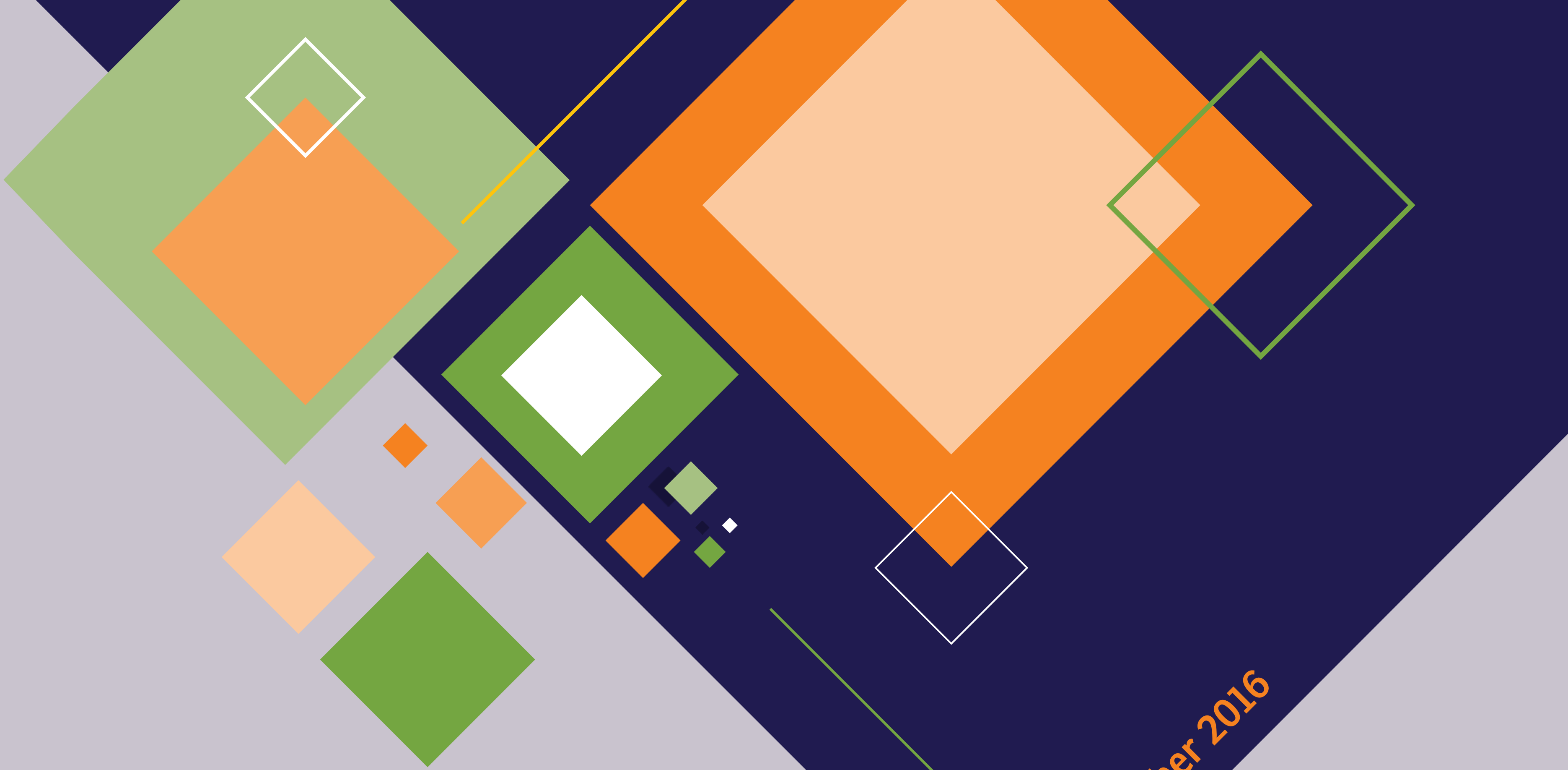

December 2016

Assessment of Knowledge, Attitudes and Practices Survey on Cancer in Selected Regions of Kenya

Report of research findings

HARAMBEE
Ministry of Health

American Cancer Society®

ps Kenya
Healthy lives. Measurable results.

