The Role of Culture in Managing the Cancer Crisis in Kenya

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Abstract:
Cancer is among the leading causes of death across the world. Knowledge about the causes of cancer, and interventions to prevent and manage the disease is extensive. However, in nations that are characterized by high illiteracy levels and conservative cultural practices, this knowledge can be inaccessible resulting in increased cancer morbidity and mortality rates. In Kenya, for instance, although efforts have been made by the government and other organizations to sensitize people about prevention, early detection and management of cancer, the disease continues to claim many lives with the latest survey ranking it third on causes of deaths in the country. This study examined how culture influences knowledge utilization and management of three types of cancer: breast, prostate and cervical. Using a qualitative design, interviews and focus group discussions were used to collect data from five counties in Kenya. Findings show that although there is huge chunk of information available about cancer, cultural beliefs shared by different ethnic groups contribute to individuals’ response to the information. Stigma, myths, and taboos held by different communities negatively affect efforts to fight the pandemic.

Keywords: Health literacy, culture, cancer

1. Introduction
According to the World Cancer Report, cancer accounts for approximately 12% of all-cause mortality worldwide (International Agency for Research on Cancer [IARC] 2008). IARC estimated that globally 7.6 million people died from cancer and that 12.4 million new cases were diagnosed in 2008. They project that, due to increase in life expectancy, improvement in clinical diagnostics, and shifting trends in health behaviors (e.g. increases in smoking and sedentary lifestyles), in the absence of significant efforts to improve global cancer control, cancer mortality could increase to 12.9 million and cancer incidence to 20 million by the year 2030.

In Kenya, the leading cancers in women are breast, esophagus and cervical cancers. In men, esophagus and prostate cancer and Kaposi sarcoma are the most common cancers. Based on 2002 data from the Nairobi Cancer Registry, of all the cancers registered, breast cancer accounted for 23.3%, cervical cancer for 20% and prostate cancer for 9.4%. In 2006, around 2 354 women were diagnosed with cervical cancer and 65% of these died of the disease (Ministry of Public Health and Sanitation and Ministry and Medical Services, 2011).

Records from the regional cancer registry at Kenya Medical Research Institute (KEMRI), show that about 80% of reported cases of cancer are diagnosed at advanced stages, when very little can be achieved in terms of curative treatment. The country has few cancer specialists who are concentrated in a few health facilities in the capital city, Nairobi. Health information on cancer whether published or non-published is either relatively rare and, or is couched in difficult texts. This makes it difficult for a great majority of the population to access cancer treatment services resulting in long waiting times causing some previously curable tumors to progress to incurable stages.

In its strategic plan, the Ministry of Public Health and Sanitation and Ministry of Medical Services (2011) have emphasized the need for action to prevent cancer, especially those related to smoking and other modifiable risk factors. Enhanced health promotion, education and advocacy is one of the key strategies the government and other partners target to improve public understanding of cancer. This is aimed at empowering the public in general, to adopt healthier lifestyles and healthcare professionals in particular to recognize the symptoms of cancer and identify people at risk or living with cancer. It seeks to improve early detection of cancer by introducing or expanding the available screening programs and putting in place mechanisms and services that are proven to save lives. Despite the above efforts, cancer continues to claim many lives with the latest survey ranking it third on causes of deaths in the country (Ministry of public health and sanitation and ministry of medical services, 2011). Previous studies in American, European and Asian contexts (Kwok & Sullivan, 2007a, Kwok & Sullivan, 2007b, O’Byrne, Kavanagh, Ugoni & Diver, 2000, and National Health and Medical Research Council, 2006) have shown direct influence of culture on chronic disease health care provision although little
has been done in the African continent. Cancer remains a major health threat in Kenya and the rest of Africa, hence the need for appropriate healthcare systems that will respond to the cultural diversity of the population. It is on this basis that this study sought to find the influence cultural beliefs and practices of the people have on the management of cancer with particular focus on breast, cervical, and prostate cancer.

