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Extent of Access to Health Information and Sources for Chronic Disease Patients in Tertiary Health Institutions in South East Nigeria: Implications for Libraries Role

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Abstract

Access to relevant health information is essential for helping people to take good decisions to enhance their health and well-being. The research examined the importance, level and sources of access to health information for patients with chronic diseases in two Federal Government Teaching Hospitals in South East Nigeria. The research is a cross-sectional survey that used questionnaire to collect data. Sample was 784 patients in two Federal Government Teaching Hospitals in South East Nigeria. Research questions focused on the importance of health information, extent of patients' access to disease, coping and treatment information. Findings show that while large majority indicated high access to treatment information, about one third to half indicated little or no access to many aspects of disease – specific and coping information. Major source of health information were health professionals. Internet, books, newspapers, pamphlets were also sources of health information. Health information providers can consider areas of low information access for possible focus when planning health information disseminating activities. For medical and public libraries in the zone, sequel to building good consumer health information collections, they should extend their services by engaging in outreach programmes to their user communities. This will serve the dual purpose of creating awareness of their collections and also improve access to quality health information to patients with chronic diseases.

Keywords: Health information Access, Health information sources, Health information needs, Consumer health information, Chronic diseases, Patient information services, Medical Libraries, Public Libraries.

Introduction

Illness and disease cause disequilibrium to the individual's well being. The provision of health information on patient's health problems and self-care at the right time may serve to encourage individuals to meet the challenges of living with the diseases and promote optimum health. Department of Health (2004) stated that there are two key types of information, both of which people need. First is general information available to all – about lifestyle options, care providers, diagnoses, conditions, self-care and treatment options (including risks), and standards of care. Second is personalized information – specifically on an individual's own condition, care options and possible outcomes.

Chronic diseases such as hypertension, diabetes, cancer, HIV and AIDS are long-term disease conditions with many associated stress factors such as physical discomfort, pain, impairment, emotional and psychological distress (Park, 2007). However as noted by Brain and Spine Foundation (2007), when patients with chronic diseases have good access to health information, they are better equipped to: improve their health and quality of life, increase their ability to take control of their health, be aware of treatment options and act as equal partners in their care. The importance of health information for patients' good self-care has led to the premise that access to health information is a fundamental right of all patients (World Health Organization, 1994; Pinnock, H. & Sheikh, 2004)

Health Information needs for managing chronic diseases

Various writers have highlighted the type of information needed by patients to manage diseases. Attfield, Adams and Blandford (2006) reported that clinical consultations provide significant reference points for the emergence of information needs. They recorded six need related themes which they expressed in the form of high-level questions:

- Am I ill?
- Who can help me?
- How can I prepare?
- Is the diagnosis right?
- Is the treatment appropriate?
- How do I manage my treatment?

Murray, Burns, See Tai, Lai, and Nazareth (2005) explained that people with chronic diseases have multiple needs, including information about their illness and the various treatment options; social support; support with making decisions; and help with achieving behaviour change, for example, changes in diet or exercise. Areas of information need for self management of chronic diseases can therefore be categorized as disease- specific, coping, treatment and lifestyle modification information needs.

Disease-specific information include information on the origin of the disease, known causes, associated symptoms, emergency symptoms, prognosis, complications, and things that might exacerbate the condition. Coulter, Entwistle, and Gilbert (1999) noted that “patients cannot express informed preferences unless they are given sufficient and appropriate information, including detailed explanations about their condition.” Patients need this information to understand the disease process and clear any misconceptions that might deter them from taking appropriate treatment to forestall undue development of complications.

Patients need to cope with the various facets of chronic diseases such as symptoms of the illness, emotional trauma of anxiety, depression and fear associated with living with the illnesses. Kalra and Baruah (2010) noted that effective management of chronic disease calls for development of coping skills. In the context of chronic disease, coping means dealing with the disease successfully, and managing it calmly. One has to learn how to handle life with these diseases, or cope with them. Information is noted as one element that is important in helping people cope positively with chronic diseases. Phipps (1986) posits that an important aspect of the ability to cope with a potentially serious illness is the desire for information about its various facets. Again according to Coulter, Entwistle, and Gilbert (1999) making sense of what is happening, identifying and satisfying information needs plays an important part in helping patients cope with the demands of their illness.

