these groups has sometimes resulted in neglect and reduced access to needed services, information, and social support systems, further perpetuating the epidemic. In countries with the highest rates of HIV, some governments have not provided consistent and accurate prevention information to their populations, violating the right to access and receive information necessary to protect one's health (Human Rights Watch, 2001b). Such rights have been set forth in international human rights covenants signed by many countries in sub-Saharan Africa and are crucial in slowing the spread of HIV/AIDS (Human Rights Watch, 2001a). When examining such violations, it becomes apparent that other more fundamental rights, such as justice, equality, non-discrimination, participation and dignity, are inextricably linked with the right to health, thus highlighting the importance of approaching public health issues from a human rights perspective (Leary, 1994; Rodriguez-Garcia & Akhter, 2000).

The Human Rights Education Approach (HRE) described by Marks (2001) has been used to facilitate the fulfillment of the human rights and overlaps in many ways with the previously described empowerment model. The HRE model, also evolving from the work of Paulo Freire, is premised on the idea that social transformation is best accomplished by allowing people to be involved in decisions that affect them, thus maximizing their potential through participation in the process of actualizing their rights. The key to achieving broad human rights education, according to Marks (2001) is through the facilitation of non-formal learning experiences outside the formal school setting (Marks, 2001). Informal activities that increase awareness and knowledge of particular human rights are the first step. As people develop a critical understanding of and can analyze their own situations, attitudes begin to change—first individually, then collectively. They begin to value their own rights, respect the dignity of others and realize their responsibility to act on the behalf of those less fortunate. Eventually, societal level behavior change can take place through the empowerment of individuals and collective action at the community level (Marks, 2001). In the context of HIV/AIDS in sub-Saharan Africa, the HRE approach appears to complement the empowerment model discussed above and may contribute substantially to the development of critical health literacy.

8. POTENTIAL BEST PRACTICES IN HEALTH LITERACY AND HIV/AIDS

8.1. Characteristics and Lessons Learned

The recently published UNAIDS (2001) report entitled "HIV/AIDS and Communication for Behavioral and Social Change: Programme Experiences, Examples and the Way Forward" called for a reorientation of HIV/AIDS prevention approaches. The need to shift away from individual behavior change communication toward social change

communication and empowerment strategies was emphasized. The report called for greater attention to be given to the roles of and interactions between socio-cultural and environmental factors, such as governmental policy, cultural norms and beliefs, socioeconomic status, and access to information and services, all of which influence behaviors and continue to drive the epidemic. Holistic, flexible, multilevel and contextual explanations and interventions were recommended to ensure efficacy and sustainability. Horizontal methods that encourage local ownership, content development, and program evaluation should be incorporated while providing needed technical assistance to ensure that stigma and discrimination are not perpetuated further. Such approaches enhance the ability of individuals and groups to become agents of their own societal changes through the stimulation of dialogue and debate around relevant issues.

The report additionally states that traditional oral communication channels, including songs, proverbs, riddles and storytelling, have been undervalued and underutilized. These methods of learning are rich in visual imagery, one of the foundations for learning. HIV/AIDS usually affects those who are hardest to reach through conventional print and broadcast media channels – the poor, the uneducated, and those living in rural areas. Culturally familiar media channels can be used to inform and inspire the more vulnerable and marginalized groups within societies. In order for such groups to gain more control over the external conditions of their lives, the positive attributes of each culture must be harnessed to prevent the further spread of HIV/AIDS and to provide care and support for those who are already living with the conditions (UNAIDS, 2001).

A recent meta-analysis of 80 case studies describing programs that claimed to promote empowerment of women for health identified the seven most commonly used methods worldwide (Kar, Pascual, Chickering & Hazelton, 2001). They included: enabling assistance; media use, support, and advocacy; public education and participation; organizing associations, unions and cooperatives; work/job training and income generation; empowerment education and leadership training, and; rights protection and legal reform. Based on this analysis, the authors proposed a set of guidelines for planning community-based empowerment and welfare reform in marginalized populations. Human rights struggles initiated by women were suggested as a means of generating wider local, national and international public support. Furthermore, they emphasized the importance of non-formal education and direct participation as a means to facilitate empowerment.

8.2. Examples

The following section provides brief descriptions of some initiatives that have addressed HIV/AIDS through promotion of health literacy. Although health literacy may not have been a stated goal, upon examination, all of these programs and projects incorporated empowerment and human rights to some degree. Relative to empowerment, criteria for inclusion included participation of targeted groups, the free flow of information or the stimulation of dialogue and debate. From a human rights perspective, the examples below served either to reduce health disparities or to decrease stigma and discrimination associated with HIV/AIDS. The following list is far from exhaustive, and health literacy may be only one outcome of a more comprehensive intervention.

