Assessment of Health Literacy Levels Amongst Cancer Surviors in Nairobi Support Groups

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Abstract— Non-communicable diseases account for 71% of deaths globally giving rise to Health literacy as a strategy in management. While this is a worthwhile, there is need to measure and assess the health literacy levels of target beneficiaries as one way of evaluating effectiveness of health education programs. This study was undertaken with the objective of measuring the health literacy levels of cancer survivors in support groups within Nairobi (Kenya). A sample of 152 members of support group were subjected to a short health literacy test covering basic health topics discussed during support group meetings. Results indicated that majority of support group members had good knowledge of health topics and requirements for healthy behaviour. It was evident that health literacy sessions had successfully increased knowledge levels amongst support group members. Key recommendations included creating robust referral links to health literacy education for all cancer survivors.

Keywords— Health Literacy; Health Literacy Test; Health Behavior; Non-Communicable Diseases

I. Introduction

Proponents of health behaviour change have identified information and education as key elements in improving or changing behavioural patterns that influence health. This concept has been referred to as health literacy and has been used as a tool for management of both communicable and non-communicable diseases. Health literacy refers to ccognitive and social skills that empower individuals to understand, and use information in ways that promote and maintain good health. It involves planned efforts to provide targeted beneficiaries with knowledge and skills that empower them to make proper health decisions [1]. As such, health literacy has been incorporated in many global and national healthcare programs, especially those managing patients with long term illness. It is assumed that these patients are likely to enjoy better health due to adoption of improved health care behavior [2]. In the last decade, health literacy has been incorporated in health education programs such as cancer psychosocial support groups. This has not only improved the health of cancer patients but has contributed to reduced cases of mortality [3]. In Kenya, the government through the Ministry of Health has developed policy documents that outline the need to avail health information and education with the aim of promoting health behaviors [4].

To this effect, several non-profit organizations in Kenya have supported this strategy and facilitated the rollout of health literacy programs for cancer patients, both at health facility and community levels. By working through organized groups commonly referred to as support groups, these organizations create opportunities for regular dialogue between cancer health care professionals and patients undergoing cancer management [5]. Through this interrelationship, cancer patients not only receive social support, but are presented with the opportunity to access updated health knowledge and information. However, it is imperative to provide health literacy that can be understood, to enable the recipient translate it to practical use. In essence, this calls for the need to measure the amount of knowledge received and understood by the recipients. In the absence of assessment of health literacy levels, health literacy providers cannot effectively adopt health education to desired recipients needs and in the long run comprise the desired purpose of empowering patients [6]. This study sought to establish the levels of health literacy of cancer survivors who are members of cancer support groups within Nairobi. It was anticipated that findings would provide that would enhance cancer health literacy programs in Kenya.

A.   Health literacy

Health literacy refers to the extent to which individuals use their cognitive and social skills to obtain, process and understand basic health information and services needed to make informed health decisions [1]. It is a conscious motivation of individuals to gain access, understand and use health information in a way which promotes and maintains good health [7]. This is achieved through employing both cognitive skills such as; reading, comprehending and analysing consequences of health decisions, together with social processes of; accessing and understanding the information, achieving self-efficacy. As a result, an individual participates in self-care through the interaction of these cognitive and social skills [8]. Through the involvement of various levels

forms of communication, health literacy invokes a patient's involvement with their self and social environment to the point of making health care decisions.

1. Benefits of Health Literacy

The need for health literacy has grown in recent decades as a result of an increasing demand for health information to meet the rise in both communicable and non-communicable diseases [5]. Health literacy has been linked to better leverage in disease preventive behaviour, early diagnosis, improved health and lower health care costs [2]. On the other hand, absence of health literacy has been defined as a 'silent epidemic' due to its contribution to poor patient self-management with effects on quality of health [9]. Various studies indicate that patients who receive health literacy manifest better self-monitoring, enhanced understanding of prognosis and appreciate the need to adopt to lifestyle changes compared to patients with no health literacy. Medical experts thus promote the use of health literacy as a primary preventive and long-term disease management strategy, both for communicable and non-communicable diseases [10].