For most chronic illness, medication is the main instrument of management. Typically, this involves long-term use. Health information is noted as being important in the use of medication as well as for adherence to the regime. For instance, Nicolson, Knapp, Raynor, and Spoor (2009) remarked that medicines are the most common intervention in most health services. As with all treatments, those taking medicines need sufficient information: to enable them to take and use the medicines effectively, to understand the potential harms and benefits, and to allow them to make an informed decision about taking them. Written medicines information, such as a leaflet or provided via the Internet, is an intervention that may meet these purposes.

To satisfy health information needs, patients need access to relevant and accurate information.

Health information access

Health information access is the patients' ability to identify and obtain relevant, accurate and suitable information to satisfy health information needs. Lack of access to health information is a problem because this might create a vacuum in patients understanding of their diseases and ultimately affect their perception of their capability to manage these diseases. According to Jones (2003) health information access comprises physical availability and personal retrievability. Physical availability is existence of sources of health information as well as physical access to the sources. The physical sources of access include print and electronic format such as books, pamphlets, and the Internet. It also includes interpersonal exchange of facts, advice, and instructions between patients and health professionals, or peers. To achieve physical access to the sources, the individual user has to know that the information exists, where it can be found, and how to navigate the institutional structures to reach it (Burnett, Jaeger, and Thompson, 2008). The individual may also need help to understand, and act on health information, especially written information (Colledge, Car, Donnelly, and Majeed, 2008). Personal retrievability is the patient's ability to gain access to health information from the available sources. This may depend on factors such as health literacy level and relevance of the information to the recipient.

Sources of access to health information for patients with chronic diseases

Health professionals constitute a very important source of access to self-management information because they have the knowledge base to provide reliable and trustworthy health information to patients. Reports from developed countries show that although patients generally obtain health information from many sources, many prefer to receive health information from their health care providers (Twyford Consulting, 2008; Fox, and Purcell, 2010).

Other sources of health information include the Internet. This digital medium is a new and valuable source of access to health information. Available on the Internet are various patient centered websites offering disease-specific information, education, and advice to patients at different level of need. Peer organizations consisting of patients with similar conditions are good platforms and sources for sharing of self-care and coping information. Libraries are also sources of quality health information. Libraries can provide access to a range of authoritative materials in the form of books, specialized journals, and monographs on a range of health issues that are potentially useful to patients. Health sciences' librarians can also play an important role in pointing consumers toward

authoritative health information online (Medical Library Association, 1996). All these sources can be harnessed to provide self-management information for patients with chronic diseases.

Noting the importance of access to health information for proper disease management, the present study sought to determine level of access and sources for patients.

Objectives of the Study

The main purpose of the study was to find out the extent of patients' access to health information on their chronic illnesses. The study also ascertained sources of health information for patients in the two tertiary health institutions.

Research Questions

1. How important is access to health information for patients with chronic diseases?
2. What is the extent of patients' access to disease-specific information?
3. What is the extent of patients' access to treatment information?
4. What is the extent of patients' access to coping information?
5. What are the sources of health information for patients with chronic diseases?

Methods

The study was carried out in the two Federal Government University Teaching Hospitals in South East Nigeria: University of Nigeria Teaching Hospital (UNTH) Enugu State and Nnamdi Azikiwe University Teaching Hospital, Anambra state. These two hospitals provide a wide range of medical and surgical services to the people of South East Nigeria and also serve as referral centers to all other hospitals owned by the State Governments and private individuals in the zone. Participants were patients with chronic diseases attending clinics in the Medical and Surgical outpatients' clinics in the two hospitals. The study focused on patients with the following diseases: hypertension, diabetes, cancer, kidney diseases, HIV and AIDs. The study was approved by the Medical Ethics Committee of the two institutions studied.

