Assessment of Factors Influencing Non-Communicable Diseases Literacy Levels in Vihiga County–A Qualitative Cross-Sectional Study

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ABSTRACT

Background: Health outcomes are closely influenced by health literacy levels. In most cases, lower health literacy levels have been found to be related to higher prevalence and incidence of non-communicable diseases (NCDs)—including cardiovascular and cerebrovascular diseases, cancer, diabetes, hypertension, and other chronic respiratory diseases. Despite this wealth of knowledge on the relationship between literacy levels and NCDs, most previous studies have been on the incidence and the prevalence of NCDs.

Aims: This study therefore sought to assess the factors influencing non-communicable diseases literacy levels, Vihiga County (Kenya).

Methodology: The study used a qualitative cross-sectional study design to collect data through questionnaires and interview guides administered through focused group discussions and key informant interviews. A sample size of 55 respondents was used in this study—mostly the IPAB project (Improving Priority and Budget Allocation to NCDs in Vihiga County) beneficiaries. The data collected from this study was coded using Microsoft excel version 25 and analyzed using statistical packages for social sciences (SPSS version 25) and inductive data analysis (IDA) for the qualitative data collected was analyzed through traditional significance test.

Results: The study reported that community health programs and initiatives on NCDs, patient support groups, culture and misinformation influence NCD literacy levels. The study findings indicate that culture and misinformation, patient support groups, and community health programmes and initiatives are three key components that need to be considered when improving NCDs literacy levels.

Conclusion: The study also concludes that IPAB project helped boost the resident’s knowledge and understanding of NCDs. The findings of this study offer critical insights to Vihiga County Government to tailor their NCDs advocacy programs to fit local context thereby enhancing the knowledge and understanding on NCDs.

Keywords: non-communicable diseases, literacy, community health, culture, misinformation

INTRODUCTION

Background of the Study

Non-communicable diseases (NCDs) are the leading killer disease in the world. In Kenya, NCDs account for more than 50% of all hospital admissions (RTI International, 2020). According to the World Health Organization (WHO, 2015a), NCDs are well on their way to becoming the leading cause of deaths and suffering in the Sub-Saharan Africa (SSA). In Kenya, and in many developing nations, chronic diseases have not been given much priority (Smitt et al., 2019). As a result, there has been minimal attention given to NCDs care right from primary to tertiary care; yet they cause a huge health, financial, and social burden to the people living with these diseases and their families (Onyango & Onyango, 2018). It is a well-established fact that prevention is better than cure and this is especially true for non-communicable diseases whose major risk factors can be modified in order to reduce and even prevent individuals from developing these diseases (Sharma et al., 2017).

In spite of the availability of information on NCDs, the discussion around this topic in Kenya has been marred with a lot of misinformation, myths and misconceptions. This has for a long time disoriented and retrogressively affected the work and effort by the health care sector to educate communities on non-communicable diseases (RTI International, 2020).
Furthermore, the concerted effort towards improving NCDs literacy levels has been greatly derailed by the advent of misinformation (Oshio & Kan, 2019). It is against this backdrop that Stowelink, with the support from Non-Communicable Alliance of Kenya has been implementing the IPAB (Increasing Priority, Attention and Budget allocation) project in Vihiga County.

This research aims at assessing the factors influencing NCDs literacy level in Vihiga County. The study is keen to understanding how IPAB project influenced NCDs literacy in the County. The study will document best practices that can be adopted to amplify and strengthen NCDs advocacy activities.

MATERIALS AND METHODS

Research Design

The study used a qualitative cross-sectional study design to obtain a snapshot of NCDs literacy level in Vihiga County and what factors influenced NCDs literacy in this county. This was administered through questionnaires and interview guides.

Location of the Study

The study was carried out in Vihiga County, Kenya where the IPAB project was being implemented. This location was ideal because there had been an implementation of a health literacy project as a result it would enable the investigators to establish the NCDs literacy level following the successful implementation of IPAB project in the study area and more importantly the factors influencing NCDs literacy in the county.

Study Population

The study population was adults from 18 years to 60 years who were affected by non-communicable diseases either as patients, caregivers, or immediate family members of the people living with NCDs. The study population was obtained from organized patient led groups of people living with NCDs. The study participants came from all the sub counties of Vihiga County represented by the groups.

Inclusion and Exclusion Criteria

Inclusion criteria

Anyone aged 18 to 60 years old and had participated in the IPAB project was eligible for the study. A respondent was also required to be able to read, write and understand.

