

Improving outcomes in cancer diagnosis, prevention and control: barriers, facilitators and the need for health literacy in Ibadan Nigeria

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Abstract

Background: Cancers constitute a significant public health problem in Nigeria. Breast, cervix and prostate cancers are leading causes of cancer-related deaths. Changing diets, lifestyles, HIV/AIDS and macro-structural factors contribute to cancer morbidity and mortality. Poor health information linking cancer risk to individual behaviors, environmental pollutants and structural barriers undermine prevention/control efforts. Studies suggest increasing health literacy and empowering individuals to take preventive action will improve outcomes and mitigate impact on a weak health system.

Methods: We obtained qualitative data from 80 men, women, and young adults in 11 focus groups to assess beliefs, risk-perceptions, preventive behaviors and perceptions of barriers and facilitators to cancer control in Ibadan, Nigeria and conducted thematic analysis.

Results: Participants demonstrated awareness of cancers and mentioned several risk factors related to individual behaviors and the environment. Nonetheless, myths and misconceptions as well as micro, meso and macro level barriers impede prevention and control efforts.

Conclusion: Developing and implementing comprehensive context-relevant health literacy interventions in community settings are urgently needed.

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Background

Cancer morbidity and mortality have increased significantly worldwide [1,2]. In Nigeria, breast, cervical and prostate cancers are the most common, accounting for 30.7%, 23.6% and 18.2%, of all cancer-diagnosis respectively [1]. Prostate cancer accounts for 25% of cancer related deaths in men and 23% and 18% of women die from complications of breast and cervical cancers [3–5]. The HIV epidemic has contributed to the increase in cancer prevalence including those associated with HPV or Hepatitis B Infection. As more than 80% of cancers is diagnosed at an advanced stage, Nigerians have the poorest 5-year cancer survival rate in the world [6–8].

The high morbidity and mortality associated with cancers in Nigeria are partly attributable to individual-behavioral factors (diet, sedentary lifestyles, alcohol/tobacco use, low health literacy, late presentation, stigma, etc.), and structural factors (environmental pollutants, pervasive poverty, inadequate resources, weak health systems),

which restrict access to prevention and treatment options [9–12]. There is a wide gap between general literacy and knowledge of cancer risk factors, and preventive actions because of lack of or inconsistent information linking individual behaviors and environmental factors to cancer risk, and lack of comprehensive prevention strategies that undermine ability to obtain, process and understand basic health information and services needed to make informed decisions [4,7,13–17]. The limited knowledge and restricted access to preventive services such as screening and HPV vaccination contribute to worse health outcomes, higher hospitalization rates and reduced ability to be involved in preventive care [17–20]. These challenges highlight the urgency for comprehensive cancer control strategies, especially improving knowledge so as to mitigate impact on an already weak health system. There is evidence that increasing cancer knowledge in settings lacking comprehensive primary care and screening services reduces incidence, morbidity and mortality [8,21,22].

The need for comprehensive prevention strategies, including educating and empowering individuals to have greater control over modifiable risk factors, is critical in settings like Nigeria. Furthermore, in the absence of population based screening and treatment programs, prevention becomes a crucial public health strategy for reducing incidence and disparity in cancer outcomes. Efforts to address the challenges of cancer in Nigeria need to facilitate individuals' ability to understand health information so they are able to interact with the health system for positive outcomes. There is no evidence that large-scale educational campaigns promoting cancer prevention are prioritized as public health strategies because of individual, cultural, economic and health system challenges [4–6,20].

Our aim was to assess and describe cancer-related knowledge, opinions, perceptions and behaviors of Nigerians by obtaining pertinent information about community members' knowledge, attitudes and practices regarding cancer risk reduction and actions to maintain healthy lifestyles. Such information is useful to inform program planning and policy formulation that will reduce cancer disparity and improve prevention and treatment strategies at community level.

Data and methods

Study setting

The study was conducted in the Yemetu Aladorin community, Ibadan. This community is a stable urban population in a densely populated location of Ibadan, one of the largest and most populous cities in Southwest Nigeria. We collaborated with faith-based organizations because of the desire to work with community institutions that are trusted and respected by their members and who are experienced in implementing interventions that promote health and wellbeing.

