



## CONSUMER HEALTH INFORMATION LITERACY: THE LIBRARIAN'S VIEW

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### ABSTRACT

*The aim of the paper is to investigate the practice of health information literacy among the patients receiving treatment on Rheumatoid arthritis and to explore the role of medical librarian in the annals of health information literacy. As there is paucity of literature on health literacy in Nigeria, this paper will help inform discussion/research on the state of HIL of Nigerians, whether health professionals and health consumers are knowledgeable of HIL. The study involved identifying 15 patients out of 19 receiving treatment, sought their consent, collected some personal data and elicited information, through the use of interview with a set of questions that related to their health condition and information. The paper finds out that adequate health information literacy is important and necessary to patients' partnership and participation in the decision-making process and for effective health care. This paper has significant implications for health literacy programmes in Nigeria, as it is clear that both written and oral (listening) health information delivery are preferable. However, a range of access, resources, and skills barriers prevent health care givers from fully engaging in, and benefitting from the intervention. The paper has significant implication for further research on other health related matters.*

**Keywords:** Health literacy, Medical librarian, Consumer health information, Rheumatoid arthritis, health information

### Introduction

Global health challenges have gained more attention in the last few years due in part to the fear of global epidemics and extreme social and economic impact of HIV/AIDS especially in Africa, which indicates a complex interface between general literacy and health literacy (Kickbusch, 2001). While general literacy is an important determinant of health, it is not sufficient to address the major health challenges facing the developing countries. A health



literacy index could become as important composite measure of the outcome of health promotion and prevention activities, and could also document the health competence and capabilities of the population of a given state, community or group as well as relate it to a set of health, social and economic outcomes. Health literacy according to Centre for Health Care Strategies Inc., (2000) is the ability to read, understand and act on health care information. Furthermore, functional health literacy is the ability to apply reading and numeracy skills in a health care setting. These skills include: ability to read medicine labels, inserts and other written health information; understand written and oral information given by the health professionals; and act upon necessary procedures and directions such as medication and appointment schedules. It must be noted that health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, and maintain good health.

More than 80% of Africans live in oral and visual cultures-cultures that learn through listening and watching, not through reading and writing. The media, which is increasingly becoming a key source of health information to some people, is gradually changing the cultures of Africans. Low health literacy is a major problem of many African societies because it contributes to the denial of health benefits to a large segment of the population. There are more hospitalization, poor ability to understand labels and health messages and poor ability to take medicine schedule, while in older people, it is linked with overall worse health status and higher mortality rates, hence the need for vibrant health information literacy among the rural populace.

Health librarian can actively develop partnership with literacy groups (adult basic education), public and private schools and public libraries to disseminate health information to the teeming grass-root dwellers. He can also be involved in the community based organizations, retired citizen facilities and even health care associations. These may take the form of providing space for meetings, health literacy materials, actively developing health literacy programs, sponsoring health literacy seminars etc. The health/medical Librarian may also need to encourage research on health literacy topics by providing relevant materials that are easy to read and understand. For the health providers, he can provide the ways in which access to Evidence-Based Practice (EBP) medical information can improve health literacy. A good example is the Medline Plus, a website tool for medical information and medical library (Schardt, 2011).

Major barriers to health information literacy in the health sector include: clinical questions that ensue during consultations; frustrations arising from endless waiting to see medical personnel; endless paper work which tend to cause delays in giving prompt attention to the infirm; inadequate time on the part of the health providers; lack of access to resources; inadequate training in understanding health literacy; and finally diverse users of health information who need information skills. This paper therefore, attempts to investigate the level or degree of health information literacy of health consumers and to explore the role of medical librarians in the annals of health information literacy.



## **Review of Related Literature**

Information is crucial, but will never be sufficient to address many of the major challenges faced by disenfranchised and marginalized people. Components of health literacy such as access to information and knowledge, informed consent, and negotiating skills must constitute part of the overall development effort. Elsewhere, Gann (1991) and Rees (1996) noted factors that have stimulated the acknowledgement of those involved in health care that patients have a set of rights and responsibilities to be given a clear explanation of any treatment or procedure proposed including any risks before deciding whether to agree to the treatment. The growing movement towards evidence-based practice has combined to push information for patients towards the top of the health agenda. Hence there is an increasing volume of literature illustrating the benefits of having well-informed patients who can partner in decision-making about health care (Greenfield, Kaplan and Ware, 1985).

The importance of health information literacy on patient care cannot be overemphasized. Several studies have been conducted on how providing patients with adequate information increased their adherence to treatment. Donovan and Blake (1992) estimated that about 30-50 percent of patients fail to follow their prescription correctly simply because they do not understand instructions fully or are afraid of possible side-effects. They concluded that lack of information is the most common cause for drug failure or relapse of illness in patients. George (1987) revealed in his study that within few minutes of leaving the consulting room, patients forgot 50 % of what they have just been told by health professionals. Furthermore, Bogear and Stichele (1919) indicated that most people would want to have more information about their treatment. Whyte (1994) asserted that provision of written drug information, in addition to verbal instruction, improves patients' knowledge about their medicine or treatment.