Exclusion criteria

Those who were critically ill and mentally challenged were not allowed to participate in the study.

Sampling Method

The study adopted a non-probability purposive cluster sampling method where individuals selected to participate in the study were considered a representative of the community and were selected in a non-random manner based on the various regions of the county and the various NCDs groups enjoined in IPAB project.

Sample Size Determination

Since IPAB project worked with five groups of people living with NCDs, 10 people were chosen from each group in close conformity with the inclusion and exclusion criteria. This brought a total of 50 participants. In order to cater for non-responsive rate, 10% was added to the sample size bringing the total to 55 participants (10/100×50=5 participants). These extra participants were from each group.

Research Instruments

The study used both self-administered questionnaire and focused group discussions to collect data. These research instruments were constructed by the investigators hence tailor-made to suit the study.

Validity and Reliability

Validity

In order to achieve validity, a pretest was conducted with few study participants under the assumption that they are representative of the study population. The pretest enabled the investigators to assess the study tools and ascertain their suitability to collect reliable data. Through the pretest, questions that appeared vague and redundant were removed and others added as appropriate.

Reliability

Reliability of the data collected was achieved through keen supervision of data collection exercise.

Data Collection Techniques

The study adopted self-administered questionnaire and focused group discussions in collecting data.

Data Analysis

The data collected from this study was coded using Microsoft Excel version 25 and analyzed using statistical packages for social sciences (SPSS version 25) and inductive data analysis (IDA) for the qualitative data collected was analyzed through the traditional significance test.

Logistical and Ethical Considerations

This research conformed with the requisite ethical standards and the respect for human rights and freedom. The study participants participated in the study on their own volition and were not coerced whatsoever. Confidentiality and privacy were upheld, and the study participants were informed beforehand.

RESULTS

Social Demographics of the Participants

The study was done among five groups with a total of 51 respondents. Most respondents (27.5%) were aged between 45-54 years old with the mean age being 43. Table 1 shows the demographic characteristics of the focus groups participants.
In terms of education level, a majority of the respondents (45.1%) reached secondary school while only 23.5% of the study participants reached the undergraduate level of education. A majority (90.2%) of the study participants were predominantly rural dwellers. Most of the study participants 39.2% (20) were out of work followed closely by those in self-employment at 37.3% (19).

The results of the inductive analysis revealed 14 themes. After removing duplicates, a total of three themes were clustered with six emergent sub-categories (Figure 1):

1. **Community health programs and initiatives**
   a. Connectors to health facilities and services

2. **Patient support groups**
   a. Source of credible information
   b. Social support
   c. Advocacy and policy

3. **Culture and misinformation**
   a. Myths on NCDs
   b. Inadequate information on NCDs

Overall, the research was able to demonstrate that in Vihiga County, the level of literacy on non-communicable diseases depended on access to community health programs, initiatives and support groups. Culture and misinformation were the primary reasons for low literacy levels for non-communicable diseases.

Detailed descriptions of the categories with quotes from the focus groups discussions (FGD) are provided below.

### Culture and Misinformation on Non-Communicable Diseases

Majority of the study participants representing 96.1% (49) correctly identified the correct description of NCDs as a disease that does not transfer from one person to the other. In addition to this 88.2% of the participants correctly identified HIV/AIDS as not being an NCD while 90.2% were able to correctly identify NCDs as being killer diseases. Clearly the participants were much aware of what non-communicable diseases are and had a general understanding of the disease.

During the focus group discussions, the participants understanding of non-communicable diseases was emphasized further as they quoted statements like:

- "NCDs are diseases not spread from one person to the other."
- "Diseases not transferable."

To demonstrate further their understanding, all groups were able to identify diabetes and cancer as the most common NCDs but also mentioned high blood pressure, mental health, and asthma as some other examples of NCDs.

When asked whether people in the community knew what NCDs are, the participants generally stated that their communities mostly do not know what these diseases are, in statements like:

- "People only get to know about these diseases once they develop them."
- "People still need education on NCDs."

On probing further, the study established, generally, that people knew that these diseases exist only that they were not aware these diseases were non communicable diseases. The group members admitted that they also had the wrong information on what non communicable diseases were, until they got the correct information through trainings and programs like the IPAB. They cited some common myths that still exist for non-communicable diseases with statements:

- "Most people still believe that these are diseases of the old and the rich."
- "... these diseases can be cured by the local healers and traditionalists."
"When one gets sick of these diseases, if they sacrifice, they will receive divine intervention."