Social and Political Movements

Though not a health literacy initiative per se, from a historical and global standpoint, one of the single most successful social mobilization efforts around HIV/AIDS occurred in the early 1980s within the homosexual male communities in developed countries (Shilts, 1987). The movement began on a grassroots level with campaigns for recognition and community education and progressed upward to combat discrimination and stigmatization, as well as secure medical treatment. Since that time, only a few developing countries have been able to successfully contain or decelerate the spread of HIV/AIDS. Although having the benefit of occurring in the contexts of unique historical events, the approaches of Senegal, Thailand and Uganda (Hogle et al., 2002) in many ways replicated those of the homosexual movement. All were founded on similar principles of ownership and human rights and had several commonalities that appear to be necessary for success (Scalway, 2002). First and foremost, they involved the free flow of scientifically accurate information through multiple media channels, reporting from a variety of perspectives and encouraging widespread public debate. Political leaders were either supportive or responsive to pressure from their constituents, resulting in legislative action. Lastly, they were all characterized by a dynamic and empowered civil society committed to addressing issues underlying the epidemic, such as gender inequality and job insecurity, rather than focusing on health-related behaviors.

A National Multimedia Effort – "Soul City"

One of the most successful national mass media efforts has been the television drama series "Soul City," which was developed to address the HIV/AIDS epidemic in South Africa (http://www.soulcity.org.za). The series has reportedly reached more than 16 million people, almost 80% of its target population. Surveys by outside agencies have shown a dose-response relationship between the number of episodes viewed and the accuracy of HIV/AIDS knowledge. Audience members have reported increased perception of personal risk resulting in the more frequent use of condoms. These changes are believed to have occurred not only as a result of seeing the television shows, but also from the stimulation of increased dialogue between parents and children and debate among friends and neighbors. Decreased negative peer pressure and stigma associated with HIV/AIDS in South Africa have also been reported (Usdin & Japhet, 2002). The messages of "Soul City" are complemented and reinforced by radio dramas, newspapers, comic books, journalist resources, marketing campaigns, and a children's program called "Soul Buddyz," many of which are made available in local languages.

The Straight Talk Foundation

The Straight Talk Foundation of Uganda was established in 1997 with the objectives of reaching out to adolescents both in and out of school, those who cannot read or write, and those who do not speak English with reproductive and sexual health messages through radio and newspapers (http://www.straightalk.org). Beginning in 1999, the foundation aired nationwide talk shows on six radio stations in urban and rural areas. The programs,

which are broadcast in a number of local languages, are hosted by teenagers and feature interviews with other young people regarding their views. An expert on the given topic is featured, giving advice and supplying up-to-date information. Listeners are encouraged to mail in questions and quiz segment responses. The foundation receives an average of 80 letters a week with prizes awarded for correct answers. The Straight Talk Foundation also publishes a monthly four-page newspaper with corresponding topics, sponsors outreach programs and Straight Talk clubs, and conducts desensitization workshops for school teachers. Monitoring and evaluation through observation, personal interviews, focus groups, questionnaires, service utilization tracking at health centers, and letter databases are conducted regularly. Based on past reports, the newspaper reaches 92% of its target audience and approximately 80% of the radio show audience is made up of boys. The foundation is seeking ways to reach girls who have greater responsibilities around the home and subsequently, less time to listen to the radio or read newspapers. Those responding to questionnaires have reported increased knowledge regarding strategies to prevent unwanted pregnancies and sexually transmitted infections, including HIV/AIDS.

The Reproductive Health Literacy Project among Refugees in Guinea

Projects developed for the primary purpose of increasing health literacy are relatively rare. One notable and innovative example was conducted with refugees in Guinea through the US-based American Refugee Committee (McGinn, 2002). The Reproductive Health Literacy Project began as a six-month pilot project in 1999 with the assistance of World Education and John Snow International (JSI) Research and Training Institute, and has since expanded to 12 sites around Guinea. To date, 2,325 women and 368 men have completed the courses with 850 women and men enrolled as of April, 2002. In total, 70 teachers, 26 of whom are men, have been trained and employed with the project. In addition, seven refugee supervisors have been hired and trained. Beginner and intermediate classes, which meet twice weekly for two hour sessions, incorporate participatory education and adult literacy techniques using reproductive health content. Techniques include games, storytelling, picture stories, and group discussions, covering topics such as safe motherhood, family planning, nutrition, gender-based violence, sexually-transmitted infections (STIs), and HIV/AIDS, depending on the needs identified by the refugees. Although most of the participants have been from Liberia, Sierra Leone and Cote d'Ivoire, classes are conducted in English at the request of the participants with discussions in local languages as needed to facilitate understanding.