CONTENTS

Acknowledgments

PS Kenya would like to thank the team of the American Cancer Society (Anne-Marie Schryer-Roy, Martine Chaussard, Jacqui Drope) and Joyce Wanderi Maina for the opportunity and trust to carry out this important research, as well as their technical guidance and patience at the reporting stage; Joel Lehmann of Infospective Research for his technical input, coordination of qualitative research and for drafting this report. Christine Awuor for the overall leadership, the implementation of the household survey and the relentless hands-on support for all aspects of the study; Dr. Mercy Njeru for the methodological strengthening and the leadership for the qualitative research; Lilian Nyandieka and Dr. Joseph Mutai for the expert input and professionally conducted focus groups, patient, caregiver and expert interviews; Daniel Olemo, Elizabeth Khisa, Agnes Onyisa and Charles Ochieng for critical support of the research activities on the ground and quality control; Carol Matiko for her support in the analysis of household data, and Dr. Nicole Bellows for the review and strengthening of the language and structure of the report. We acknowledge and appreciate the generous facilitation provided to the team by Robert Makori at Kenyatta National Hospital, and the CEO's office and staff at Moi Teaching and Referral Hospital. This study would not have been possible but for all the cancer patients, caregivers, cancer survivors and the key informants, who generously shared their time, stories and insights with the study team.

Acronyms

ACS	American Cancer Society
CAM	Cancer Awareness Measure (validated UK-based cancer awareness questionnaire)
HBM	Health Belief Model
HPV	Human papillomavirus
IDI	In-depth interview
IEC	Information, Education and Communication
JHC-CCP	John Hopkins Center for Communication Programs
KAP	Knowledge, Attitudes and Practices
KNH	Kenyatta National Hospital
MOH	Ministry of Health
MTRH	Moi Teaching and Referral Hospital
NGO	Non-governmental Organisation
PSK	Population Services Kenya

Executive Summary

The Kenyan Ministry of Health (MOH), in collaboration with the American Cancer Society (ACS), the John Hopkins Center for Communication Programs (JHC-CCP), Kenyan cancer professionals and civil society organisations, have partnered to increase the availability, quality and effectiveness of information, education and communication (IEC) materials for cancer in Kenya.

Within that context, the ACS Global Cancer Prevention team supported a study to provide information about the state of cancer knowledge, attitudes and practices in Kenya, known as the "KAP survey". The findings of this survey are intended to help inform the planning, implementation and evaluation of health education interventions in Kenya. ACS and its partners are also using the findings of the KAP to inform the adaptation of existing ACS IEC materials for use among cancer patients, caregivers and health care workers in Kenya.

The study seeks to address both the priorities of the general population and those affected by cancer, specifically patients, survivors, caregivers and health professionals. The ***Health Belief Model*** (HBM), attempts to explain and predict health behaviours based on attitudes and beliefs of individuals, serves as the conceptual framework for data collection and analysis related to behaviour-change communication.

The KAP study was carried out between March and July 2016 using a mixed methods research design that emphasized qualitative data from in-depth interviews and focus group discussions (FGDs), which was then complemented with quantitative data from a household survey. The qualitative research phase consisted of open-ended in-depth interviews with both urban and rural cancer patients, caregivers, expert stakeholders and health professionals. In addition, semi-structured FGDs involving cancer survivors and members of the general population were carried out. The total qualitative sample consisted of nine FGDs and 56 in-depth interviews.