A questionnaire named *Patient Information Access Questionnaire* was part of the instruments used to collect data for the dissertation study. The *Patient Information Access Questionnaire* reflected the structure of the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Group (EORTC QLQ-INFO 26) questionnaire (Arraras, et al. 2007). The EORTC QLQ-INFO 26 questionnaire items assessed the level of information received by cancer patients in general. *Patient Information Access Questionnaire* was however developed to suit the scope of the study. It

elicited importance of health information to the patients, and level of access to coping and treatment information they received from health professionals and obtained from other information sources. Access to disease information was measured using seven items ($\alpha = .827$) that relate to information on disease prognosis. Access to coping information was measured using six items ($\alpha = .916$) that dealt with various aspects of coping with chronic diseases. Access to treatment information was measured using six items ($\alpha = .902$) that dealt with treatment and adherence issues.

Response options for the information access variables were on a four-point scale: of (4) Much information (3) Some information (2) Little information (1) No information.

The questionnaire also measured sources of access to health information. Fourteen different sources were listed ($\alpha = .871$): Respondents rated how often they obtained information from the sources on a four-point scale of (4) Very Often, (3) Often, (2) Occasional, (1) Not at all.

Data Collection

Questionnaires were hand administered to patients by the researcher and research assistants in the Medical Outpatient clinics, the Oncology Clinics, and the Retroviral Disease Clinics of the two hospitals. One thousand and eighty questionnaires were distributed to the patients 784 properly completed questionnaires were obtained. This represents 73% of the distributed questionnaire. Two hundred and thirty-four copies were not properly completed, while Sixty- two copies were not returned.

Method of Data Analysis

Descriptive statistics were calculated to obtain results from the data. All computations were done using SPSS Computer Software Package Version 17.

Results

Demographic characteristics of study participants

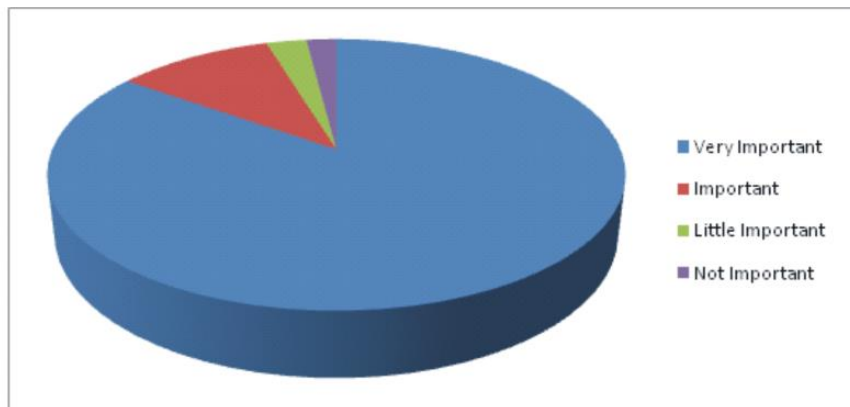
There were more females than males among the 784 participants in the study and they constituted almost two-third 480 (61.2%) of the respondents. Males were 304 (38.8%) in number. Almost equal numbers 271(36.6%) and 272 (36.7%) were aged 30-44 and 45-64 respectively. Eighty-four (10.7%) participants were aged 18-29, while 157 (20%) were aged 65 and above. More of the patients have Tertiary education 238 (30.4%), 226 (28.8%) have Primary education, 211 (26.9%) were trained up to secondary level and 108 (13.9%) have no formal education. The highest percentage 337 (43%) of the respondents had HIV and AIDS. This is followed by hypertension 204 (26%), diabetes

131(16.7%), co-morbidity of hypertension and diabetes 52(6.6%), cancer 40 (5.1%) and kidney disease 20(2.6%).

Perception of the Importance of Access to Health Information to Management of Chronic Diseases

To find out if the patients need access to health information on their diseases, they were asked to rate the importance of having health information on their illnesses. Figure 1 shows patients’ perceptions of the importance of health information to the management of their chronic diseases. Large majority of 747(95.3%) rated access to health information as very important and important in the management of their diseases. Only a small percentage (4.7% n= 37) rated access not important or of little importance.

Figure 1: Importance of Access to Health Information



Extent of Access to Disease-Specific Information

Figure 2: Extent of Access to Disease-Specific Information.

