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Access to Health Information by People Living with HIV/AIDS in Nigeria

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Introduction

Information is an indispensable for human development. Losce (1990) describes information as the knowledge communicated or received concerning particular circumstances. In the opinion of Okwilagwe (2000) information is an input, which reduces the level of uncertainty in any decision process. It is a crucial factor for a healthy life. Access to quality health information is critical to many facets of health care design and delivery.

Health information is published and unpublished knowledge on all aspects of health and healthcare. Individuals seek healthcare information for reasons ranging from curiosity to self-diagnosis and treatment (BIREME/PAHO/WHO, 2008). This is particularly true for people living with HIV/AIDS (PLWHA). Nigeria has an estimated 3.5 million infected persons (FMINO, 2007). It is imperative that they be adequately empowered with information to make the right decisions pertaining to their health.

The role of information for PLWHA cannot be ignored. Information is vital to relieve pain and discomfort, both physical and mental. As posited by Peterson and Obileye (2002), information helps extend and improve the quality of life by reducing viral load. The absence of information can lead to interrupted treatment and self-medication (Colebunder, et al., 1997). Access to quality healthcare information and knowledge by PLWHA is very essential. In a survey carried out by Erica (2008) on barriers to equitable access to health information, major barriers were lack of political support, information infrastructure and workforce capacity, and the high cost of accessing up to date, timely, and relevant information.

In Nigeria, HIV/AIDS was first identified in 1985 and reported at an international conference in 1986 (Adeyi, et al., 2006). It is a significant barrier to development as 170,000 Nigerians died from AIDS in 2007 alone (UNAIDS, 2008). The country has already surpassed the 5 percent explosive prevalence phase; thus far, this disease has killed more than 1.3 million and orphaned more than 1 million children (FMINO, 2007). The infection rate in Nigeria varies across state and communities. The main mode of HIV transmission in Nigeria is largely through unprotected heterosexual sex. Factors such as poverty, sexually transmitted infections (STIs), social and religious norms, and political and social changes (e.g., labor migration) contribute to increasing rates of HIV in Nigeria (National AIDS/STD control programme/FMOH, 2001). There have been efforts geared at halting the spread of HIV/AIDS by governmental and non-governmental organizations (NGOs), community-based organizations (CBOs), faith-based and media organizations, and other international agencies such as USAID, PEPFAR, Bill and Melinda Gates Foundations, CIDA, DFID, etc.

In spite of research and intervention efforts for prevention and treatment, access to appropriate health information by PLWHA in Nigeria constitutes a great barrier (NACA, 2005). To halt the spread of HIV/AIDS, access to quality health information by PLWHA is a sine qua non. That is the focus of this study.

Objectives of the Study

To ascertain the challenges of access to health information by PLWHA in Nigeria, a survey was carried out with the following objectives:

- Identify the demographic characteristics of people living with HIV/AIDS, (PLWHA).
- Identify the sources of health information used by PLWHA.
- Determining the frequency of access to health information by PLWHA.
- Identify constraints in accessing health information by PLWHA.

It is hoped that this study will help policy makers, healthcare providers, health workers, information providers, library and information professionals, and other stakeholders in the health sector to respond positively to the information needs of PLWHA by identifying such needs and exploring avenues to improving access to health information.

Methodology

The survey research design was adopted for the study. The population of people living with HIV/AIDS was drawn from the south south zone of Nigeria. This zone was chosen because it has the median HIV sero prevalence rate of 5.2 percent, the 2nd highest in Nigeria (National AIDS/STD control programme/FMOH, 1999). The sampled population of the study is made up of PLWHA who were at a Conference on AIDS and Sexually Transmitted infections in Akwa-Ibom state in Southern Nigeria on 11 th -14 th November, 2008. This conference was held under the auspices of AIDS Prevention Initiative in Nigeria (APIN). The instrument used for data collection was a questionnaire. The questionnaire was administered by a research assistant to PLWHA who volunteered to be respondents for this study. A sample of 120 people living with HIV/AIDS was randomly selected. Data was analyzed using descriptive statistics.

Findings and Discussion

Table 1: Demographic Characteristics of PLWHA

Variables	Frequency	Percent
Age:		
15 – 20	12	10 percent
20 – 24	30	25 percent
25 – 29	24	20 percent
30 – 34	22	18.3 percent
35 – 39	18	15 percent
40 – 44	8	6.6 percent
45 – 49	4	3.3 percent
50 – 54	2	1.7 percent
55 – 59	-	-
60 and above	-	-
Gender		
Female	79	65.8 percent
Male	41	34.2 percent
Occupation		
Distance Workers	29	49.2 percent
Former Sex Workers	21	17.5 percent
Artisans	20	16.7 percent
Politicians	20	16.7 percent
Business	18	15 percent
Public Servants	12	10 percent
Level of Education		
Tertiary Education	59	49.2 percent
Secondary Education	39	32.5 percent
Students (still schooling)	12	10 percent
Primary Education	10	8.3 percent
No Formal Education	-	-
Status		
Married	36	30 percent
Single	29	24.2 percent
Widow	18	15 percent
Divorce	17	14.2 percent
Pregnant	12	10 percent
Orphan	8	6.6 percent

Table 1 above indicates that a majority of PLWHA are between the 20 and 29 years old, presumably because this age group are more actively engaged in unprotected sex. Women (65.8 percent) are more effected than men (34.2 percent). This implies that they are more exposed to high risk sexual behaviour as a result of several factors, including cultural practices such as polygamy, traditional bias, early marriages of young girls, and lack of power of young married women to insist upon the use of a condom during sex (Population Council, 2007).