Research design

We utilized a qualitative research design to elicit data that describe participants' cancer awareness, knowledge, attitudes, and health enhancing behaviors to prevent cancer. This design provided an opportunity to obtain rich, context-specific data, which illustrated not only individual perceptions and beliefs regarding cancers but also the cultural context that informs such perceptions and practices. The Institutional Review Boards of the authors' institution granted ethical approval.

Sampling and participant selection

We used multi-stage sampling techniques to select participants. Stage one was the purposive selection of the Yemetu Aladorin community in Ibadan North local government area (LGA) based on a variety of factors including convenience, ease of access and a history of

collaboration between the community and researchers from COM-UI. In stage two, we purposively selected (three) Christian and Moslem congregations in the community. These are the two dominant religious groups in Nigeria. Prior to selection of each congregation, the senior pastor or imam was contacted, informed about the study and invited on behalf of their congregation to participate. In stage three, after several weeks of announcing the study at worship services, and inviting interested members to sign up, congregation leaders compiled a list of interested congregants. Using this list, a random sample of respondents was selected after stratifying individuals into four groups based on age and gender. A total of $N=80$ individuals who fulfilled the eligibility criteria were selected to participate in the focus groups. Eligibility criteria included being Nigerian of any ethnicity, having resided in the LGA within the last two years, at least 18 years old and able to speak either English and/or Yoruba, the two languages widely spoken in the study areas. We excluded persons who had received a cancer diagnosis in the last 12 months or who were somehow too impaired to provide informed consent.

Each participant was presented with an informed consent sheet that explained the purpose of the study, why they were being asked to participate, what kinds of questions they would be asked if they choose to participate, information about incentive payment, as well as possible risks and benefits of participating. When requested, a member of the study team provided further clarifications about the study and informed consent procedure to participants seeking such clarification. All recruited participants were required to review, sign and date the informed consent sheet prior to seating in discussion sessions.

Study procedures

Overall, 11 focus group discussion sessions were organized between February and March 2013 for youth, adult men and women. All focus group sessions involved participants with homogeneous characteristics except for two youth focus group sessions that were deliberately organized as mixed gender groups. Approximately half of all participants were men; groups were separated by gender because certain discussion focused on gender specific cancers. Separating groups by gender was expected to foster open and candid dialogue. In the case of two mixed gender youth focus groups, the purpose was to explore how different gender dynamics influenced participation in discussion sessions and how male and female young adults respond to questions asked.

For each group discussion sessions, at least 10 and no more than 12 participants were invited to participate. Sessions were held in private rooms located within the church or mosque premises or other community owned facilities such as schools. Each discussion session lasted between

60 and 90 min. Each participant received an incentive of 1500 Naira (approximately US\$10) to compensate them for their time and effort in participating. Prior to starting the group discussion, each participant completed a one page demographics form to document length of residence in the community, current age, languages spoken, employment and income status and whether they had personally received a diagnosis of cancer.

Measures

Each focus group session was organized around a series of specific, open-ended questions adapted from the Health Information National Trend Surveys (HINTS), which has been previously described (www.hints.cancer.gov). In addition, participants were asked about social-contextual factors that facilitate or hinder cancer related beliefs and attitudes, personal risk assessment and community actions to foster cancer prevention, as well as input regarding effective strategies/mediums for disseminating cancer prevention educational materials.

Analytic approach

Initial data processing began with the transcription of audio recording of each group discussion in the language used conduct the session. Transcripts in Yoruba were translated into English and verified for consistency and accuracy. All transcription and translation work was done by participating medical residents at the College of Medicine, University of Ibadan who served as facilitators, notetakers or as observers during the session. Transcriptions were checked for completeness and scanned to ensure that personal identifiers had been deleted. After transcripts were verified for consistency and accuracy, they were uploaded into QDA Miner open-source qualitative analysis software [23]. Using this software, inductive thematic text analysis was performed by iteratively reviewing, interpreting and discussing verbatim texts by local residents on their ideas and opinions about the domains that were explored. Our analysis of the text resulted in developing codes, which were organized into themes of interest related to each domain before they were applied to the transcripts by the authors. Disagreements regarding applied codes, or whether codes fit into a theme of interest, were discussed by authors to reach a consensus. The results were mapped onto an ecological framework and organized based on whether they are individual or structural barriers and facilitators to cancer prevention and control, which formed the basis for the results presented.