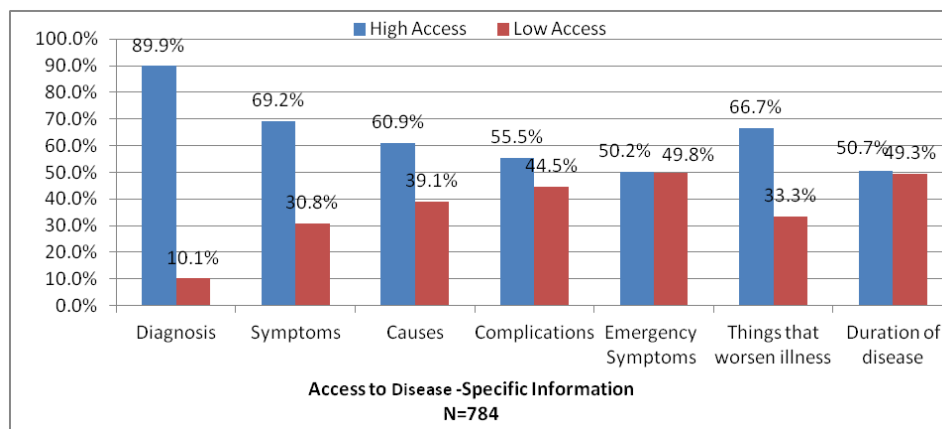


Figure 2 shows Patients' ratings of level of access to disease-specific information in terms of high access (some or much information) and low access (little or no information). Disease diagnosis was the only area where a large majority 642(81.9%) indicated having high access to information on their diseases. About two – third indicated high access to information on symptoms of disease 542(69.2%), things that worsen the disease 523(66.7%), and causes of disease 477(60.9%). About half the patients indicated high access to information on complications of disease 55.5% (435), duration or chance of cure 50.7% (398) and emergency symptoms of the disease 50.2% (393). However, this range of access shows that about one third to half the patients indicated they received little or no disease – specific information.

Extent of Access to Treatment Information

Figure 3: Extent of Access to Treatment Information

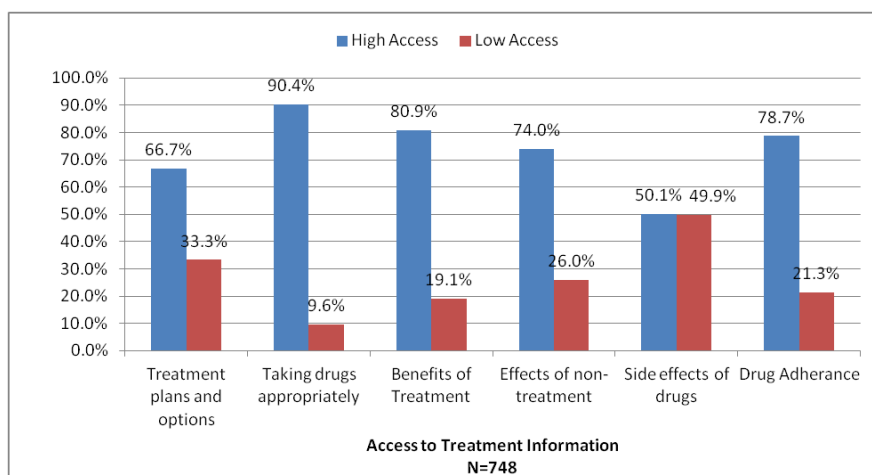


Figure 3 shows patients' ratings of level of access to treatment information. Majority of the respondents indicated high access (some or much information) to the items of treatment information. Seven hundred and nine (90.4%) of the respondents indicated high access to information on how to take prescribed drugs correctly. Large majority 635 (80.9%) also indicated high access to information on benefits of treatment. A high percentage (78.7% n=617) received information on importance of drug adherence and the effects of non-adherence 580 (74%). However, only slightly above half indicated high access to information on side effects of drugs 50.2% (393). This means that a high percentage of 391 (49.9%) indicated little or no access to information on side effects of their medications.