2. Forms of health literacy communication

These refer to the various modes of transmitting health literacy education from health care providers or agents to targeted beneficiaries. These forms can be used individually or as a combination, depending on the intended purpose or audience abilities and limitations. Some health literacy proponents encourage the use of a combination of delivery modes, to increase coverage and satisfaction to the audience [11]. As much as health literacy information can be presented in various forms, it should be structured and communicated in a manner that is simple and comprehensive to the target audience [9]. The use of simple language and presentation of material, is key in ensuring that information is not only clearly understood by recipients but can also be retained and repeated to other people [5]. Information on all forms of health literacy material should be designed to fit the audience needs and abilities of comprehension [12].

One form of health literacy communication is through written communication which contains relevant printed health information on health issues. It may include tools such as; a menu planner, medication schedule and instructions, an activity checklist, a health goal planner, medication reminder stickers, meal preparation instructions [13].

Verbal forms of health literacy information can also be used in the form of individual or group discussions with a health care provider [14]. This form of health literacy communication allows for dialogue between health literacy providers and the audience providing the opportunity to evaluate what the audience knows and what they need to know and tailoring information to yield maximum satisfaction [11]. Examples of verbal health literacy education is through support group discussions, health education seminars, one-on-one doctor and patient discussions.

Audio visual forms of health literacy communication are designed to make the information easier to understand as well as leave a lasting impression in the minds of the [15]. Videos are particularly useful for demonstrating self-care activities while audio forms are most practical for individuals who are visually impaired. Examples of video health literacy communication are; Posters, booklets/pamphlets or screens (Televisions, tablets, computers monitor) broadcasting slides, videos or computer programs. [16]. In addition, audio health literacy communication could be in the form of pre-recorded audio clips, podcasts, and live radio broadcasts [17].

B. Measuring Health Literacy

Majority of health literacy measurement tools are short and simple with the intention of assessing the functional health literacy level of respondents. This entails assessing the basic understanding of medical terms, processes as well as advice on healthy behaviour practices [18]. In most cases, these tests are administered orally and in some cases with the help of visual aids such as flash cards.

1. Tools for Measuring Health Literacy

There is no one universally accepted measuring tool, but rather a blend of existing tools to measure cognitive and social skills of various populations in respect to related health issues. These tools may employ the use of objective or subjective measurement modes providing both quantitative and qualitative data. Objective modes directly test an individual's skills when an interviewer asks questions and records responses at nominal or ordinal level, while subjective modes rely on patient self-reports and experiences [19]. This study makes reference to the database of health literacy tools as used by various researchers seeking to measure different aspects of health literacy either objectively or subjectively [20]. Examples of commonly used tools are; "The Test of Functional Health Literacy in Adults (TOFHLA)" and the "Rapid Estimate of Adult Literacy in Medicine (REALM)" which largely measure reading and pronunciation skills of interest for health care [21]. Other tools are more specific to the health issues in context such as the Newest Vital Sign (NVS) was developed to measure reading, comprehension, and numeracy using a nutritional label and a 6-item questionnaire.

II. Methods

Through the use of a sampling list of registered cancer support group members in Nairobi, the researcher determined the sample size with reference to Krejcie and Morgan sample determination formula for finite populations at 95% confidence level [22]. In total, 152 cancer support group members were interviewed from 5 sub counties in Nairobi.

Data collection was undertaken through administering a closed ended test of 15 objective questions based on topics discussed during the support group meetings. These test questions were based on; nutritional knowledge, medication adherence, understanding basic health parameters, calculation (of appointment dates, times, dosage), understanding basic cancer treatment and management strategies as well as diagnosis. All respondents were requested to fill out this test independently at the end of each survey interview at an average time of 4-5 minutes. Further probes on some of these responses was undertaken during the key informant interviews. All responses were cleaned, entered and tabulated in excel. Percentages and reported narrative have been used to present these findings.
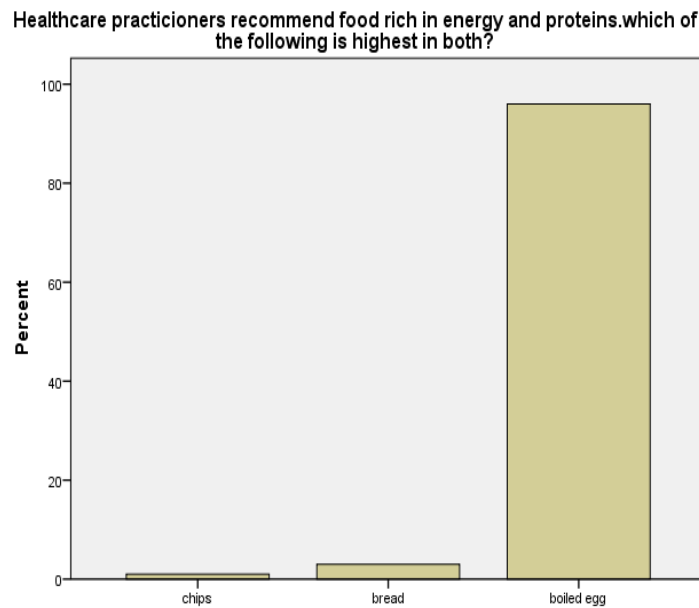
III. Results