Participants' characteristics

Adult participants ranged in age from 28 to 74 years while youth participants ranged in age from 18 to 24 years. All

participants had lived in the community for more than two years. All the adults were employed or self-employed, but most were classified as low socioeconomic status. Participants reported being Christian (58%) or Moslem (42%), completed at least six years of primary school education and considered themselves relatively healthy, having not obtained a cancer diagnosis in the past or currently dealing with any obvious medical condition or illness.

Results

We focus on three salient themes widely expressed across groups regardless of gender, age, religious affiliation or other participant characteristics.

Awareness, perceptions and beliefs about cancers

Participants demonstrated high level of awareness of different type of cancers considering that most reported they have 'ever heard' of cancers and their causes. Awareness of cancers was mostly based on known cancer diagnosis in the communities, or those reported in the local news, and on social media. Indeed, several participants reported knowing someone or a close relative who was diagnosed with a form of cancer in the recent past. The most common cancers mentioned included breast, prostate, cervix, lung and colon and not surprisingly differed by gender with female groups mentioning gynecological cancers while males mentioned prostate cancer. Most participants mentioned cancer risk factors including smoking, poor diet, environmental pollutants, noise or honking from cars, lack of physical activity, alcohol, genetics and risky sexual behaviors. Despite this awareness, there were conflicting information and misperception regarding how each risk factor contributes to different types of cancers. Overall, participants demonstrated an awareness of cancers and its impact on health and well being, but gaps remain in knowledge of how these factors specifically contribute to cancers.

Barriers to cancer prevention and control

Participants' perceptions of barriers to cancer prevention and control reflect a broad set of factors within a socio-ecological framework, such as intra-personal (individual), inter-personal (social network), community (geographic/neighborhood) and socio-structural (macro level).

Barriers associated with intra-personal/individual characteristics

Intrapersonal/individual barriers, which increase susceptibility to cancers, include low educational attainment, low socioeconomic status, old age, unhealthy lifestyle and lack of access to information. Adult males and females frequently cited older age and low socioeconomic status/

inadequate incomes as increasing the risk to develop cancers, while younger participants cited low level of education, low incomes, unhealthy lifestyles and lack of access to information. Older participants believed that the risk of developing a particular form of cancer was almost inevitable as one advances in age, a risk that is exacerbated by low socioeconomic status including lack of resources to seek adequate health care for a variety of age-related conditions. As one participant said,

'It [Cancer] is a disease of old age, almost inevitable. Old people are more likely to develop cancer because there are certain things the body can no longer do anymore when you are old' (Adult Male, Yekere Central Mosque).

Younger participants shared the view that susceptibility to any form of cancer is heightened among individuals with low level of education because they lack the means or knowledge to seek relevant information to minimize the risk and are more likely to indulge in behaviors that increase risk. Discussion with male youths highlighted socioeconomic factors that constrained young people's unwillingness to obtain information on cancer prevention because, *'They are more willing to spend money on things that would get them noticed by their peers.'* Although access to the internet as a source of information has significantly increased for young people, the vast majority are still unwilling to take advantage of the opportunity to seek health enhancing information or may even be skeptical about the authenticity of information from sources that are largely anonymous. One participant reported:

'Young people value their time on the internet too much to use it on researching information that may or may not be true, that they may or may not know' (Youth Male, Christ Apostolic Church).

Youth participants alluded to other intrapersonal factors that inhibit individual action toward cancer prevention including *'fear,' 'embarrassment,' 'ignorance,' 'myths'* and *'lack of privacy to ask questions.'* One participant's comments echoed the consensus of the group,

'People are too afraid or embarrassed to seek relevant information about the causes of cancer or any preventive measures because of cultural and superstitious beliefs that when you seek such information, you are inadvertently inviting misfortune and bringing the disease upon yourself' (Youth Female, Yekere Central Mosque).