In Nigeria, for instance, studies on health information literacy are very scanty except a few that were conducted not long ago. Ajayi (2002) conducted a study on patients suffering from hypertension and receiving treatment in a clinic, the result of the study shows that the level of health information literacy of the patients was low, not much information were given to the patients on the illness they were suffering from. Also, Ajayi and Adewale (2010) carried out a pilot study on mothers whose children were undergoing rehabilitation in a nutrition clinic for malnutrition; the outcome shows that mothers were not well-informed. Recently a survey of information literacy among medical students in the College of Health Sciences, Niger Delta University, Yenagoa, Nigeria, revealed that medical students have poor skills in information literacy (Baro, Endouware, and Ubogu, 2011) and concluded that medical librarians and faculty members should collaborate to integrate information literacy skills into the medical curriculum.

## **Nature of Rheumatoid Arthritis**

Rheumatoid arthritis is described as a chronic systemic disease characterized by inflammatory changes in joints and related structures. It is an autoimmune disease that causes



chronic inflammation of the joints. It occurs in women more often than men (ratio 3:1) between ages 35-45. The cause is unknown but genetic factors may also play a role. Even though infectious agents like viruses, bacteria, and fungi have been suspected but none has proven as the cause. Predisposing factors include: fatigue; emotional stress; infection, etc. In most cases, it commonly affects smaller peripheral joints of hands and also involves wrists, elbows, shoulders, knees, hips, ankles and jaw. If un-arrested, the affected joints progress through four stages of deterioration: synovitis, pannus formation, fibrous ankylosis and bony ankylosis.

The disease is characterized with these symptoms: fatigue, anorexia, malaise, weight loss, slight elevation of temperature, etc. In most cases, joints are painful, warm, swollen, limited in motion, stiff in the morning and after periods of inactivity, and may show crippling deformity in long-standing disease. Against this background, most patients with rheumatoid arthritis have to regularly attend outpatient clinics. Some clients have additional extra-articular manifestations such as subcutaneous nodules, eye, vascular, lung or cardiac problems. In order for the patient to become functionally independent, he must be instructed (educated) and trained, hence the need for health information literacy.

### **Methodology**

The study employed a descriptive survey method which involved identifying respondents of 19 patients receiving treatment for rheumatoid arthritis in a hospital. Selection of patients involved firstly examining the needs of a group of rheumatoid arthritis outpatients attending a clinic for health information literacy. In the final analysis, 15 patients (3 males and 12 females) were identified who kept their regular appointment. Respondents were selected after obtaining permission from the patients waiting to see the doctors. The permission sought for their readiness to participate in the study and further get the consent of the hospital authority. Some personal data were then gathered from them. Interview method was used to elicit information. This method was adopted so as to have personal interaction with the respondents. Self prepared and well structured questions were asked which they responded to. The results of the interview were then analyzed with simple percentage.

### **Results**

#### *Profile of Respondents*

The ages of the respondents ranged between 45 and 60 years. Virtually all of them were educated literates. There were twelve (12) males and three (3) females, all residing in cities.

**Table 1: Areas that patients needed information**

| S/N | Information needed                            | Respondent | Percentage (%) |
|-----|---|------------|----------------|
| 1.  | Causes of Rheumatoid arthritis                | 14         | 93.3           |
| 2.  | Possible complication of Rheumatoid arthritis | 7          | 46.7           |
| 3   | What is the prognosis?                        | 15         | 100.0          |
| 4.  | Why were you placed on some drugs?            | 8          | 53.3           |
| 5.  | Symptoms the drugs are expected to relieve    | 5          | 33.3           |
| 6.  | Likely side-effects of the drugs              | 10         | 66.7           |
| 7.  | Length of time the drugs have to be taken     | 12         | 80.0           |
| 8.  | Where to store the drugs                      | 3          | 20.0           |
| 9.  | Other drugs that were safe to take            | 6          | 40.0           |
| 10. | Kinds of diet to be eaten                     | 13         | 86.7           |
| 11. | Why are they good for you                     | 9          | 60.0           |
| 12. | Possible life style change                    | 6          | 40.0           |

In Table 1, the respondents were requested to indicate areas where they needed information most. A list of items was presented to them; the result shows that they needed information in all areas. For a patient to effectively participate and have good outcome of his treatment, he needed to be well informed on his illness and treatments. This is an indication that patients need vital information on their health, and this is the area where the medical librarian can be of help.