2. Objectives
The research aim was to investigate the role that culture plays in the screening, prevention, and management of cancer in Kenya. This aim was achieved through the following objectives:
   a) Determine the existing knowledge on cancer among cancer-risk populations in Kenya.
   b) Establish cultural factors that influence screening, prevention and management of cancer in Kenya.
   c) Formulate strategies that can be used in the screening, prevention and management of cancer.

3. Literature Review
The Kenya National Cancer Control Strategy (NCCS) 2010-2016 identifies some of the risk factors of cancer to include ‘tobacco use, being overweight or obese, low fruit and vegetable intake, physical inactivity, harmful use of alcohol, sexually transmitted HPV-infection, HIV infection, urban air pollution and indoor smoke from household use of solid fuels’ (P. 8). Among the fundamental principles guiding the strategies of cancer prevention according to NCCS include evidence-based approach focusing on best practice and recognition and respect gender and cultural diversity (P.13). The report goes further to propose preventive strategies and interventions including tobacco control, promotion of healthy diet and physical activity, control of harmful use of alcohol, control of environmental exposure to carcinogens, and control of biological agents that cause cancer. Although mentioned in its report, the strategic plan however does not come out clear on the role for gender and cultural diversity on cancer management and interventions.

Culture in a broad sense refers to the cumulative knowledge, experience, values, beliefs, attitudes, religion, notions of time, roles, spatial relations, concepts of the universe, and material objects and possessions acquired by a group of people over time through individual and group striving (Spencer-Oatey, 2012). Different cultural groups think, feel, and act differently. Cultural attitudes may impact negatively on screening behaviour, resulting in under-screening for cancer. These attitudes and barriers are often strongly related to cultural norms engrained in communities. According to Fiscella et al. (2000), health care choices and behaviour may be impacted by multiple variables including: geographic access, transportation, education, knowledge, literacy, health beliefs, racial concordance between physician and patient, patient attitudes and preferences. The significance of any one of these factors would however vary by patient and physician.

Culture affects a person’s knowledge of cancer; their explanatory models and their psychological responses to diagnosis (Eisenbruch 1989). Health and illness may be taken-for granted experiences of everyday life. When they are asymptomatic, they may be unlikely to suspect that they may have diseases (Kwok and Sullivan, 2007a). Among different cultures or ethnicities, there exists misinformation about cancer. For example, one study suggested that patients more often reported incorrect beliefs about cancer, such as high blood pressure, exposure to polluted air being a cause of cancer, or surgery causing tumors to spread (Wong-Kim, Sun & DeMattos 2003). In another study, patients who believed that “surgery causes lung cancer to spread” (Lin, Mhango, Wall, et al. 2014: 490) were less likely to receive stage-appropriate treatment, even when tumors were not at advanced stages. Other studies that examined cancer knowledge, beliefs, and attitudes of Filipino Americans, Korean Americans, Vietnamese Americans, and Chinese Americans found that 71% of Vietnamese American women in the study did not know what cancer was, whereas 25.7% of Chinese Americans believed that cancer was contagious. Among the Asians, cancer was viewed as a taboo subject, and often led to discrimination and rejection by their community. Women were also found to fear that female health professionals would not be available to undertake screening, thereby potentially compromising the modesty of the patient (Ward et. al. 2006, Miles et. al., 2004). These fears lead to avoidance or delay of cancer treatment (Wong-Kim, Sun & DeMattos 2003).

Kwok and Sullivan, (2007b) found that if women were unaware of any sign of illness in themselves, they would not attempt to discover disease through screening for fear of making themselves feel ill. Women would focus on preserving and promoting health and overall well-being rather than try to detect unknown disease by screening. While some communities belief that they are not at risk for particular cancers (Miles, et. al., 2004), others lack the knowledge regarding screening (Pennay, 2009, DoHA, 2008).