In adult and youth discussion groups, participants discussed the importance of adequate nutrition, physical exercise and healthy lifestyles in cancer prevention but highlighted personal challenges to eating nutritious food, getting adequate physical exercise, and other impediments

to leading healthy lifestyles. For example, the constraint to eating nutritious diets is attributed to low incomes, limited options, proliferation of genetically modified foodstuffs and the prohibitive cost of staple food items. Adult participants reported that the only form of physical activity for most people was the daily long walk to and from work because of prohibitive cost of transportation, although they agreed that the unwillingness of many individuals to engage in rigorous physical exercises to maintain a healthy body mass index is because *'some people are just lazy.'* Others talked about the lack of infrastructure or an enabling environment as the greater barrier:

'We are too poor to eat healthy foods...We only manage what we can find or afford. If you don't have a lot of money, you can't afford to discriminate on the kinds of food you eat. As for exercise, we get a lot from walking several kilometers to work. Of course, we are doing this because the cost of transportation is too prohibitive, which is a good thing because it forces you to exercise' (Adult Male, CAC Church).

Young adults in particular noted that, *'The only avenue for getting physical exercises is through participation in sports activities,'* which they acknowledged is insufficient. Still some participants felt that ignorance and fatalistic attitudes were the greatest barriers among those living unhealthy lifestyles, with smokers, illicit drug users and those engaging in unprotected sexual activity as examples of those who ignore the implicit danger in behavior.

Barriers associated with interpersonal factors/social and community networks

Social and community networks featured prominently in the discussion of interpersonal barriers in cancer prevention and control. Participants agreed that social networks, including churches and mosques, were critical in the role they play informing citizens about cancer risk and prevention. They expressed the view that neighborhood associations and peer groups can facilitate cancer prevention by sharing information and helping individuals' live healthy lifestyles, but the lack of resources incapacitated them in intervening on behalf of members. Youth groups emphasized the role of leadership and described several examples of how leaders were instrumental in rallying members to take action when confronted by challenges that threaten the wellbeing of the group but *'bemoaned their leaders lack of enthusiasm in cancer prevention.'*

'Our leaders only talk when someone is known to have died from it [cancer]. I don't think it is necessary to wait until someone dies from a disease before leaders talk about it. If they had done so earlier, the dead person may still be alive' (Youth Male, CAC Church).

Discussants also highlighted the role of family and friends in cancer prevention. Young people for instance noted that parents and older family members were unwilling to provide information about cancers linked to sexual behavior. In an era of increasingly liberal attitudes toward sex and sexuality, cultural norms of acceptable behavior inhibit honest discussion of cancers of the reproductive tract and HPV vaccination between adults and young people. Young people, especially females, expressed frustration that such information was hardly available from teachers or the school curricular, leaving them with no guidance when they tried to figure out what is factual from the multiple sources available.

Christianity and Islam are the two dominant religions in Nigeria, and more than 90% of the population identified with either of these religions. The prominent role of religion and 'faith' in the lives of Nigerians meant that religious leaders are enormously influential opinion leaders. Participants differed in their views of how religious leaders have impacted perceptions and attitudes toward cancer prevention and control. On the one hand, adult participants were more likely to report that faith-healing often promoted by religious leaders contributed to reducing the incidence and prevalence of cancers, but youth participants were more likely to consider these leaders to be part of the problem, suggesting that while there is a place for miracle or faith healing, success in cancer prevention and control is more attainable when individuals seek medical intervention rather than relying exclusively on faith.

Socio-political and contextual barriers

Socio-political/contextual barriers are unique because of the geopolitical make up of Nigeria. Male youths described the difficulty in providing and receiving information about different cancers in a geopolitical setting of 260 tribes, 350 dialects and multiple religions. Although English is widely spoken and more than 80% of Nigerians speak and understand 'pidgin English,' challenges remain with packaging information on health issues intended for a diverse audience. Participants highlighted the potential of disseminating information through basic and smart mobile phones but acknowledged that such efforts would reach only the educated, affluent and young people. Additionally, this may prove to be ineffective in reaching less educated, non-affluent, older and largely rural populations.