Through the community projects like the IPAB project and other partner led activities in the county, NCDs awareness was increasing significantly.

**Community Health Programs and Initiatives**

When asked about the impact of IPAB project on their understanding on NCDs, three themes arose. IPAB project had contributed towards better understanding of NCDs, increased NCDs advocacy activities at the county level and improved linkage of NCDs patients to local healthcare facilities, clinics and hospitals. All the groups agreed that IPAB project improved their understanding on NCDs through the regular trainings and through the NCDs modules provided during the trainings. It was also recognized that IPAB project had contributed to policy advocacy as members of all the groups were trained on advocacy and had engaged four times with the county and relevant policy makers on ways of improving policies on NCDs. Specifically, IPAB project advocated for introduction of NCDs clinics to ease access to services and the provision of NCDs drugs as part of essential medication in government owned healthcare facilities (Government, V. C., n. d.). Finally, the groups shared that the IPAB project enabled them to connect with healthcare providers and the health facilities where they would access services. Ultimately the project managed to strengthen the health system by improving access and referral systems to the relevant health facilities.

** Provision of screening equipments**

The study participants unanimously submitted that community health programs and projects need to provide support in terms of sourcing the basic equipment’s for NCDs diagnosis and management. The two most mentioned tools included the digital blood monitor and the glucometer machines. They suggested that these machines be provided to community health workers who often walk door to door in the community or the village clinics. This was because they had the highest chances to reach everyone in need in the community.

**Sustainability mechanisms for groups of PLWNCDs**

The groups also suggested a few ways that such projects would positively support them in the long run. These included developing business plans for the groups and providing funds for the groups to start businesses, run and managed by the groups. They agreed that this was the best way such projects could support the fight on NCDs citing benefits of this action. Through a group led business the group and its members could easily support themselves and they could be able to pay for drugs and other medications. The idea of joint business will also help the members to be bonded while attracting more people living with NCDs to join the group. Below is what the study participants had to say:

“If such projects help us by starting a group business for us and training us on how to run basic business i.e., buying us a cow and allowing us sell its milk or opening a grocery shop for us where we can bring our produce and sell, this will be the glue that keeps the group together, attracts more members to he groups and allows us take care of our conditions without having to beg.”

**Involvement of community health workers and volunteers**

The groups commented on the fact that such projects needed to engage more community health workers and volunteers so that even after the project implementation period was done, the community health workers would still be able to routinely check up on these groups of people living with NCDs and connect with the health system.

One such support statement was, as follows:

“Without engaging more community health workers in the project, once you are gone the group might have difficult time connecting with the health services and the community health workers who have latest news on what’s happening in the NCDs space in the community.”

**Role of Patient Support Groups**

When asked whether NCDs were important health issues that needed to be focused on in the community, all groups thought they were a very important aspect. When asked why it was important all the groups mentioned that most people do not know of these diseases early on and when they do its late and the community has to chip in to support and that the individual and the family suffer a lot when these diseases are finally discovered. Statements like:

"NCDs makes one suffer and the community has to pay for them to get to India for treatment."

and

"When one gets this disease, it’s a burden to the community since the medication is high, children stop going to school and the community is affected."

were shared across the divide.

The groups contributed a great deal in shaping the perception of individuals on non-communicable diseases. When asked to identify the statement that is true, a majority, 88.2% responded by choosing the statement, ‘people living with NCDs can live long normal lives with the right care. 9.8% participants chose the statement ‘cannot live normal live.’ Only one participant chose ‘suffer and die quickly’ to be a true statement about NCDs.

When asked on what ways the groups could deal with the NCDs burden three themes arose, social support, sensitization and policy advocacy. All groups agreed that there was a huge gap in awareness and education on NCDs, some resounding statements included:

“The community needs thorough sensitization and education on NCDs.”

"Sensitization is not only for the youth but for the whole community including policymaker and community health volunteers."
On social support, communities indicated that they could be able to organize themselves to be able to support members within the group handle some of the costs associated with NCDs care like medication, food, and psychological support as 82.4% of the participants knew someone living with non-communicable diseases.

All community groups agreed that advocacy for policy change was one of their most important roles if the focus on NCDs change was to improve. They recognized that the Government has the power to improve NCDs care in the local clinic and they recognized that they had a role to constantly advocate to the policy makers to improve priority and education to NCDs and its funding so that services are accessible down to the village. One memorable statement on this issue was, as follows:

"We as stroke patients and diabetes patients, we live with many other NCDs, currently there is just one medical facility in the county that can handle our regular checkups and physiotherapy, if we can get the Government to listen and make necessary changes, we will continuously live miserable lives with poor care. Therefore, we must continue to advocate!"