In some members of the community, regular breast screening is not viewed as relevant because individuals’ destinies are predetermined by God (DoHA, 2008). In studies with Italian community, cancer was described in metaphors. Participants believed that recovery from cancer was impossible even if a person received treatment (Severino et.al, 2009). Penney (2009) found that a lack of confidence and a sense of embarrassment with regard to seeking help or information on bowel cancer (16% versus 9% of the total sample) and being less comfortable with self-administration of a FOBT (59% ‘comfortable’ versus 81% of all those aged 50 years or more) were critical barriers to participation. Gifford (1990) similarly found that embarrassment was a primary cultural barrier for participation in breast and cervical cancer screening by older Italian women.

It is apparent that culture varies from community to community. This means that understandings of, attitudes, behaviour, community specific health profiles, vulnerabilities and decision making processes regarding cancer in these communities also vary. Knowledge of this cultural variation is critical in ensuring access to services and improved outcomes.

4. Methods
The research adopted a qualitative approach. Interviews, focus group discussions and document analysis were used in data collection. Interviews involved four medical practitioners working in general and oncology departments in Kenyan public hospitals.
The interview guide consisted of general queries and probes where necessary. Sample questions used in the interviews include the following: (a) What information about cancer do you provide to: adult males, adult females, youth b) How do you convey such information (probe for the communication strategies; language(s) used; form of the information given; mode of conveyance (e.g. spoken: textual; mobile phone messages; internet; chief’s baraza) c) What cultural beliefs, practices in this community make it difficult to talk about the cancers that affect the youth/ adult males/ adult females (d) How can these beliefs and practices be dealt with? Information from this source was not meant for generalization to the wider population but was instead meant for bringing an insight of experiences on the influence of culture in cancer management. A total of 30 men and women participated in focus group discussions. All adults were of potential interest; therefore we had one FGD in each participating county. Each FGD was constituted by six participants of varied ages, with no previous history of cervical, breast or prostate cancer symptoms or diagnosis. This method was used in order to acquire an exploratory understanding of Men and women’s beliefs about cancer, their attitudes, perceptions, predisposing factors and, or activities to cancer-and personal health-related factors, information, and services for detecting cancer and strategies adopted in the dissemination of information about cancer. Five FGDs lasting 45 min to 60 minutes were conducted in Nairobi, Nyeri and Meru, Kajiado and Kitui counties. Discussions were audio-recorded and later transcribedverbatim.

5. Findings and Discussions
Findings from this study indicate that culture, has a huge influence on how cancer is discussed and managed in Kenya. It affects how patients and families perceive truth about a diagnosis, treatment, and how they cope with the disease. Sometimes there are conflicting doctor–patient interactions when each is from a different ethnic group. Besides language barrier, doctors in the interviews reported that sometimes they were unable to address cultural barriers to screening because patients do not volunteer culture-related concerns regarding screening. Still, some patients don’t want to know if they have cancer. The doctor observed that there is a general lack of awareness of what cancer is and how to deal with it and the expectation that the patient has the right to know the truth is not always the norm. The family is the one that makes the medical decisions when one of the members is sick. These cultural differences also affect the view of truth telling. The family frequently receives the cancer diagnosis and clinical plan before the patient. The patient and family regard the family as having the primary decision making responsibility. Some of the cultural practices raised and their influence on cancer screening, prevention and management are discussed in the following section.

5.1. Misconceptions
Misinformation from friends and family and a lack of knowledge about cancer treatments may lead to considerable misconceptions. There was a feeling of fear, which was expressed by the participants in the focus groups discussions about contracting cervical cancer from their spouses. For instance, one participant reported that her co-wife had recently been diagnosed with cervical cancer and she expressed her fear of contracting the disease since they shared a husband. She further noted that she wouldn’t go for screening for fear of being diagnosed with the disease, a move if turned positive, she said, would accelerate her death. The reluctance to go for screening and the fear of getting infections or diseases when being screened for cervical cancer reflected limited health literacy about the screening procedure. This was consistent with other findings in earlier studies, where women boycotted screening due to attitudes of fear (Cooper 2011).