**Table 2: Mediation of Health Information Literacy**

| S/N | Mediation                                       | Responses | Percentage (%) |
|-----|---|-----------|----------------|
| 1.  | Oral literacy forms                             | 10        | 18.5           |
| 2.  | Visual arts (diagrams, pictures, paintings etc) | 13        | 24.1           |
| 3   | Written information                             | 11        | 20.4           |
| 4.  | Internet sourcing                               | 05        | 9.3            |
| 5.  | Mixture of both                                 | 15        | 27.7           |
|     | <b>Total</b>                                    | <b>54</b> | <b>100.0</b>   |

Table 2 reveals that 27.7% of the respondents preferred a mixture of oral and written information, while 24.1% favored visual arts as mode of passing information, which they thought would constantly be a reminder; demonstrating the fact that one can easily forget what was verbally told. This result concurs with the earlier study of Whyte (1994) that written information, in addition to verbal, improves patients’ knowledge about their treatment because they would always remember the instruction given at the clinic since they could always read it from time to time.

**Table 3: Information sought from health providers**

| S/N | Information from health providers | Response  | Percentage (%) |
|-----|-----------------------------------|-----------|----------------|
| 1.  | Physician                         | 7         | 15.6           |
| 2.  | Pharmacist                        | 4         | 8.9            |
| 3   | Nurses                            | 15        | 33.3           |
| 4.  | Medical Librarian                 | 2         | 4.4            |
| 5.  | Information on leaflets/labels    | 9         | 20.0           |
| 6.  | Colleagues in the Clinic          | 7         | 15.6           |
| 7.  | Self                              | 1         | 2.2            |
|     | <b>Total</b>                      | <b>45</b> | <b>100.0</b>   |

In table 3, the respondents disclosed that whenever they attended the clinic, nurses gave them more 33.3% information than any other health care personnel, and that the medical Librarian, who is regarded as information provider to health professionals only provided little information. Information on leaflets/labels (20.0%) was deemed helpful. Patients not receiving adequate information on their treatment might be due to no time “*syndrome*” of doctors and nurses and consequently leading to poor service to patients and eventually poor outcome of treatment. This however agrees with Khudair and Cooke (2008) that because of workload in the hospital, health professionals do not have enough time to adequately attend to their patients’ needs. Here, the medical librarian can do a lot by providing enough information to patients.

**Table 4: Time spent during consultation with doctor**

| S/N | Time spent for consultation | Patient   | Percentage (%) |
|-----|-----------------------------|-----------|----------------|
| 1.  | 0 - 5 minutes               | 8         | 53.3           |
| 2.  | 5 - 10 minutes              | 4         | 26.7           |
| 3   | 10 - 15 minutes             | 2         | 13.3           |
| 4.  | 15 - 20 minutes             | 1         | 6.7            |
|     | <b>Total</b>                | <b>15</b> | <b>100.0</b>   |

In table 4, the patients/respondents were also asked to quantify in minutes how long they stayed with their physicians on each visit. Majority (53.3%) affirmed that they did not stay more than five minutes per visit, 26.7% indicated 5-10 minutes, while the least was 6.7% translating to 15-20 minutes stay per visit. This finding is a confirmation that patients were not given adequate attention and enough information whenever they came for a review. This can be attributed to a long list of patients waiting to be attended to by the physicians.

**Table 5: Sources of Health Information Consulted**

| S/N. | Sources                                | Responses | Percentage (%) |
|------|--|-----------|----------------|
| 1.   | Medical literature in the library      | 10        | 18.2           |
| 2.   | Electronic media (Radio, TV. Internet) | 14        | 25.5           |
| 3    | Daily Newspapers                       | 7         | 12.6           |
| 4.   | Magazines                              | 5         | 9.1            |
| 5.   | Friends who are health professionals   | 9         | 16.4           |
| 6.   | Other patients                         | 10        | 18.2           |
|      | <b>Total</b>                           | <b>55</b> | <b>100.0</b>   |

In table 5, the respondents verbalized other sources of health information consulted. Electronic media (25.5%) appeared to be more used, while medical literature (18.2%) in the library and information from other patients were consulted. Others such as information from friends who are health professionals (16.4%) and daily newspapers (12.7) were also sought. The respondents were given the opportunity to choose more than one option. Even though the respondents are educated, result in table 5 reveals that they seldom read to gain information. This is an identified trend in most Nigerian culture. It is an indication that the reading culture is low compared to what obtains in contemporary world. Therefore, medical and health librarians have the herculean task of promoting and encouraging patients to read. This can be accomplished by making available relevant reading materials in common rooms designated for doctors and nurses, outpatient clinics, wards, etc. Thus, in this age of ICT, electronic resources should be inclusive.

### **Conclusion**

The results of this survey application suggest that adequate health information literacy is imperative to patients’ partnership and participation in the decision-making process and for effective health care. Moreover, health professionals need to develop proper skills for information literacy so as to influence their patients. This study therefore recommended that medical librarians and faculty members should collaborate in integrating information literacy skills into the medical and nursing school curricula. For workers in health care environments, adequate training should be organized on their seminar/clinical days, and during induction process of the new staff. The impact of health information literacy programme can be measured by the outcome of the patients. Furthermore, adequate attention should be given to patients whenever they come for review in order for patients to ask questions on their state of health. Medical Librarians should endeavour to provide information in form of leaflets, handbills, posters, etc. on various illness or diseases and make them available in various outpatient clinics.





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