Findings from this study indicated that health literacy tests had not previously been conducted within support groups, but rather support group leaders performed informal assessments regularly made based on knowledge levels discerned during monthly support group meetings. This was done through *asking general questions on cancer* and using this feedback to assess for information gaps within the membership. Although results from these informal assessments had not been recorded by the time of this study, support group leaders used this technique to *discern how regular an individual was in attending support group* sessions. It was assumed that regular attendance of support group meetings increased a cancer survivor's knowledge of general issues regarding cancer.
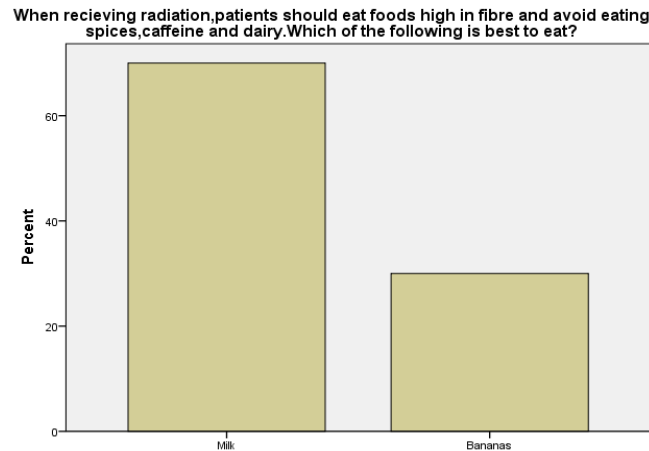
Nutritional Knowledge

Findings indicate that 96 per cent of respondents had good knowledge of *foods rich in energy and protein*, while only 30 per cent had correct knowledge of *specific foods rich in fibre* and best eaten during radiation, which in that case was *banana*. Figures 4.1 and 4.2 below present these findings;

**Figure 4.1** Foods rich in Energy and Proteins

Healthcare practicioners recommend food rich in energy and proteins.which of the following is highest in both?

Figure 4.2 Nutrition during Radiation

Adherence to Treatment

Adherence to treatment was measured by the taking of medication at the right time and understanding the importance of taking the right dosage. Results indicated that the majority of group members understood the right time to take their medicine (97%) and also the importance of taking the right amount of medication to take (98%). It was interesting to note that the respondents were aware that taking more than prescribed dosages of medication did not result to improved medical results as diagram 4.3 below describes;

Figure 4.3 Adherence to Medication
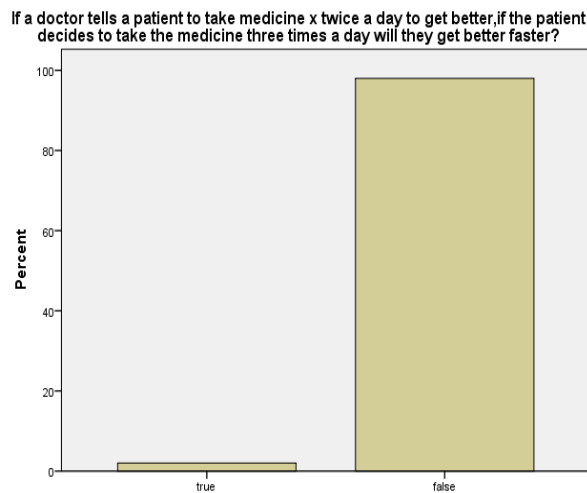
In this study, 98 per cent of the respondents were aware of the importance of adherence and its practical application. Some of the causes of non-adherence in the study were mentioned as; '*missed doses*', '*more or less than prescribed doses,*' '*change of medication without medical advice.*'

