

Full Length Research Paper

Implication of communication formats on HIV and AIDS information for persons with disabilities in Kenya

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Provision of information is one of the strongest tools for fighting HIV/AIDS, and various organisations in Kenya have put tremendous efforts to provide information on HIV and AIDS prevention. However, despite these efforts, the people with disability particularly those who are blind or deaf are still being excluded from accessing information due to communication formats used by HIV/AIDS service providers. The audio-visual channels such as radio, television, newspapers, large bill boards, internet, lectures or brochures being used to provide information on HIV/AIDS to the general population are discriminative since they require the use of sight and hearing. This study examines implication of communication formats on HIV and AIDS information to persons with disability in Kenya. Data for this study was collected specifically from blind and deaf students through interview and focus group discussion. Results indicate that people who are blind or deaf do not access HIV and AIDS information given to the general population and that language used is complicated and technical. HIV and AIDS information should be provide through accessible disability-friendly communication formats such as talking computers, Braille, sign language and symbols.

Key words: Communication formats; Disabilities; HIV and AIDS

INTRODUCTION

According to the World Health Organization, 10% of any population suffers from mild to severe disability and this figure is likely to be higher for the developing countries. Eighty percent of this population live in the developing world with a larger population in rural rather than urban areas (Groce, 2003). The global literacy rate for adults with disabilities is as low as 3% and in some developing countries the literacy rate goes as low as 1%. (Groce, 2003). Literacy is an important aspect of understanding HIV/AIDS messages. Majority of people with disability are poor, stigmatized, and marginalized without reliable income and only a small fraction in Africa can attend formal education making access to information a serious challenge (Ingstad and Whyte, 1995; Henderson, 2006).

Historically, the provision of medical, social and economic services to people with disabilities have always been considered last when the non-disabled members of the society have received their due share. In most cases, they have only been remembered when the organizations working for and of people with disabilities raise concern

about their exclusion and marginalization from services (Handerson, 2006). Recent studies on HIV and AIDS and people with disability have demonstrated the same trend, where individuals with disabilities have been left out.

Service providers and professionals working in HIV and AIDS have assumed that individuals with disability are sexually inactive and are therefore at a lower risk of HIV infection (Groce et al., 2004). There has been a misconception among the general population and researchers that people with disability are not sexually active and therefore not at risk of being infected with HIV and AIDS. This misconception is wrong since persons with disabilities have the same psychological and emotional needs just as the non-disabled. The assumption that disabled persons are not sexually active has led to lack of information and resources to ensure safer sex for them (Groce, 2003).

Individuals with disabilities have been excluded from accessing information on HIV prevention, treatment and care services due to the use of inappropriate communication formats. Information regarding HIV/AIDS epidemic has been provided by those members of the society who are not disabled and do not understand the community of disability (Managham and Wilson, 2006).

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Members of disability community have their own cultures in which they share their physical or cultural characteristics. For example, the deaf community has a shared identity through challenges of communication and being misunderstood by the hearing community. They share oppression that is demonstrated through insufficient access to information, inability to obtain jobs, discrimination against certain vocations, lack of captions on television programmes and lack of sign language. In Kenya, among the population that is most at risk are the blind and those who are deaf and it is also the most neglected group in the provision of information on HIV prevention.

Communication formats in HIV/AIDS and disability

Provision of information has been used as a tool for fighting HIV pandemic since knowledge of HIV/AIDS is directly related to source of information. HIV/AIDS affects all aspects of human life including; personal identity, social problems, sexuality, sickness, morality, stigma and discrimination (Groce et al. 2004, Possi, 2001). It has been the practice by HIV/AIDS service providers to pass information in mass to large, anonymous and heterogeneous receivers (Possi, 2001). It is often assumed that when information is given to the general population, those with disability will automatically be able to access it. From this assumption the person with disability is expected to fit in the world built to meet the needs of the non-disabled. If a person who is deaf or blind has difficulty accessing information displayed on billboards or printed brochures, it is taken for granted that the person is blind and not that the billboards or brochures are not designed for the blind (Kochung, 2000).