The proliferation of information and misinformation is regarded as another socio-contextual barrier fueling myths, misconceptions and misperceptions about cancers, creating suspicion and mistrust for the existing sources of information. As reported by a male participant:

'Information comes from several sources and you cannot separate truth from falsehood. You cannot rely on information when there's no trust or the information is

contradictory. We need help in clarifying this confusion so we can save lives' (Adult Male, Yekere Central Mosque).

The mass media was criticized for its role in disseminating information about epidemics, including HIV and AIDS, especially when a lot of confusion and misunderstanding had been propagated in the process. Adult males discussed in depth how myths and misconceptions about HIV/AIDS contributed to the stigma that inhibited earlier interventions and noted that the same trend is happening with cancers because, 'People are afraid to disclose that they have cancer.'

Structural/policy barriers

Participants highlighted structural and policy barriers that continue to hinder efforts in cancer prevention and control. Health system factors such as poor services, low skilled personnel, outdated equipment and inadequate infrastructure were most often mentioned as the most significant barriers. These factors are directly linked to poor governance, lack of political leadership and an abundance of policy-makers more interested in promoting selfish interests. Participants were unanimous that, 'Politicians and government can do a lot more to stem the epidemic of cancer'.

Further, they described how endemic corruption and lack of legislation have stifled efforts to limit the impact of smoking and other environmental pollutants that drive the cancer epidemic. The perspective of many discussants was that corruption was the single most important barrier to the success of any initiative to improve the health of Nigerians, negatively impacting access to resources that facilitate healthy lifestyles or limit environmental pollutants. Young discussants were of the opinion that, 'Politicians were only interested in holding on to office and not improving the lot of the masses. There is no result to show for the huge sums they allocate to healthcare due to endemic corruption'.

The absence of a coordinated health literacy campaign typifies how structural barriers such as lack of leadership, political will and failure of civil society continue to hamper efforts in cancer prevention and control. Participants recounted a variety of interventions to improve health and wellbeing; however, many of these initiatives are repetitive, uncoordinated and too often focused on the wrong issues. There was consensus that without genuine coordinated efforts toward comprehensive cancer prevention, myths, misperceptions, confusion and stigma will abound.

Facilitators of prevention and control

The discussion regarding how to facilitate cancer prevention and control yielded a rich insight into participants' view that everyone has a part preventing and limiting the

impact of cancers. These discussions reflect opinions expressed by an adult male participant who said, '*Cancer does not discriminate. It is a scourge that will be tamed when everyone plays a role.*' Access to information and health services, risk reduction, eliminating exposure to environmental pollutants, adopting healthy lifestyles, avoiding peer pressure and monitoring one's health were identified as actions individuals could take to minimize risks. Adult participants emphasized access to health services, while youth groups emphasized increasing cancer health literacy through provision of timely, relevant and accurate information '*So that people know the risks and what to do when they need help.*' Male youths further expressed the desire for religious leaders to de-emphasize '*faith-healing*', which has become widely accepted as a cheaper alternative to seeking costly medical intervention with no guarantee that it will yield the expected outcome. They suggested that religious leaders encourage parishioners to take advantage of available medical services rather than promoting faith healing.

'The important thing is for religious leaders to encourage people to do regular health check ups and seek care in a timely manner. Televisions and newspapers should also take responsibility by providing accurate and relevant information to people so they know what is right and wrong' (Youth Male, St. Paul's Church).

Discussants suggested institutions such as media, religious, educational and civil society as important role players to facilitate prevention and control by rallying their members, providing information and promoting healthy behaviors and lifestyles.

Additionally, there was unanimous consensus that solutions to the problem of poverty, which increases susceptibility, is the responsibility of government more than individuals or communities. They suggested governments should enact policies to tackle poverty, improve health infrastructure, promote access to information, and resources needed to minimize impact on individuals and communities and to sponsor research to facilitate an understanding of actions that will contribute to overall prevention and control. Youth discussants reported knowledge of the HPV vaccine but openly debated the government's role in facilitating access to the entire population of adolescent girls rather than a privileged few.