Reading and Understanding Health Parameters

The functional health literacy levels of the respondents were tested by their ability to read and understand what the normal levels of temperature and haemoglobin were, and use this information to decide a cause of action in a given situation. These two parameters were monitored during regular routine check-ups since they provided a general indication of the health status of an individual. Results indicated that 95 per cent of respondents provided the correct response *to determining whether a Hb level of 9.7 g/dl was within normal range* based on health information provided. In addition, 96 per cent of respondents were also able to

interpret health information related to body temperature, and understanding that temperature higher than 40.1° C required medical attention. A sample of these findings is shown in diagram 4.4 below;

Figure 4.4 Reading and Understanding Basic Hemoglobin Levels
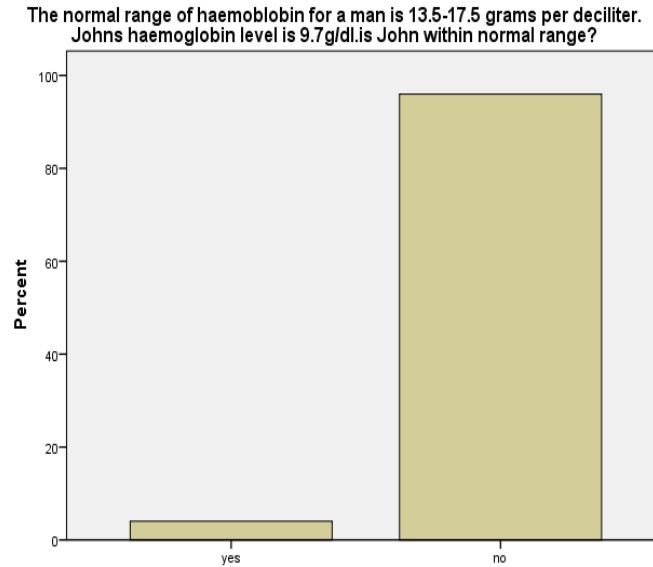
Understanding Cancer and Tumor Management

Understanding cancer and tumour management was assessed using questions that sought to assess the respondent's knowledge and understanding of their health situation. Results showed that 94 per cent understood what *palliative care* involved, with 88 per cent of the respondents understanding what it meant to *describe cancer as Stage 1*. In addition, 84 per cent of those interviewed could correctly differentiate between a *benign and malignant tumour*, while 86 per cent were aware of the *reason tumour samples were taken*. Another 83 per cent understood that an *inoperable tumour* could not be managed through surgery. Figure 4.5 and 4.6 present some of these findings.
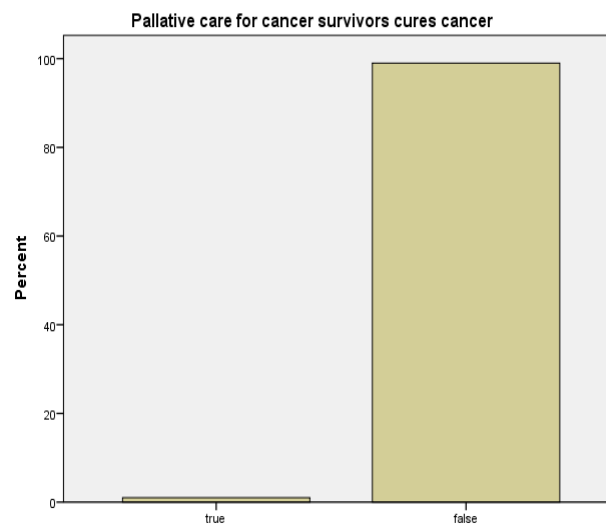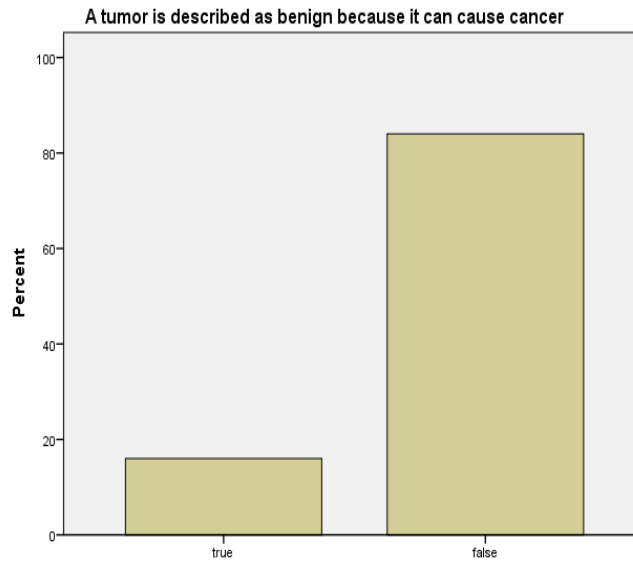
Figure 4.5 Understanding Palliative Care