Passing information through print or electronic formats is good as it can reach a large population but it has always excluded people with disability particularly those who can not use their sight or hearing. When information is passed through print and electronic formats, then a proportion of the population is left out. This practice is discriminative since such information cannot be accessed by people who are blind or deaf (Managhan and Wilson, 2006). Information on HIV and AIDS is continuously being passed through radio, television, newspapers, large bill boards, internet, lectures or brochures which require the application of functional senses of sight and hearing if they have to be accessed and understood.

The understanding of HIV/AIDS messages passed through print and electronic formats does not only require accessing that particular information, but demands the ability to receive and process the information cognitively. It also requires certain level of literacy for one to be able to perceive, construct and interpret meaning conveyed in the message. The population receiving the message is expected to have good level of reading proficiency in

the language used in communicating HIV/AIDS messages. However, persons with disability in Kenya have low level of literacy and their proficiency in the two national and official languages (English and Kiswahili) used are poor as they live in rural areas where mother tongue is the main language of communication. Despite all these, agencies fighting AIDS pandemic in Kenya have used the two languages to do special promotional activities, features, and letters to the editors and opinion columns in newspapers and magazines in order to reach the general population with information on HIV/AIDS (KDHS, 2003).

The electronic media formats require equipments that use electricity which is not easily available in rural areas where the majority of people with disability live. According to Kenya Demographic Health Survey, 2003, there are education programmes on HIV and AIDS on both local and national radio stations but these do not take into considerations the needs of people with disability. These radio and television programmes normally involve non-disabled members of the society to discuss issues related to HIV and AIDS and rarely use persons with disability for the same purpose. Internet is increasingly being used to enable individual members of the society to exchange ideas on various topics, research findings and conferences with their fellow friends, however, those who are blind are limited in using internet facilities (Fungo, 2003).

Persons who are deaf or blind normally cannot access information through vision or hearing. While those who are blind do not benefit much from the information given through prints, large billboards, internet and televisions, the deaf do not gain from information given through radios verbal lectures and televisions. According to a study done by Kochung (2009), the deaf and blind mainly rely on information they get from second or third party and through informal social systems in which at times misinformation is construed to be the truth and passed to others (Meletse and Morgan 2006). Communication formats through billboards in urban areas and along major roads have been used in awareness campaign and sex education but the information sometimes do not reach the blind who cannot read the large billboards displayed along the roads and posters displayed in public places. The majority of HIV/AIDS awareness activities are concentrated in urban areas and do not reach rural areas where the majority of people with disability live.

Implications of Communication Formats on HIV/AIDS and People with Disability

The discovery of the virus that causes HIV and AIDS up to the development of effective prevention, treatment and management has occurred within 20 years. This is a short period for persons with disabilities to develop

strategies for dealing with a disease particularly taking into consideration that HIV is a highly stigmatizing condition associated with sexual and illegal drug use.

Providing disabled persons with HIV/AIDS message presents a critical problem to service providers due to lack of alternative communication modes and illiteracy among the people with disability (Meletse and Morgan, 2006).

Most persons with disabilities grow up in environments that encourage them to depend on non-disabled persons who communicate and make decisions for them within health care and social environments. In such environments the information usually reaches the disabled when it is too late. There have been cases where due to lack of communication the deaf have failed totally to know not only how the disease is contracted but its existence (Adoyo, 2006).

Lack of awareness on the need to reach persons with disability by the professionals in fighting HIV/AIDS pandemic has been a barrier to design, implementation and evaluation of effective programmes in Kenya. Many service providers are unaware and insensitive to the complexities of their communication with disabled persons. There have been cases where health care professionals who treat deaf patients have made a deaf patient to be pleased and relieved to having been told through interpreter or written communication that she or he is HIV positive (well or good) and does not need medical treatment. Things become more complicated when the service provider explains further to a deaf person that "it means you have HIV inside your body".