The quantitative household survey was designed to capture some of the different socio-cultural realities in Kenya. Six counties were purposely selected for data collection: two urban counties (Nairobi and Mombasa), three mixed urban/rural counties (Kajiado, Kisumu, and Nakuru), and one predominantly rural county (Murang'a). A two-stage stratified probability sample design was used to achieve representativeness; a response rate of 60% was achieved.

While this study does not necessarily represent the overall experience of cancer in Kenya, as it focused on patients of the two largest public hospitals and households in a selection of counties, this research produced many relevant findings on the knowledge, attitudes and practices of both the general population and the cancer community.

Findings about cancer knowledge, attitudes and practices in the general population

The term ***general population*** is used here to refer to the Kenyan population of all age groups and not to those who have experience with cancer. In the general population, the study found differences in knowledge, attitudes and practices among people from different socio-economic backgrounds, from urban and rural settings, and from different regions in Kenya. Key findings from the general population include:

- People knew that cancer is a disease that society fears and that can kill. Most individuals were aware that cancer is a non-communicable disease that tends to run in families, while some knew it was also associated with lifestyle choices, such as diet, exercise, smoking and alcohol use.

- While cancer itself was seen as a serious disease, the signs and symptoms of cancer were often not seen as severe enough to warrant timely health care seeking behaviour.

- Myths and misconceptions about cancer's origins existed among the general population, with some respondents attributing cancer risk to the use of make-up or other beauty products, "loose" sexual behaviour, and the use of "illicit alcohol" (as opposed to alcohol in general). While not a prominent belief, the myth that witchcraft is the cause of cancer still existed, particularly in rural areas. The misconception that perhaps caused the most direct harm to cancer patients and their family was the common perception that being diagnosed with cancer amounts to receiving a death sentence.

- Several knowledge gaps and uncertainties existed. Little was known about cancer screening, early detection and the different types of cancer.

- The main reported barrier to seeking screening services was fear of discomfort related to the screening process itself, particularly for cervical cancer screening in rural areas.

- Financial barriers inhibited health care seeking in response to symptoms that could have potentially indicated cancer, particularly the costs of diagnostic tests, for which there were no standards, at least not ones known to the general population.

- Stigma and isolation was a major problem for patients with a cancer diagnosis, with the general population often avoiding cancer patients or being overly grim in their sympathies and not offering encouragement. In rural areas, stigmatization of cancer was a larger problem, with victim-blaming being more prominent.

- Nearly all the participants interviewed in focus groups and individual interviews expressed a strong preference for using interpersonal channels to communicate cancer-related messages to the general population. Specific examples given where interpersonal communication could be practiced were schools, Chief's Barazas, interactions with community health workers, hospitals, chama meetings (women's savings groups) and social events.

- Mass media was also seen as a valuable communication channel. Radio was the most referred to source of information about cancer especially among rural respondents.

- The recommended priority areas for community education efforts and general population communication campaigns were to: (1) correct perceptions of individuals who underestimate their susceptibility to cancer, and increase the understanding of cancer signs and symptoms that, if ignored, can be dangerous and lead to a more severe condition; (2) reduce the stigma that is associated with cancer patients being seen as "almost dead" and encourage open communication about the disease with everyone, including those affected; (3) explain risk factors and causes of cancer; and (4) address the fear of the screening procedure and outcomes for early detection.

Findings about the cancer experience in Kenya

For this research, those affected by cancer consisted primarily of cancer patients, survivors, caretakers, and health care providers. A caregiver is defined as someone who provides physical, emotional, spiritual, financial, or logistical support to a cancer patient. Some of the findings that derived specifically from interviews and focus groups of those who were affected by cancer echoed those of the general population. However, other findings described specific needs and experiences of the cancer community. Key findings are summarized below.

Patients and survivors

- By the time someone becomes a cancer patient in Kenya, they have often experienced a long journey in seeking health care from various health professionals, sometimes including traditional or herbal healers.