The focus group discussions also revealed beliefs about treatment. In the case of prostate, cervical or breast cancers, individuals fear the discovery of these cancers and worry about seeming defective or less feminine or masculine to their partners. For instance, there was a fear of losing breasts and uterus as these body parts represent the female part of them and their ability to fulfill an important role of a mother, ‘missing a body part, will render one incomplete’. This statement also reflects the woman’s fear that she will be left by her spouse, if the female parts of her body are removed. One female participant reported that she had witnessed a case where a man yielded to pressure from his parents to divorce his wife because she had been diagnosed with breast cancer. She notes, ‘they seemed oblivious of the stage the cancer was at the time nor survival possibilities; “luckily the lady went through treatment and now she is cancer free, but she was never accepted back to her matrimonial home.’ The male participants confessed that sometimes pressure from family and the community is too much when a spouse is diagnosed with any type of cancer. They referred it to as ‘cultural bondage’ where family and the community has more say than an individual on who one marries and brings up family with.

Similarly, it emerged from the FGDs that an association of male organs with masculinity lead some men to worry that treatment for prostate cancer could cause sterility and impotence. Focus group discussions revealed that men delay seeking treatment due to fears that treatment will render them sterile or prevent them from being intimate with their wives or partners. This, coupled with the sensitivity of the parts of the body affected compels men to suffer silently and only resort to treatment when they cannot bear the pain any further.

Another participant expressed that ‘if you cut into the cancer, it will spread immediately all over the body’. Others perceived cancer treatment to be as bad as, or worse than, the disease itself. Misbelief and wondering about cancer and fears of the test procedure explain respondents’ perceptions of cancer, the barriers to screening, and reasons why they do not attend screening.

5.2. Considered a Death Sentence
Cancer is considered a death sentence, frequently referred to in silent tones. This is particularly true for people with low financial resources. Treatments seem not to offer much hope, and in many cases, a diagnosis of cancer is kept as a secret from the patient. Focus group discussions revealed two disparate views on disclosure. Those with negative attitudes to a cancer diagnosis believed that fear and worry would kill the patient or make them worse, or that the psychological suffering which results from knowing you have
cancer would reduce the quality of the patient's life. They argued that you should tell the patient that she/he has another disease, while telling the family she/he has cancer and seeking their cooperation in giving the treatment. Those with positive attitudes to a cancer diagnosis thought that you had to be aware in order to receive treatment and look after yourself. They did not think one could be treated without knowing that she/he had the disease. They noted that treatment was essential and felt that the patient ought to be actively involved in the treatment process. The doctors also noted that in practice, they do not tell patients they have cancer, but instead they tell a member of the family, “it depends on the individual patient and the stage of the cancer... Families try to protect the patient, and decide if the patient should know’. They believe that open discussion of serious illness may provoke unnecessary depression or anxiety in the patient and may eliminate hope. A patient who is already in pain should not have to grapple with feelings of depression as well.