Nearly one quarter of the respondents are distant workers. NACA (2003) categorized distant workers to include migrant workers concentrated around the oil extracting industries, public servants who work away from their spouses, and long distance transport workers. This is follow by sex workers (17.5 percent). According to the Federal Ministry of Information and National Orientation (2007) this group constitute an important reservoir of HIV. Table 1 also shows that the disease has permeated all spheres of human endeavour.

Most (40 percent) of the people living with HIV/AIDS had one form of tertiary education or the other, while (24.2 percent) and (8.3 percent) had secondary and primary education respectively, (10 percent) are students. Also, majority of PLWHA (30 percent) are married, while (14.2 percent) are single. Divorcees accounted for (24.2 percent), Widow (15 percent), pregnant women (10 percent) and orphans (6.6 percent). This denotes that HIV/AIDS disease cuts across all status groups as earlier affirmed by Peterson and Obileye (2002).

Table 2: Sources of Health Information used by PLWHA

Sources of Information	Frequency	Percent
Workshop/seminars	105	87.5 percent
Medical/Health officers	101	84.25 percent
Mass media	92	76.65 percent
Non governmental organisations	98	81.75 percent
Friend/ colleagues	82	68.3 percent
ARV Trial Centers	72	60 percent
Donor agencies	68	56.7 percent
Hospitals	68	56.7 percent
Posters	44	36.7 percent
NACA/SACA Offices	20	16.7 percent
Churches	2	1.75
Ministry of health	18	15 percent
Journals	_	_
Libraries	_	_

Table 2 shows multiple responses in relation to the sources of health information used by the PLWHA. The responses indicated that 87.5 percent, 84.2 percent, and 81.7 percent of the PLWHA get information on health related issues through workshop/seminars, medical and health officers, and non-governmental organizations (NGOs) respectively. Very few (15 percent) and another handful (16.7 percent) get information through Ministry of Health and NACA/SACA offices.

It is important to know that PLWHA are not accessing information through journals and libraries as shown in the table above. This is in consonance with Anunobi (2006) that libraries are not doing enough to promote the prevention and treatment of HIV/AIDS in Nigeria.

Table 3: Frequency of Access to Health Information by PLWHA

Frequency of access	Frequency	Percent
Very often	79	65.8 percent
Often	38	31.7 percent
Rarely	3	2.5 percent
Very rarely	_	_

Table 3 shows that PLWHA access health information regularly. The continued survival of PLWHA depends on the amount of relevant health information at their disposal.

Table 4: Types of Health Information of PLWHA

Types	Frequency	Percent
ARV Medication	117	97.5 percent
Drugs availability and affordability	117	97.5 percent
NGOs activities	100	83.3 percent
Human Rights	85	70.8 percent
ARV trial centers	82	68.3 percent
Care and support	82	68.3 percent
Nutrition	79	65.8 percent
Foreign aids and donors	72	60 percent
Technical and vocational training	44	36.7 percent

Table 4 also reflects multiple responses to types of information of PLWHA. ARV medication and the availability and affordability of drugs ranked highest, at 95.5 percent. This corroborates Peterson and Obileye (2002) that access to drugs is one of the crucial components of care and support for PLWHA. This is followed by NGOs activities 83.3 percent. This may be connected with the fact that NGOs such as Civil Society Consultative Group on HIV/AIDS in Nigeria (CISCGHAN), Society of Women Against AIDS in Africa-Nigeria (SWAN), in collaboration with international agencies such as the Bill and Melinda Gates Foundation, DFID, USAID, and UNICEF are intervening in key areas in response to HIV/AIDS (Onwuliri and Jolayemi, 2006).

A majority of the respondents want information on human rights. This is partly due to the stigma and discrimination faced by PLWHA, who may seek to know more about their rights. Nutrition accounted for 65.8 percent, showing the importance of adequate nutrition for PLWHA. Akinyele (2005) posits that lack of nutrition makes people who are affected by HIV succumb more quickly to the full disease. Further responses from table 4 indicated that 65.6 percent want information on technical and vocational training. This is to enable PLWHA to contribute meaningfully to the economy.