- When receiving the diagnosis, patients were often told in a curt or inappropriate manner, with nobody to support him or her. Later, patients were faced with the task of disclosing their diagnosis to their family members, often risking stigmatization and emotional pain. Some patients were never informed of their cancer because doctors and/or the patient's family decided it was better to withhold the information.

- The greatest challenge for cancer patients was dealing with the financial implications of the disease, with the high cost of treatment and medication. Many survivors and patients reported that it took them a long time until they could start treatment, as they first had to raise the required funds. To raise the necessary funds for cancer treatment, patients often depended on the support of others. The financial cost of cancer also had social repercussions as well, where some patients recounted how people had started avoiding them because of the fear that they would be asked to contribute or feel guilty about not having contributed enough.

- In addition to fears of mortality and financial stresses, cancer treatment also posed substantial logistic problems like obtaining referrals, arranging transportation and accommodation for treatment and finding the appropriate drugs when stock outs occurred.

- Numerous patients and survivors reported that the single most important step cancer patients had to take to handle their situation was to accept the fact that they had cancer. Coping mechanisms reported by patients included their religious faith as well as having a good support network of family and friends.

- Two critical knowledge gaps were identified for cancer patients and survivors. First, hardly any patients were aware of the existence of cancer support groups. Second, patients often did not know that they had a right to request more information from the health provider and that they could ask about the prescribed and alternative treatment options.

- Most patients received the bulk of their information about cancer from their doctors, and to a lesser degree, nurses. Other information sources were rarely cited but included support group members, friends, and the Internet for younger patients.

Caregivers

- Caregivers were most often close family members, such as spouses, parents, or children and they played a crucial role in the support of patients, sometimes tasked from the beginning to disclose the diagnosis to the patient. The tasks of caregivers were many, and support by a wider network of family and friends was recognized as essential to preventing burn out and exhaustion.

- A range of additional important practices for caregivers that were identified as having a positive impact on both the patients and the caregivers themselves included: avoiding pity for the patient, making sure the patient was accompanied to appointments to avoid seclusion and loneliness, asking questions of providers, encouraging open talk of cancer to dispel stigmatization, and practicing a healthy lifestyle.

Health care providers

- The sample of health care providers interviewed was not large enough to generalize to the broader health care provider population; however, the findings are relevant for discussion about the knowledge, practices, and opportunities for improvement among health care providers for the treatment of cancer.

- Outside of large hospitals, health care professionals usually concluded that a patient's symptoms were a result of common diagnoses and did not order tests that would indicate cancer. Most doctors and health professionals reported being unaware of the 2013 Kenyan national guidelines for cancer.

- According to cancer survivors and patients, communication skills were lacking among many health care providers. Examples included instances where patients were not told in advance that a biopsy was being taken to test for cancer and some were not told the diagnosis. Those who did personally communicate the diagnosis to their patient often did so in a situation where the patient was not accompanied by a relative or friend. Additionally, many providers communicated the diagnosis in a rather insensitive way, used technical jargon and sometimes avoided the word 'cancer'.

- Education of health professionals on cancer symptoms and signs that suggest diagnostic testing or referral were seen as a top priority. Improvements in this area, particularly continued medical education strategies for general practitioners, clinical officers and nurses, were thought to have potential to substantially increase early diagnosis of cancer in Kenya.

Recommendations and conclusions

From the research, five priority areas for a community education strategy for cancer awareness emerged:

1. Correcting perceptions of individuals who underestimate their susceptibility to cancer
2. Increase the understanding of cancer signs and symptoms
3. Decreasing the fear of cancer screening
4. Reducing stigma associated with a presumed "death verdict" of cancer patients
5. Making risk factors of cancer more salient in promoting a healthy lifestyle.

The household survey found differences between counties, genders and rural/urban settings in perceived cancer susceptibility, lifestyle-related risk factors like alcohol use and diet and different patterns of media use. The analysis found that in addition to the five priority areas, there is a need to focus on outreach to rural Kenya and to target messages based on setting, gender, age and county.