Discussion

Cancer is now a significant public health problem in Nigeria. Changing health practices, weak health system with inadequate infrastructure for diagnosis, early detection and treatment; the long-term impact of HIV; and little cancer related knowledge, poor health seeking behaviors and little prevention and control policy are among factors

increasing cancer cases [24–27]. Our findings highlight several individual and structural factors that must be urgently addressed in novel and innovative ways if Nigeria is to successfully contain the emerging crisis.

Consistent with results from previous studies, we found that awareness of cancers is high [1,2,5–7,17,28–33], although gaps exist in knowledge of linkages between modifiable and non-modifiable factors and susceptibility to risk. Such knowledge is critical to enable individuals to take preventive action for enhancing their wellbeing. Addressing these gaps requires comprehensive prevention strategies with health literacy as the cornerstone to empower individuals to make informed decisions that facilitate prevention and early detection.

Multiple socio-ecological factors further limit individuals' abilities in reducing susceptibility to cancer risk. At the intrapersonal level, there is insufficient, often contradictory information, to comprehend and take effective preventive actions. Despite an overall literacy rate of 70% [13], and increasing access to the internet as a source of information, most Nigerians are unable to grasp relevant and factual information aimed at prevention, early detection and care. In addition to socioeconomic factors that constrain access to information, fear, embarrassment or concerns about privacy also hinder access to appropriate information. The theory of reasoned action [34] illustrates why young people especially may be less enthusiastic in obtaining cancer information, thus highlighting the importance of targeting social norms and attitudes in interventions that promote cancer health literacy.

Studies have highlighted the importance of psycho-social support in cancer prevention [35,36], especially in contexts where stigma is pervasive for perceived mysterious illnesses. Social networks are important sources of psychosocial support and are critical in providing information and access to services. Our data show houses of worship represent a potential resource in cancer prevention that is yet to be fully annexed in cancer prevention. Encouraging community action in cancer prevention is effective in combatting health related stigma [37,38].

Nigeria's geo-political composition as a multi-ethnic, multicultural, multi-religious and multilingual entity uniquely challenges a concerted national effort aimed at cancer prevention. Nonetheless, intervention to improve cancer health literacy can succeed if carefully planned and coordinated to take advantage of Nigeria's complexity and geopolitical characteristics. For example, the widespread use of '*Pidgin English*' provides an opportunity to reach 90% of the population with uniquely tailored health messages. Similarly, Nigerians' devotion to and respect for religious leaders offers the advantage to disseminate targeted health messages through these revered institutions [39,40].

The structural barriers are attributable to lack of political will and poor governance. Despite a nascent

democracy, the political class requires a strong leadership that can tame corruption at all levels of government. There is widespread belief that a strong leadership can easily address the structural barriers plaguing the health system.

Despite the highlighted challenges, there is optimism that comprehensive cancer prevention and control are feasible in Nigeria if all segments of the population are willing to take part in raising awareness and encouraging adoption of healthy behaviors to reduce cancer risk because of modifiable factors. Such efforts must begin by developing and packaging a comprehensive health literacy intervention that is culturally sensitive, widely applicable and takes account of the complexities of the targeted audience. Perhaps, given the differences in attitudes and perceptions toward cancers between adult and youth participants, different educational interventions should be developed for different population groups.

Conclusion

The interpretation of these results warrants caution given the nature of participant selection and the qualitative data, which may have missed the perspectives of those not represented in the sample. Nonetheless, our results highlight the urgent need to implement a cancer health literacy campaign to complement other cancer prevention and control strategies including the roll out of HPV vaccination. In particular, education about modifiable risk factors will empower individuals to have greater control over unhealthy lifestyles and the ability to navigate the healthcare system if the need arises. Nigeria lacks a population-based screening and treatment program therefore making implementation of a comprehensive health literacy intervention is critical strategy in reducing disparity in cancer outcomes.

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