Extent of Access to Coping Information

Figure 4: Extent of Access to Coping Information

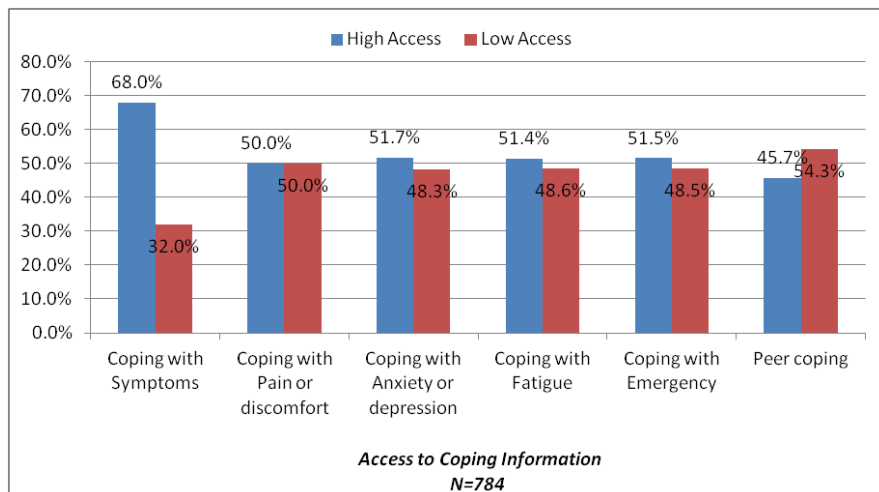


Figure 4 shows patients’ ratings of level of access to coping information. There was low access to coping information except for information on coping with symptoms of diseases where a higher percentage of 68% (533), indicated high access (some or much information) to this information item. Slightly above have the respondents have high access to information on coping with anxiety (51.7% n=405), coping with emergency 51.5% (404), and coping with fatigue 403 (51.4%). Half of the patients 392 (50%) have high access to information on how to cope with the discomfort or pain associated with the diseases and less than half 45.7% (358) have high access to information on how others are coping. This level of access for coping information shows that almost half the patients indicated receipt of little or no information on how to cope with anxiety, emergency, fatigue and the discomfort or pain associated with their diseases. More than half (54.3%) indicated low access to information on how others are coping which might indicate low interactions with peer groups.