Table 5: Constraints to Information Accessibility by PLWHA

Constraints	Frequency	Percent
Location of health care officers	112	93.3 percent
Inadequate fund	105	87.5 percent
Distance of ARV trial centers	102	85 percent
Shortage of qualified personnel	92	76.7 percent
Information materials not explicit enough	78	65 percent
Stigmatization and discrimination	72	60 percent
Absence of HIV/AIDS data/information exchange network	62	51.7 percent
Ineffective communication strategies	44	36.7 percent
Information materials not available in the library	_	_

The greatest constraints to access information by PLWHA as indicated in the table above, included location of health care officers (93.3 percent), inadequate fund (87.5 percent), distance of ARV trial centers (85 percent), and shortage of qualified personnel (76.7 percent). Akinyele (2006) points out that the number of trained medical personnel in HIV/AIDS epidemiology and care is inadequate. ART services are available in only 44 treatment centers in the country, with only 4 in the entire South South Zone (FMINO,2007). ARV treatment is almost non-existent in many teaching and secondary hospitals. These factors make it expensive to get information. This confirms Erica (2008) regarding barriers to equitable access to quality health information in South Africa.

Other constraints includes stigmatization and discrimination (72 percent), absence of HIV/AIDS data/ information exchange network (62 percent), ineffective communication strategies (36.7 percent), and information materials not explicit enough (78 percent). Communication is ineffective because PLWHA may find it difficult to understand available health information, because of the inexplicit nature of the materials, replete with medical jargon. Also PLWHA are shunned or disregarded, and not allowed entry into some hospitals, or are segregated with little attention from the rest of clinical and hospital populations. This discourages PLWHA from accessing relevant information.

Implications for Library and Information Service

The revelation in this study, that libraries are not sources of health information used by PLWHA, is a challenge to information professionals in Nigeria. The reason for this may be either that the library has not been consulted or that the needed HIV/AIDS information resources are not available in the library. There has been a shift in emphasis from the information provider to the information consumer. Consumers' needs must guide organizational strategy (Kunneke, 2001). To this end information repackaging to address specific needs of PLWHA becomes necessary. As reported by Iwhiwhu (2008), Saracevic and Woods (1981), and Bunch (1984), “repackaging” describes how an information service selects appropriate materials, reprocessing and packaging the information and arranging the materials in a way that is appropriate to the user. Rosenberg (1987) discusses this kind of repackaging in providing information to illiterate or semi-literate people in the Southern Sudan. Boadi (1987) mentions that abstracting and indexing, SDI, translation services, bibliographies, special bulletins and other current awareness services, are all forms of information repackaging.

Repackaging depends on the availability of information materials in libraries. Libraries must collect information on HIV/AIDS prevention and treatment. Advances in ICT should be used to facilitate this kind of repackaging. Information professionals must have the requisite professional qualifications and the subject knowledge to repackage information to meet the information needs of people living with HIV/AIDS in Nigeria. Workshops and seminars in this regard should be encouraged by libraries. Library

and information service professionals should collaborate with NGOs and other agencies to disseminate information. The Nigerian Library Association should be more involved in raising awareness of HIV/AIDS and other diseases. Such awareness is important n increasing knowledge and changing behaviour.

Conclusion and Recommendations

The study shows that the respondents need information on ARV medication, drug availability and affordability, NGO activities, human rights, ARV trial centers, care and support, nutrition, foreign aid and donors, as well as technical and vocational training. They rely more on workshops/seminars and medical/health officers for the provision of their information needs. Location of health care officers, inadequate funds, distance of ARV trial centers, shortage of qualified personnel, and information materials that are not explicit enough, among other things, were seen as constraints in accessing health information.

The study also shows that respondents do not use the library or that health information materials for PLWHA are not available in the library. To encourage the use of the library by PLWHA, efforts should be geared toward information repackaging to address specific needs. The following are recommended in the light of the findings of this study:

- Libraries should collect HIV/AIDS information materials. These materials should be made accessible to all library users.
- Libraries should educate users and organize awareness and outreach services in collaboration with NGOs on the subject of HIV/AIDS.
- Teacher librarians should educate their pupils through various information media on ways to prevent sexual transmission of HIV as well as treatment of HIV/AIDS.
- Library associations should be involved in public education on HIV/AIDS.
- There is a need for training and retraining of information experts to address the information needs of PLWHA in Nigeria.

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PLWHA This is used to denote an infected person and does not represent the existing network of People Living with HIV/AIDS in Nigeria. It is used in a general sense to mean all people infected with HIV/AIDS.

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Appendix: List of Terms

- ARV - Antiretroviral
- NACA - National Action Committee on AIDS
- SACA - State Action Committee on AIDS
- FMOH - Federal Ministry of Health
- IDA - International Dispensary Association

- OI - Opportunistic Infection
- STI - Sexually Transmitted Infections
- UNICEF - United Nations Children Education Fund
- UNAIDS - Joints United Nations programme on AIDS
- USAID - U.S. Agency for International Development
- DFID - Department for International Development