A number of formative and process evaluations were conducted during the various phases of this project. Most recently, a follow-up study (McGinn, 2002) to assess the potential intermediate and long-term effects was conducted using a test of literacy skills and a survey questionnaire with 549 randomly selected former students. In-depth interviews for qualitative analysis were conducted with 22 former students. Unfortunately, results were limited by lack of reliable pre- and post-test records and use of recall data. Researchers identified several benefits, including increased awareness of and utilization of reproductive health services, as well as increased use of contraceptives, especially oral pills and injections. Though not originally specified as a project goal, an increased level of empowerment, referred to as *boldness*, through participation was reported by the

refugees and eventually came to be perceived as a positive attribute of the project. Participants reported communicating more about reproductive health with partners and feeling more confident about speaking up in public meetings.

FilmAid International

The activities of FilmAid International (FAI), a non-profit organization founded in 1999 by concerned members of the film and entertainment industry, appear to contribute positively to health literacy development (http://www.filmaidinternational.org). The organization was conceived as an independent humanitarian outreach program serving refugees and internally displaced persons by providing psychological relief through films. Following FAI's initial success with Kosovar refugees in Macedonia, the group was adopted as a project of the International Rescue Committee (IRC). The focus of the organization has since expanded to address issues related to health, human rights, peace building and environmental preservation. Since late 2001, FAI has been operating three programs at Kakuma Refugee Camp in Kenya, including a participatory video project, evening film screenings, and daytime educational screenings. FAI's participatory video project trains youth and young adults to collaborate in the design and writing of films and public service announcements. Students learn to conduct interviews, document camp events, operate video/film equipment, and edit footage for the final production. The evening screening events typically include a public service announcement, cartoons, a short educational film, and a feature film. A mobile cinema rotates through different camp zones, allowing thousands of refugees and local Kenyans to view films free of charge. Most films come from African countries and are selected for viewing by a refugee advisory committee based on cultural appropriateness and community needs. Some past film topics have included education for girls, conflict resolution, teenage pregnancy, and HIV/AIDS. The smaller-scale daytime educational screenings are followed by discussions in which people are encouraged to ask questions and express their views. FAI also employs and trains refugees and Kenyan nationals as projectionists, maintenance crew, security personnel, translators, managers and discussion facilitators. While the films and videos used in these programs are considered tools to facilitate health literacy, it appears that the process of participating in FAI-sponsored events may, in itself, be an empowering and health promoting activity.

Internet-based Initiatives

A number of innovative Internet-based initiatives designed to empower women and journalists, potentially improving health literacy, have recently been established in sub-Saharan Africa. The Zimbabwe Women Resource Center and Network (ZWRCN) in Harare, Zimbabwe, has opened an Internet café, which offers one-day training sessions. The mission of the organization is "to enable women to make informed decisions about political, economic, and social aspects of their lives in public and private spheres" (http://www.zwrcn.org.zw). Developed with support from US-based Women Connect!, ZWRCN teaches women to conduct information searches and use email, allowing them to interact with the global community. Women who have participated in training sessions report feeling more confident and more readily willing to use new technologies.

The Media Resource and Advocacy Center (MRAC) of Nigeria has conducted training workshops for journalists on computer/Internet-assisted reporting of reproductive and sexual health and human rights issues. The training sessions were designed to equip journalists from various media outlets and international news agencies with skills necessary to report on topics that are often ignored by or rarely reported in a comprehensive manner by the general press, such as sexuality education, female genital cutting, abortion, sexual violence/coercion, maternal mortality, and HIV/AIDS. MRAC is a project of Development Communication (Devcoms) Network and Surulere Lagos Nigeria, a health communication NGO working to increase understanding of scientific issues and participation in health development (The Communication Initiative, 2002b).

9. RECOMMENDATIONS FOR POLICY AND PRACTICE

A number of policy and practice recommendations have the potential to advance the concept and level of health literacy in relation to HIV/AIDS in sub-Saharan Africa, as well as other developing regions. First and foremost, in order to control the epidemic's expansion, health communications and education programs must not limit their operations to prevention messages, but rather address the interrelated components of the HIV/AIDS continuum—prevention, care and support (UNAIDS, 2001). From a human rights perspective, health literacy may contribute to the protection of those who are HIV-negative, promote testing and treatment among those who are HIV-positive, and reduce stigma and discrimination against those with AIDS. IEC efforts directed at HIV/AIDS have begun to, and must continue to take into account larger contextual issues that affect societal behavior (Figueroa, Kincaid, Rani & Lewis, 2002).