Figure 4.6 Understanding different tumors

Reading, Calculation of Health Information

The ability of respondents to read and conceptualize health information that required simple calculation was tested in relation to; appointment timings, timing of medication, radiation sessions, dietary prohibitions. Results indicate that 94 per cent correctly calculated an *appointment date* while 90 per cent were able to calculate the *correct time to take medication* if instructed to do so in a set number of hours. An assessment of the ability to count the total *number of radiation sessions* was arrived at correctly by 92 per cent, while a similar percentage (92%) was able to *calculate the actual time to refrain from food and drink prior to medical procedures*. The figure 4.7 below presents a sample of these findings;

Figure 4.7 Calculation of Medication Timings
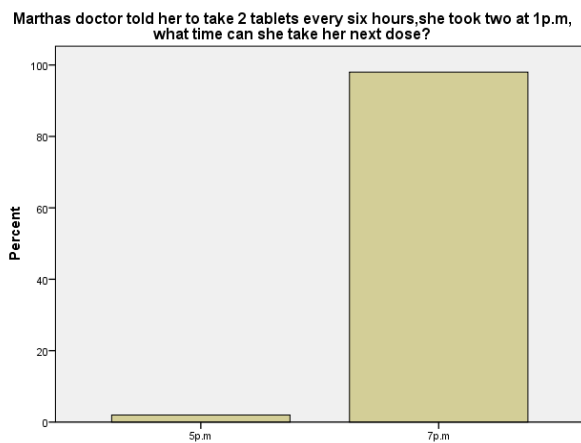
IV. Discussion

Nutritional Knowledge

This assessment of the knowledge on recommended diet presented disparate knowledge levels existing in one thematic context. A large number of respondents (96%) had good knowledge of *foods rich in energy and protein*, while on the other hand only 30 per cent answered correctly when tested on their knowledge of *specific foods rich in fibre* and thus best eaten during

radiation. Although there is indication that support group members may have a good general understanding of basic nutrition elements, these results point to an existing difference in opinions held over some dietary requirements.

Some studies have attributed dietary disparities amongst individuals with health literacy to psychosocial factors such as self-efficacy, which invokes an individual's confidence in actions that are assumed to produce self-benefit [22]. This resonates with the theoretical model of planned behaviour which postulates that individuals are more likely to engage in behaviour that they have belief in [23]. In addition, the individual may have available opportunities and resources to perform a behaviour, for example; time, money, information and knowledge, skills, support of others. This was confirmed by follow up interviews with support group leaders who confirmed that the above results could have reflected the general belief amongst many support group members that the consumption of readily available milk is important in the general health of Cancer survivors. In this case the individual may be convinced of the effectiveness of certain diets in managing a disease and thus rate its intake higher than any other recommended diet. As such, the influence of social and cultural dietary practices impacting on food choices should not be ruled out and could influence individual choices despite health literacy education [24].