The in-depth interviews were designed to better understand the reality and needs of cancer patients and caregivers. The results showed that while many of their challenges cannot be addressed with communication alone, they would greatly benefit from practical information related to financing, treatment, nutrition, pharmacies and drug prices, hospital navigation and low-cost accommodation. There was very little knowledge among patients about support groups, free activities, and benefits provided by cancer support organisations. Making this information accessible to all cancer patients in Kenya immediately upon their diagnosis, along with messages that help patients to cope with their illness and the social repercussions, would be a great improvement. It is probable that if the various cancer organisations in Kenya combined their efforts for communication and information with that goal in mind, they could have a transformative impact.

Outside the domain of communication and information, three additional priority intervention areas to improve the situation of cancer patients were identified by this study:

1. Supporting initiatives to achieve universal health coverage so that catastrophic health expenditures can be reduced and eliminated;
2. Strengthening efforts to set up and maintain more cancer support groups for patients with different types of cancer in more regions of Kenya, so that all patients have an opportunity to join a support group; and
3. Increasing the cancer diagnostic capacity of health professionals across the country, which involves the development of curricula and integration of cancer-related modules in pre-service and in-service training.

1

Introduction

1.1 Rationale for a knowledge, attitude and practice study on cancer in Kenya

Strategic communication using information, education and communication (IEC) materials constitutes a cornerstone of prevention, health promotion and patient support interventions. Based on early anecdotal evidence and consultations in 2015 by the American Cancer Society (ACS) with the Kenyan Ministry of Health (MOH), cancer experts and civil society, the following perceptions emerged with relation to existing IEC materials in Kenya:

- While numerous IEC materials were available for cancer patients, caregivers, and communities, few of these were developed for populations with low levels of literacy, and many of the materials were not culturally appropriate. As such, there was an expressed need to produce quality cancer IEC materials that better met the needs of local cancer patients, caregivers and their communities.
- Cancer patients in Kenya typically sought care once the disease had progressed to advanced stages and had little pre-existing knowledge to navigate the complex emotions and treatments associated with a cancer diagnosis.
- Healthcare professionals in the public sector were overstretched and, despite their best efforts, did not think they have enough time to impart cancer education to their patients.
- Cancer, of all types, was surrounded by myths and stigma that likely constituted a barrier to healthcare seeking behaviour and to cancer patients finding support in their communities.
- For the general population, the disease itself and its causes and risk factors tended to be unknown to many people, posing a real challenge for prevention efforts.

With this in mind, MOH, in collaboration with the American Cancer Society (ACS), the John Hopkins Center for Communication Programs (JHC-CCP), Kenyan cancer professionals, and civil society organisations, partnered to increase the availability, quality and effectiveness of IEC materials for cancer.

The idea was to adapt existing, up-to-date, evidence-based IEC materials that ACS had previously developed for its domestic cancer prevention and patient support mission. These materials are well-known and highly utilized sources of information for cancer patients in the USA, and increasingly for its international health partner organisations seeking to provide similar quality cancer information to their own constituents. It was recognized from the start, however, that these materials did not contain the most relevant information for the Kenyan context and evidence was needed to support the adaptation of these materials for the local context. In response, the ACS Global Cancer Prevention and Early Detection team supported PS Kenya to conduct a study to provide information about the state of cancer knowledge, attitudes, and practices in Kenya, known as the “KAP study”. The findings of this survey were intended to be used for the following two purposes:

- **Provide guidance for priority-setting, messaging, and budgeting in the national cancer prevention strategy**
- **Work with local partners to adapt existing ACS IEC materials for use among cancer patients, caregivers and healthcare workers.**

This research has been conducted to meet the different needs of various key stakeholders. For ACS, the research is intended to complement an existing country strategy in the national hospital setting. Specifically, ACS currently supports initiatives aimed at enabling treatment completion, including lodging, patient navigation and patient information, as well as increasing access to chemotherapy, radiotherapy, and essential pain medicines. All these activities share a common need to provide improved information for patients, caregivers and health professionals. This need has also been expressed on multiple occasions by several Kenyan non-governmental organisations (NGOs) and substantiated by the JHP-CCP, engaged by ACS to support these efforts.