Sources of Health Information

Figure 5: Patients' Sources of Health Information

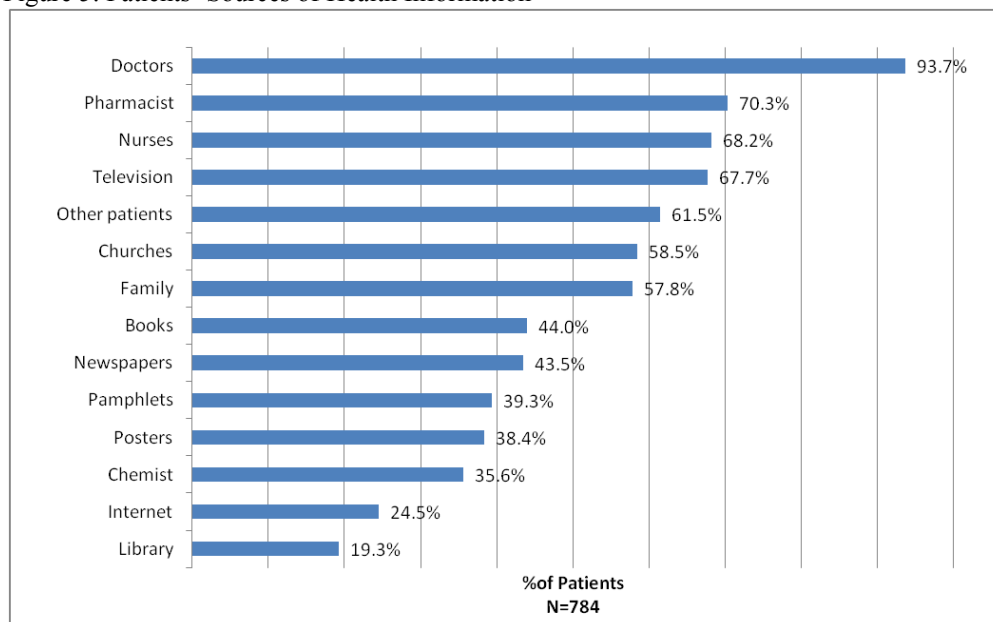


Figure 5 shows patients' sources of health information. Generally human sources were major sources of access for the patients (Figure 5). Doctors were the major source of health information with 756 (93.7%) indicating receiving health information (occasionally to very often) from this group of health professionals. Others are Pharmacists 551 (70.3%), Nurses 535 (68.2%) and other patients 482 (61.5%), Churches 459 (58.5%), family (57.8%) and Chemist or patent medicine dealers 279 (35.6%). Notable percentages also have access to information from mass media sources such as television 531 (67.7%), books 345 (44%), newspapers 341 (43.5%), pamphlets 308 (39.3%), posters 301 (38.4%), and the Internet 192 (24.5%). The least source of health information is the library. Majority of respondents 633(80.7%) did not access health information from the library.

Discussion

The study looked into access to health information for patients with chronic diseases in two Federal teaching hospitals in South East Nigeria. Findings from data analyzed showed that responses to questions on level of access to various information items needed to support self-management of chronic diseases varied. Large majority (74% to 90.4%) of the patients indicated high access to five items of treatment information compared to access to items of disease specific and coping information where one third to half the patients indicated having little or no information on almost all

aspects of their diseases and how to cope. This suggests that these patients may not have obtained relevant and accurate information to satisfy health information needs and indicate there is information gap for many of the patients. This information gap is greater for coping information where almost half the patients indicated they have little or no access on information on how to cope with the physical and emotional challenges of their illnesses. Coping information is especially important as it can empower patients to maintain a good quality of life while living with these lifelong illnesses.

This information gap might create a vacuum in patients' understanding of their diseases and ultimately affect their perceptions of their capability to manage these diseases. Poor perceptions may lead to low quality of life. The information gap therefore points to a problem that needs to be addressed considering that very large majority of the patients considered access to information as being important and very important to the management of their diseases.

The level of information access recorded in this study is in the range reported by Adler et al., (2009) that more information were received by oncology patients about diagnosis, spreading and possible causes of the disease, and less information was received on patient support groups, coping with the disease at home and psychological support. However, there is difference in receipt of treatment information which ranked as the most accessible information for patients in the present study, but was less received by the oncology patients.

Patients' Sources of Health Information

Doctors were the predominant source of health information. A very high percentage (93.7%) of the respondents indicated receiving information from this group of health professionals. This result is consistent with findings from other parts of the world which reported that health professionals especially doctors are the predominant, highly trusted and preferred sources of health information for patients with chronic diseases (Hesse, 2005; Burkel2006). Results also indicated that some of these patients use other mass media sources such as television, books, newspapers pamphlets, booklets and the Internet to obtain health information. It is noteworthy that 24.5% of Internet usage found in the study is within the reported range of 4.0% to 41.5% of Internet use by cancer patients (Muusses, Weert and Dulmen, 2011) This is an indication that the Internet as a new source of health information also has potentials that can be exploited to provide these groups of patient in Nigeria self-management information.

Low levels of access to many aspects of self-management information for a good proportion of the respondents underscores the need to develop resources that will ensure that all patients who need information have access to quality health information at the point of need and at all times. Health professionals in their pivotal role as providers of self-management information to patients can facilitate the use of other information sources by directing or referring patients to the sources (Schauffler, 1999) such as libraries, validated and relevant websites, peer support organizations etc.