According to Perlman and Leon (2006), some persons with disabilities have taken the initiative to be involved in the fight against AIDS. Those disabilities with no intellectual dysfunction such as the deaf and the blind have been successfully used as peer educators since they understand members of their community better. This kind of practice has been experimented at the Galludet University in the US where the deaf themselves have been trained to be peer health advocates teaching their fellow students about safe sex. This is also similar to Multiply Agent system used in Brazil where deaf people who have been trained are used to visit places mostly frequented by the deaf population. In some communities some deaf persons or those with mild mental retardation have been married by their communities to widows infected with HIV/AIDS by their deceased husbands. Sometimes due to misinformation some deaf people have thought that HIV is a disease of the hearing people.

Lack of adequate and right information has led to a situation where some deaf people perceived HIV/AIDS as a family disease when two brothers suffer from the same disease. Women with disabilities face sexual exploitation and abuses from men who are non-disabled perceive women with disabilities as free from HIV virus. The main objective of this paper was to examine the implication of communication formats on HIV/AIDS information for

those who are blind and deaf in Kenya. Specifically, the study intended to find out from what sources people with disabilities obtain information on HIV/AIDS, and how current communication formats affect them in accessing HIV/AIDS information.

METHODOLOGY

Participants

The data for this study came from blind students and deaf students who were studying in three institutions. These institutions included one University and two middle colleges. As a part of this study, face to face interview was conducted with the students at their institutions of learning. Because this study was interested in specific communication formats, only those who met the following criteria were used; (1) ability to read and write (2) understands English/Kiswahili languages (3) enrolled in an institution.

Purposive sampling was used in this study and all those who met criteria from the three institutions were invited to participate voluntarily. In the two colleges the staff was used to help in the recruitment of the participants while at the university the researcher did it himself. Participation was completely voluntary and the final sample included 20 blind persons and 15 deaf.

Measures and Procedures

Items that were used in interview schedule and FGD were translated into Kenya Sign Language (KSL) for deaf participants and transcribed into Braille for blind participants. Interviews with deaf participants were done through sign language interpreters. There were two translators used during the interviews and focus group discussions and they were provided with the interview schedule to discuss and agree on the content and intent for each interview question. The two translators explored various KSL translations in an attempt to maintain the content and intent while ensuring the linguistic accuracy. The items used in interview schedule and FGD with blind persons were transcribed into Braille and given to blind participants. Although the method of collecting data was through interview and FGD, it was necessary to have the items in Braille format in order to ensure that the content and intent was maintained.

Specifically, the interview was conducted by the researcher himself and was assisted by trained research assistants. Interviews were conducted in private rooms while focus group discussions were done in small rooms within the institutions.

RESULTS

In order to answer research questions, the responses from the interviews and FGD were analyzed and themes emerged. The data from the two categories of disability were merged. Similar questions were asked to the two groups. Demographic characteristics of blind persons and those who were deaf showed some differences. The deaf were younger than the blind on average and there were more females among the blind than the deaf the female blind participants were more active in the interview and FGD than the deaf females.

Sources of information on HIV/AIDS

All the participants expressed that information on HIV and AIDS is important to everybody including those who are blind and the deaf. About 92% of participants in this study said that people with disability are more at risk than the non-disabled. The sources of information were different between the deaf and the blind participants. While the blind participants reported that their main source of information is through radio and friends, deaf students get information on HIV and AIDS from other deaf friends, posters and Kenya National Association for the Deaf. Deaf participants reported that they have received some information on HIV and AIDS through text message on their mobile phones and further suggested that they be given free services on mobile phone when asking information on HIV and AIDS. All participants further reported that non-disabled persons were favoured by the society because they have more communication formats such as internet, newspapers, radio, television, spoken language, large bill boards and print media. One blind participant said "I wonder a university is not able to transcribe even one handbook with basic information on HIV and AIDS in Braille? Are we so useless?"