5.3. Taboo Language
In Kenya, culturally, reproductive language is prohibited between genders and age groups. Cultural taboos do not allow people to talk openly about some diseases. Talking about breast, cervical or prostate cancer symptoms or body parts affected by the disease involves the use of what is considered taboo language. For example, prostate and cervical cancer is highly stigmatized because they affect those ‘parts of the body you don't openly speak about’. Cervical and breast cancers present symptoms that women are reluctant to disclose to their doctors, and they may be even less willing to undergo the necessary physical exams to investigate the cause of such symptoms. Breasts in some Kenyan communities, for instance, mean more than feed for young ones. Among the Luo community, it was revealed that elderly people use breasts to cast curses to those who offend them and unless the cursed person goes through a cleansing ritual, he/she would not have peace throughout his life. For prostate cancer, there is no specific name for it, as areas affected are too private to mention. In most Kenyan communities, it is referred to as ‘ugonjwa ya wazee’ (Kiswahili translation for “men’s disease”) and people often address it in low tones due to culture-specific reasons, and the sensitivity of the disease. In the Kikuyu community, the breast unlike the other two types of cancer, is more visible and the participants reported that although it was still seen as a private part of the body, it was not affecting areas ‘below the belt’ and the fact that it affected mostly women, it was much talked about openly in the community than prostate and cervical cancers. One doctor in the study reported that he did not experience much cultural challenges from the youth with regard to screening and communicating about breast, prostate or cervical cancer. However when attending to elderly patients especially those from the rural areas, cultural issues have emerged. First, these patients present when the cancer has advanced to advanced stages most probably because of their reluctance to talk about the symptoms. Secondy, when they come, they want to decide on who should attend to them as this has a cultural implication. For instance, an elderly man from the Maasai community would not want to be attended by a female doctor and it is worse if the doctor appears younger as this would make free discussion difficult.

5.4. Age and Gender Differences
It was also revealed that elderly people do not want to reveal their ailments to their children who would otherwise facilitate the treatment process. Culture does not permit parents to talk about their private parts to their children. Unless they have a neutral person they can confide in, they could live with the disease as long as it is bearable. When they visit hospital, depending on the age and gender of the medical staff they find, they may be reluctant to explain their ailment. For instance, in the Kikuyu and Maasai communities who believe in a patriarchal system, cases of prostate cancer are dealt with silently. Even spouses keep silent about their husband’s conditions as it would be demeaning to expose them. Contrary, women talk about breast cancer openly and would seek treatment at the earliest opportunity possible. The account of one of the doctors interviewed suggest that the digital rectal exam (DRE) to screen for prostate cancer, and the PAP smear to screen for cervical cancer are considered by some to be extremely invasive. Some of them do not readily accept to go through the procedure. This was echoed in the focus groups where men and women reported that they would be embarrassed about some screening procedures and would reject them as they were a violation of their virility.

5.5. Stigma
Fears about cancer treatment causes stigma. Discussions in the focus groups showed that people perceived cancer to be a fatal disease. Cancer symptoms or body parts affected by the disease, and the belief that nothing can be done to prevent cancer and that cancer is always fatal cultivated stigma. Treatment of cancer is considered by many to be a financially devastating burden to the family because of associated expenses for diagnosis, treatment, and patient support. Patients see themselves as a burden to their families while some families consider a waste of resources seeking treatment as the person will eventually die. Others believe that cancer is contagious and therefore they will try to keep off from those positively diagnosed a practice that leaves victims feeling rejected and stigmatized. The cost of cancer treatment exacerbates the situation because, as expressed in the focus group discussions, screening is needless since they cannot afford the treatment cost “Knowing my cancer status will stress me and make me die faster”.

5.6. Witchcraft
The issue of witchcraft as a cultural belief and a cause of cancer was discussed and raised in the focus group discussions. Participants reported that in most Kenyan communities, any sickness/death is attributed to a super natural being. For example, traditionally, in the Luo community, cancer (known by a different name) was attributed to witchcraft (chiira).When one showed symptoms related to cancer, they often sought healing from witch doctors. Although some of these beliefs and practices seem to change with improvement of health care, the participants reported that there are families that still uphold the practices. Potential harm of such alternative
medicine is, however, huge because medical attention is sought when it is too late. One focus group participant gave a case of a relative who suffered from prostate cancer. At first, it was believed to be a punishment attributed to some evil he had committed. The family sought treatment from herbalists and witch doctors in vain. By the time he went to hospital, his condition had worsened and he passed away after a few days. “We are burying him this weekend and this is someone with educated sons and daughters”, he noted.