Implications for Libraries Role in Nigeria

Results of the study show that a sizeable number of patients have access to health information from televisions, books, newspapers, Internet. These are information resources found in a standard library. Yet quite a very high percentage of these patients do not access health information from the libraries. This calls for re-evaluation of roles of medical and public librarians in Nigeria as sources of health information. The medical library as an information resource has potentials to provide access to quality, reliable, and up-to-date health information to patients with chronic diseases. Gathoni (2012) noted that in regions that lack adequate information systems, librarians can play a role facilitating access and use by information seekers, because they are: aware of the needs of users, familiar with new information and communication technologies to meet local needs, and have access to some current sources of evidence-based information. Medical librarians in many countries have expanded their role by developing diverse initiatives to provide information to patients. For instance, The United States National Library of Medicine maintains some important consumer health information websites such as *MedlinePlus*, and *ClinicalTrials.gov*. These websites provide reliable, up-to-date and accessible information for the consumer as well as health care professionals (Pullen, Jones and Timm, 2001)

While the internet is a major source of health information and libraries in developed countries can harness it to provide health information to the people, it is not so in Nigeria where many do not have access to the Internet and when available, the services are costly and epileptic. Quality of health information on the internet is also of concern. There is no control measure for information posted on the Internet. Some may contain misinformation which may prove dangerous for consumers. Patients may therefore need help in identifying quality and safe information. This issues accentuates the need for libraries to be involved in making information available to people. Low use of libraries as recorded in the study may mean that people in the study areas may not be aware of information services libraries can provide. There are established medical libraries in the two institutions studied. There are also functional public libraries in the two states with branches spread out in many towns of

the states. Since majority of the respondents considered access to information as being important and very important to the management of their diseases, librarians in these libraries should develop vibrant consumer health information resource collections and take a more proactive role in creating awareness of these collections and services in the libraries. Outreach is the key to creating this awareness for making health information accessible by libraries. Libraries are accomplishing outreach programmes by working with schools, churches, senior citizen centers, and other community-based programs (Chobot, 2010). Outreaches will help people know that information exist, can be found in libraries and can be accessed freely.

Outreach to patients in a setting like the teaching hospitals studied may be in the form of participation in peer group meetings which is highly organized for illnesses like HIV/AIDs. Librarians can seek platform to introduce the importance of seeking information in disease management, the library collections and its advantage in providing quality information. Since some of the respondents in the study access health information online, librarians can also create awareness to very credible health information websites. The librarians can also work in partnership with health professionals to strategically place easy to read pamphlets and leaflets in the clinics with reference to more information being available in the libraries.

However, for access in the community, the public libraries are in the best position to reach out to the people (McDaniel, Babcock-Ellis and Hernandez, 2011). Public libraries operated mobile library services in this region. These services were used to provide information to the underserved communities. For creating access to health information, the idea of reaching the underserved can be reintroduced and accomplished through outreach programmes. In planning the outreaches, management of the Public libraries need to set up an outreach team that will coordinate the outreaches. This will help ensure coordinated attention to the programme. The outreach teams of the libraries can plan variety of programmes designed to raise awareness of the public library collections and services to the people and also increase access to quality health information. These programmes can be in the form of librarians participating fully in community programmes such as churches and town meetings which are regular activities in the South East. Very popular is the women's general meeting held in August every year popularly known as 'August meeting.' This is a great gathering of women every year in all towns in South East Nigeria. Lots of important information including health information is shared in the gatherings. The librarians involved in outreaches can plan an outreach schedule to these meetings where they can give presentations on health information and its access through the libraries. Also they can arrange to work in partnership with health professional and

support the presentations in these meetings through the use of pamphlets, posters, leaflets audio-visual presentations that are tailored to health literacy level, and education of the communities on a variety of health topics. Parker and Kreps (2005) suggested the use of non-written materials to convey important information to patients with limited health literacy. Even patients who read well often prefer non-written materials, including straightforward picture books, videotapes, audiotapes, or multimedia presentations. Information materials should be provided in Igbo and English languages and in non technical terms. All these efforts may help people with chronic diseases to consciously seek and obtain health information that may empower them to take good decisions on their health.

Conclusion

Findings of this study showed that large majority of the patients considered health information to be important to the management of their chronic diseases, yet a good proportion of the patients reported low access to vital information needed to help understand and cope with the challenges of living with chronic diseases. Health information providers including librarians, health professionals can consider these areas for possible focus when planning health information disseminating activities. For medical and public libraries such activities include developing vibrant consumer health information resource collections and creating awareness and usage through outreach programmes. However further research is needed to identify inhibitors to free flow of information to these patients and strategies to apply that will ensure patients have equitable access to self-management information needed to live successfully with chronic diseases.

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