Level of language used in various communication formats

All the participants reported that English or Kiswahili which are the main languages used to pass information on HIV and AIDS are a challenge to them because neither is their first language. The deaf participants said that some of the languages used to communicate concepts in HIV and AIDS are difficult and technical for them to comprehend. That printed materials are written in advanced English without pictures. One deaf participant reported attending a workshop on HIV and AIDS awareness but the language used by the facilitator was too technical for sign language interpretation. Participants further reported that information on HIV and AIDS should be in short clear sentences and as far as possible should include use of signs and photographs. A deaf participant

expressed his disappointed after a long discussion with his deaf friends before he could understand the meaning of being positive after HIV testing since positive meant something well to. Blind students showed concern for terms used, that the sighted members of the society use to describe those who are suffering from HIV and AIDS. For example, at one point people who are suffering from AIDs are thin and weak while at the same time those who are looking healthy and fat are carriers.

Inadequate and misinformation

About 90% of the participants expressed that in various occasions they have been given very little or sometimes misinformation by non-disabled on HIV and AIDS. One participant narrated a case in which he was made to believe that HIV is family disease when two brothers had died from the same disease. One blind young man participant reported that he was always warned by his sighted peers to be careful of beautiful ladies because they are carriers of the virus but later learnt that the sighed go for the same ladies.

Discriminative presentations on radio and television programmes

Both deaf and blind participants reported discrimination on the use of promotional activities on radio and television programmes on educating people and sharing of experiences on the effects of HIV and AIDS on individuals. Participants who were blind reported that although their main source of information is radio, they had not heard a blind person making any presentation on either local or national radio station. The same view was held by deaf participants, who said that the televisions have ignored the feelings and experiences of deaf people.

Current communication formats

All participants in this study emphasized lack of access to information and over reliance on hearing people. They further expressed the need to have accessible formats such as audio tapes, Braille, captioned videos, KSL. All the participants reported that current communication formats used in giving information on HIV and AIDS are limiting and discriminative. The deaf complained of use of non face to face technologies such as emails and phone that depend on speech and hearing. They also reported lack of sign language interpreters at all areas frequented by the deaf. The blind reported that large billboards and printed materials do not reach them

DISCUSSION

The study found out that the current communication formats are main barriers and are hindering the blind and deaf population from accessing HIV and AIDS information. Although all participants in this study were people who are literate, both the deaf and blind did not gain from prints. Most of the deaf could not access prints such as newspapers and brochures and when they accessed them, the language used was too technical and difficult. This situation may be associated with the use of either English or Kiswahili which is not first language for the deaf. Low reading ability among the deaf population may also contribute to low rate of readership of print materials. The blind participants though had good reading level in Braille had no single reading material on HIV and AIDS information in Braille format. The findings showed that the deaf get information on HIV and AIDS through their deaf peers who have also received it from their hearing friends and it is likely that by the time the facts and ideas reach them it is already distorted by the friends and society.

Although agencies fighting AIDS pandemic in Kenya have used various communication formats through bill boards, postures, newspapers and magazines, radios, televisions to persuade people to change their way of life in relation to HIV and AIDS, the information in most cases do not reach the blind who cannot read large billboards and the deaf population who cannot read listen to radios or uncaptioned television news.

CONCLUSIONS

People who are blind are unlikely to learn from books while those who are deaf get visual messages from television but miss to learn complete meaning of the message because news and informative television programmes are often not captioned. That text messages on HIV and AIDS be made free for deaf persons

Communication formats on HIV and AIDS information for people with disability should be accompanied with alternative modes of communication that includes; well trained sign language interpreters, captioned media, sign language posters, free telephone with visual and audio text message system for emergency needs, Brailled materials, large prints and captions, pictures and diagrams. Health practitioners who intend to pass information to the general population including those with disabilities should pay attention to literacy level of target group particularly when such information is intended for the people with disability and those living in rural areas.

They need to train and use disability HIV counsellors so that persons with disabilities can access their services in the community.

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