5.7. Religion
Related to the belief of witchcraft is the practice of religion. Participants reported that religious beliefs help them to cope with complex ailments such as cancer. Religious beliefs influenced their medical decisions, especially when patients are seriously ill. Families and friends resorted to serious prayer and even encouraged the patient to seek forgiveness from God in case it was a punishment for sinful acts committed. They expressed a strong impact of prayer on the patient and close family. Prayer gave them hope for healing as well as assurance of eternal peace and life after death. The participants however noted that while places of worship could be possible places to disseminate health knowledge, the lack of professionals to convey the right information leaves members of the clergy and laymen to educate members on cancer. The information they give sometimes is inaccurate and confusing, thus reports one participant:

so much information is given out there, we are told not eat this, not to eat that, not to do this… so many don’ts; it is confusing. We need the right people to give us the right information…”

The above concerns are confirmed by the varied responses participants gave regarding preventive measures for cancer. For example, they gave a range of measures that should be followed to prevent cancer including; eat lemons, avoid drug abuse, stop heating food in plastic containers, avoid sugary foods, avoid heating food in microwave, avoid processed foods, reduce amount of protein foods eaten, avoid fatty foods, avoid drinking cold water immediately after meals, avoid X-rays, avoid direct sunlight, avoid multiple sex partners, stop smoking, among others.

6. Conclusion
Culture does influence the way people seek, receive, utilize and manage knowledge on cancer. This however varies from community to community. Improved strategies tailored to patient culture are essential. Approaches geared towards minimizing cultural barriers that hinder accessibility to services and treatment need to be sought. In order to increase the acceptance index of the target population with respect to cancer screening practices, there is need to demystify cancer and let the population know that cancer is real and it must be named and tackled. Medical practitioners require cultural competence so as to establish trusting relationships with patients and to relate to patients of varying ethnic and cultural backgrounds. Survivors could team up to create awareness and positive attitudes towards the cancer screening so as to have better outcome.

7. Recommendations
Awareness is the ‘number one’ strategy to improve cancer prevention and control. People need guidance in understanding that cancer is not a complex disease. Media coverage should aim at reducing cancer-related stigma by providing information on topics such as cancer management; screening and early detection; treatment options and even cancer survivorship. There is need for health promotion activities tailored towards improving information knowledge levels about cancer. For the purpose of narrowing the knowledge gap, there is need for suitable ways of encouraging uptake, ensuring flexibility of screening procedures, provision of appropriate educational materials, and enhancing the interpersonal linkage between health personnel and the people. People in rural Kenya seem to have scant knowledge about cancer. Much of the information on cancer has not been translated to vernacular so it reaches only those who understand English and Kiswahili. Easy to read booklets that use simple language and pictures should be prepared and issued in all health outlets. Such information should be written both in English and translated in the local dialects used in Kenya. Information could also be disseminated in CDs, postcards, posters in the shopping malls and newsletters. Efforts to promote screening should consider the health communication barriers of low health literacy and limited English proficiency to encourage more people to go for screening.

Medical practitioners should be prepared for a diversity of attitudes, values, and practices. They need to understand peoples’ beliefs and perceptions to provide for effective delivery of public health programs and awareness in the communities. For instance, they need to understand different cultural perceptions of the patients and respect their beliefs and culture. This would give people assurance and confidence to seek medical services at will.

The cultural myth, stigma, and financial devastation that all too often accompany a diagnosis of cancer negatively affect efforts to increase cancer awareness. Demystifying cancer through survivorship campaigns and availing cost sharing packages will play important roles in changing this stigma. Other ways include widening forums for cancer awareness to schools, churches and even social gatherings. There is need for cancer survivors to openly discuss the journey of treatment to give assurance that cancer is not a death sentence. Vernacular mass media channels and schools are also key resources for dissemination. People with cancer need information and emotional support for themselves and their families.

8. References