Adherence to Medication

The large number of respondents who understood the importance of adherence to medication (98%) was impressive. This is because adherence is linked to better patient health outcomes in many cases, providing indication that support group members had knowledge supported by personal perceptions, beliefs that positively affected their attitude and self-motivation towards adherence. This observation is supported by the health belief model, which proposes that an individual weighs risks, costs, susceptibility and severity of the disease before accepting or rejecting treatment [25].). In this case, the respondents in the study demonstrated their belief in the benefits of adhering to treatment with the anticipation of positive health outcomes. This was likely influenced by exposure to information and support from attending support group meetings. Some key informants said that the need to frequently *attend all radiotherapy and chemotherapy sessions* on time, as well as *taking all medications as prescribed* by the doctor, was a key topic at support group sessions. It is thus evident that members of support groups understood the importance of adherence in improving quality of life.

Reading and Understanding Health Parameters

An average of 96 per cent of respondents could interpret basic blood and temperature levels which were considered within normal range from background information provided. These results mirror the confidence held by support group leaders who mentioned that all support group members are provided with basic information of identifying poor health indicators through benchmarking this against normal body parameters. This ability to self-monitor vital signs has been recommended as a practice amongst individuals living with Non communicable diseases. It has been associated with self-initiated adjustments in lifestyle, improved health seeking behaviour and reduced admissions to hospitals [26]. This corresponds with the health belief model which postulates that a person's health behaviour is triggered by a personal belief in perceived threat of illness or disease. As such, the ability to correctly interpret vital signs provides an individual with information that enables them to evaluate potential risks or benefits of pursuing a health decision [27].

In this study, it is evident that most support group members are able to correctly identify vital health parameters with only 5 per cent being unable to do so correctly.

Understanding Cancer and Tumor Management

The above results reflect a basic understanding of cancer management strategies as well as disease progression. Such knowledge is considered paramount in enabling a patient to embrace holistic health practices. Medical experts strongly advocate that cancer patients should understand their tumour progression and treatment options, motivating them to choose and follow through treatment decisions. This is especially the case since many new support group members often struggle in accepting their new health status and are keen on understanding how to improve it. It is thus not surprising that one key informant emphasized the importance of conveying information about cancer tumours in a manner that *satisfied the curiosity of the individual*. This was reiterated by support group leaders who said that new members lack information on these subject areas as compared to older support group members who hear this *information repeated often.*

The above observations reflect the tenets of health promotion theories which are based on the principle that resources including information are essential in effecting personal changes [28]. In this case, the need to provide accurate information as desired by patients should be of primary consideration for any health care provider

Reading, Calculation of Health Information

These findings are significant since they are directly related to important aspects in improving the quality of life of cancer survivors. Findings from a study of health literate older people living with hypertension was linked to medication adherence and

subsequently contributing to a higher quality of life [29]. However, this can only be achieved if providers do ensure that patients are able to correctly comprehend instructions related to dosages. Patients may often misread or misunderstand instructions accompanying drug use, a phenomenon experienced even amongst patients who are literate [30]. As such, it is imperative for health care providers to ascertain their patients' understanding of the drug usage. One way to do so is through teach-back, where health care providers ask cancer survivors to repeat instructions or medical information provided prior. As such, a health care worker can correct any wrong information held by a support group member and equally assess general health literacy levels associated with medication timings.

V. Conclusion

In this study it is evident that although no formal tests on health literacy are administered to cancer survivors in Nairobi, most support group members have acquired a functional understanding of health literacy topics. This indicates a measure success in the current health literacy delivery programme. However, the existence of a small percentage of individuals lacking functional health literacy provides an opportunity to tailor information needs to specific groups. At the same time, the existence of social and cultural dynamics that may influence the uptake of health information should be taken into consideration.

VI. Recommendations

This study makes the following recommendations based on the findings;

1. Health care programs should design systems that facilitate direct referral of new cancer patients to health literacy sessions as a continuum of care. In addition, these programs should initiate standardized cancer *health literacy testing* evaluations to assist in identifying information needs and gaps amongst beneficiaries.
2. Government agencies could evaluate the current Cancer IEC information packages and adopt them to current needs amongst diverse target populations. This includes designing information according to; age, gender, education level. In addition, the use of digital technology will provide diverse options to encourage demand driven information seeking behaviour amongst targeted cancer survivor beneficiaries. More so, these digital platforms can be used to provide updated and accurate cancer treatment and management information for all survivors.

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