Health literacy can be advanced through multi-level and cross-disciplinary approaches to HIV/AIDS program development (UNAIDS, 2001). Professionals from various fields, including public health, information science, social psychology, anthropology must share their expertise and collaborate for improved understanding of the underlying determinants of disease risk. Partnerships between governments, civil society, and the private sector should be cultivated further, building on the strengths of already existing institutions, such as schools, churches, and workplaces. Expansion of health literacy programs into settings with highly vulnerable populations, such as brothels, prisons, refugee settlements, and national border-crossings should be considered.

In so doing, the power and reach of the press and popular entertainment media must not be ignored or underestimated. When possible, HIV/AIDS-related storylines should be incorporated to help subdue fear and negate misconceptions and false beliefs (UNAIDS, 2001). Entertainment professionals can play dual roles as both advocates and educators. Investments in the recruitment and education of creative and inquisitive individuals will be required, as well as national policies that allow for the free flow of information. By relating stories from multiple perspectives, the general public may be encouraged to be more skeptical regarding claims of cures for AIDS, as well as more compassionate towards those living with the disease (Fox, 2000).

Health literacy can be enhanced through both traditional and contemporary entertainment media. Community festivals and celebrations can incorporate HIV/AIDS-related issues into songs, dances, puppet shows, plays and storytelling, thus building on positive cultural attributes (Airhihenbuwa & Obregon, 2000). Media advertising, marketing and public relations strategies can be utilized to target high-risk audiences with culturally appropriate content and message framing. Interventions using radio, television and film also appear to be promising tools for health literacy development, particularly those with participatory components.

Human rights activists and humanitarian aid organizations must also sustain their efforts to search for new ways to stimulate changes relative to HIV/AIDS. To their advantage, the Internet can be used to rally international support against repressive national regimes and cultural practices that feed discrimination and stigma (Bray, 2001). Although advances in telecommunications may only directly benefit a minority, such as students, business owners, the wealthy and better-educated, they may indirectly benefit everyone by connecting these influential groups with each other and with expatriates abroad. Such connections could eventually reshape the political and social environments in countries across Africa.

Given the inherent challenges associated with assessing the impact of health promotion and health literacy programs (Coombes & Thorogood, 2000), development of appropriate and measurable indicators is necessary. Rootman and colleagues (Canadian Public Health Association, 2002) are currently in the process of developing a composite index that may be used to measure health literacy on the national level. Articulating the role that health literacy plays in reducing HIV/AIDS will require a combination of quantitative and qualitative research methods with attention to processes, in addition to outcomes. Ideally, baseline evaluations should be conducted prior to implementing new programs, followed by periodic evaluations at regular intervals on a long-term basis. Evaluation results should be analyzed and disseminated in a timely manner to facilitate program changes, and use of best practices. Project planning and monitoring should be conducted with direct involvement of the local population in determining needs, establishing goals, and developing culturally-sensitive strategies. By using participatory approaches, a more comprehensive picture of changes happening on the individual, family, community and societal levels may be ascertained, with the added benefits of strengthening technical skills, fostering local ownership and building community capacity (UNAIDS, 2001). Ultimately, health literacy goals should become institutionalized at the national level, a process that could be encouraged by donors, including new funding sources such as the Global Fund to Fight Malaria, Tuberculosis and HIV/AIDS.

Lastly, health literacy initiatives aimed at HIV/AIDS need to be carefully evaluated relative to the degree to which they address human rights and empower individuals, civil society, and communities. Indeed, societal change and empowerment, rather than knowledge or behavioral change, may be the most important outcomes of such initiatives. Using a human rights perspective that incorporates social, cultural and political contributions to the HIV/AIDS epidemic can be one of the most successful means of empowering and mobilizing people (NGO Networks for Health, 1999).

10. CONCLUSIONS

A number of critical lessons have been learned through past efforts to control the spread of HIV/AIDS in sub-Saharan Africa. While access to information and preventive health services were necessary and important, they have not been sufficient to reverse the epidemic. Shifting attention, energy and resources toward the development of health literacy, with a focus on both human rights and empowerment, has the potential not only to yield positive epidemiological transitions, but to produce synergistic benefits in human, social and economic development.

For further information on health literacy, the following on-line resources are recommended:

Health Literacy Studies, Department of Health and Social Behavior, Harvard School of Public Health at http://wwwhsph.harvard.edu/healthliteracy/literature4.html.

Health Education Database, Leeds International Health Promotion at http://www.hubley.co.uk

Canadian Public Health Association, National Literacy and Health Program at http://www.nlcp.cpha.ca/c1hrp/index_e.htm

Pfizer Health Literacy Initiative at http://www.pfizerhealthliteracy.com

The Drumbeat Newsletter, The Communication Initiative at http://www.comminit.com

Contact: E-mail: ilona.kickbusch@yale.edu / Tel: (203) 785-2861.

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