The Health Promotion unit in MoH has an equally compelling mandate, shared by ACS, to reach healthy Kenyans to reduce their exposure to cancer risk factors by providing communication to the general public that promotes healthy diets, regular physical activity, and reduced tobacco and alcohol consumption. In addition, awareness of the importance of cancer screening and vaccination need to be communicated for effective cancer prevention and early diagnosis.

The study seeks to address both the priorities of the general population and the cancer community, specifically patients, survivors, caregivers, and health professionals. This report is therefore separated into three main sections:

I - Communication for those directly affected by cancer (patients and caregivers)
II - Communication for the general population and people with symptoms
III - Communication for health professionals

Based on the interviews with key informants, various positive efforts have already been made to develop or make IEC materials available. Most of the existing materials consisted of printed booklets, pamphlets and posters, targeted either at cancer patients or at the general population. The format and style (English-only for many products and in a relatively complex language) did not yet adequately address the needs of the targeted populations. For more detail on existing materials and efforts, see the Annex[1].

The ***Health Belief Model*** (HBM) was selected by this study as the conceptual framework for data collection and analysis related to behaviour change communication. The HBM is a psychological model that attempts to explain and predict health behaviours by focusing on the attitudes and beliefs of individuals (Figure 1). The HBM was developed in the 1950s as part of an effort by social psychologists in the United States Public Health Service to explain the lack of public participation in health screening and prevention programs. Since then, the HBM has been adapted to explore a variety of long- and short-term health behaviours, including sexual risk behaviours and the transmission of HIV/AIDS. The key variables of the HBM are as follows[2]:

1. **Perceived Threat:** Consists of perceived susceptibility and perceived severity of a health condition.
2. **Perceived Susceptibility:** One's subjective perception of the risk of contracting a health condition.
3. **Perceived Severity:** Feelings concerning the seriousness of contracting an illness or of leaving it untreated, including both medical and social consequences.
4. **Perceived Benefits:** The believed effectiveness of strategies designed to reduce the threat of illness.
5. **Perceived Barriers:** The potential negative consequences that may result from taking particular health actions, including physical, psychological, and financial demands.
6. **Cues to Action:** Events, either bodily (e.g. physical symptoms of a health condition) or environmental (e.g. media publicity) that motivate people to take action. This aspect of the HBM has not been systematically studied.
7. **Self-Efficacy:** The belief in being able to successfully execute the behaviour required to produce the desired outcomes (This concept was introduced in the model by Bandura in 1977).

---

[1] Annex available online: http://www.cancer.org/health-care-professionals/our-global-health-work.html

[2] Source: Rosenstock I., Strecher, V., and Becker, M. (1994). The Health Belief Model and HIV risk behaviour change. In R.J. DiClemente, and J.L. Peterson (Eds.), Preventing AIDS: Theories and Methods of Behavioural Interventions (pp. 5-24). New York : Plenum Press