One group also mentioned that data collection was key and that the groups could had a role to continuously helping the collection of relevant data that could be used as evidence when advocating to the policy makers.

**DISCUSSION**

The aim of this study was to assess the literacy levels for non-communicable diseases in Vihiga County. With limited research available for non-communicable diseases this research is critical in adding to the knowledge available in the NCDs space. Non communicable diseases continue to be on the rise in Kenya and in SSA and in locations like Vihiga County where there are low-income levels, the research offers a unique perspective (RTI International, 2020).

Culture came out as a key influencer of how people understood and communicated messages on non-communicable diseases and this is in agreement with findings in a research made by Setel (2003) that shared similar sentiments. Myths and misconception are still a big issue when it comes to how communities understand non communicable diseases. The research revealed that whilst communities may know examples of non-communicable diseases, their understanding of what these diseases are and what causes them still need to be reemphasized. The study reveals a gap in the understanding of these diseases and the importance of improving NCDs literacy through various community programs.

Community health programs and initiatives like the IPAB project mentioned by the community, were some of the best ways to get information and understanding of these diseases at community level. This finding was similar to a narrative review done by Philip et al. (2018), where community-based health programs showed greater success in influencing behavior. Some of the strategies that were lauded by the community as being effective in ensuring wholesome learning on NCDs included actual training by trained community health workers and health professionals. After the initial training it was important that members of the community have a document or a source of information where they can refer and reteach themselves on concepts that they may not have understood earlier. This included simple items like brochures and training modules that the community could read and understand. Also, connecting community projects to the Government initiatives was another strategy that was supported that contributed to sustainability of community health programs and boosted referrals to the Government health facilities. Finally, whilst training is important, practical demonstrations was key in ensuring the community fully understood the concepts. These could include trainings on blood pressure measurement. Community health programs that want to make sustainable impact need to consider other elements besides the individuals’ health. For instance, by improving the economic aspects of the members of the community the program actively contributes to improving the health of the community members by enabling them make health a priority.

Another key element that contributes to improving the health literacy for NCDs in the community is community groups. This finding was similar to work done by Manning et al. (2019) in South Africa who found similar findings that supported the important role of community groups as an effective component of such initiatives. The study revealed that people in the community work best when they are in groups and this is because groups multiple benefits to them. First by working in groups members of the group have an opportunity to see firsthand their fellows living with NCDs which improves the understanding, reduces stigma and changes the perception that the community has on people living with NCDs. Groups also allow for joint action especially when it comes to advocacy activities on NCDs at both local and regional levels. Finally, the benefit of working in groups is that besides enhanced learning in the groups, the members receive psychosocial care and support.

Overall, this study showed that a basic understanding of NCDs exist but there is a lack of deeper connection on the prevention and management of these diseases. According to the WHO Commission on Social Determinants of Health, poorer groups are more likely to have poor health outcomes, and recent research has linked this to a lack of health literacy (WHO, 2015b, 2015c). Public health initiatives aimed at early identification and management of NCDs should begin with a better understanding of how culture influences health literacy. The researchers discovered emerging patterns and categories using an inductive method and study. Themes resurfaced during the focus groups, indicating that saturation had been reached at the analytical stage. With a larger number of focus groups, more categories would have likely emerged; but, with the data available, the three presented categories emerged.

**CONCLUSIONS**

The study concludes that the study respondents had sufficient knowledge of NCDs. While the study attributes the
level of knowledge on NCDs to IPAB project, other isolated partner led projects in the same field might have contributed too—although the study did not verify such. While some of the study participants did not correctly identify the correct statements in relation to NCDs, it was not statistically significant and not widespread among the respondents.

Similarly, this study concludes that IPAB project had numerous benefits to the residents of Vihiga County especially the members of the groups we worked with. The project highlighted the plight of people living with NCDs, voiced their grievances to the policy and decision makers, created and strengthened their social support groups and rekindled NCDs advocacy spirit in the County.

Lastly, this study concludes that culture and misinformation, role of patient support groups and community health programs and initiatives are three key components that need to be considered in any program aimed at improving literacy for non-communicable disease since these components greatly influence community’s understanding on NCDs.

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