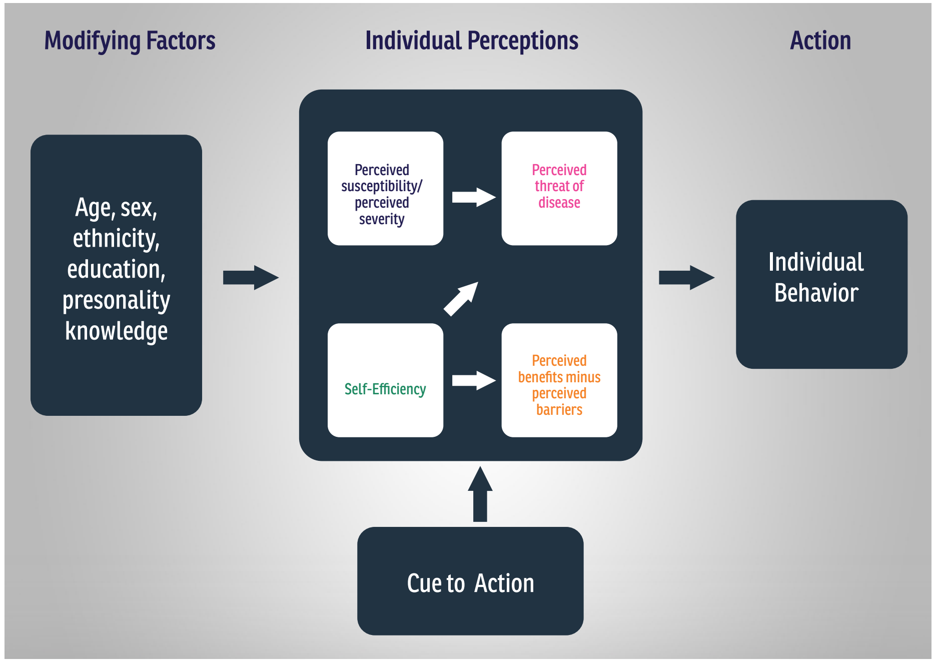

Figure 1: Health Belief model Schematic[3]

The HBM was used as a framework to guide aspects of the study that were related to behaviour and behaviour change. This influenced the design of sections of the discussion guides, survey questionnaire, and the presentation of results, which address key variables of HBM.

1.2 Study methodology

The KAP study used a mixed methods study design that emphasized qualitative data from in-depth interviews and focus groups, which was then complemented with quantitative data from a household survey.

Qualitative research

The qualitative research phase consisted of open-ended in-depth interviews with cancer patients, caregivers, expert stakeholders and health professionals. In addition, semi-structured focus group discussions involving cancer survivors and members of the general population were carried out.

The interviews with cancer patients and caregivers were conducted at Kenyatta National Hospital (KNH) and Moi Teaching and Referral Hospitals (MTRH). The focus groups with cancer survivors in Nairobi were led at the Faraja Cancer Support Trust and Aga Khan University Hospital, and included former and current patients at private hospitals. In Uasin Gishu, the focus groups with survivors took place at MTRH.

Four focus groups with the general population were conducted: two in the urban area of Nairobi (in Lumumba and Harambee estates, representing middle and lower urban socio-economic backgrounds, one female and one male group) and two in rural areas of Uasin Gishu county (one in the Kapsenget and one in the Lotonyok location, which are at different distances from Eldoret Town, one male and one female with no distinction made between socio-economic backgrounds).

The in-depth interviews with experts and stakeholders included health professionals (a community health worker, a nurse, two oncologists and a nutrition and herbal health practitioner), two representatives of the Ministry of Health, four representatives of different cancer-related NGOS, and one participant from a pharmaceutical company that manufactures cancer medicines.

---

[3] Source: http://www.med.upenn.edu/hbhe4/part2-ch3-main-constructs.shtml

The total qualitative sample consisted of nine focus group discussions and 56 in-depth interviews, as summarized in Table 1.

Table 1: Composition of the qualitative sample

Respondent group	N=	Interview type	Interview sites	Age	Gender split
Cancer patients. Types of cancers participants suffered from included breast, cervical, esophagus, prostate, colon, karposi sarcoma, salivary glands, thyroid, throat, gastric cancer, skin and nasal cancers.	26	Individual in-depth interviews (IDI)	KNH: 15 IDI MTRH: 11 IDI	32- 67 years old	10 male 16 female
Caregivers accompanying cancer patients to treatment	19	IDI	KNH: 14 IDI MTRH: 5 IDI	25 – 60 years old	11 male 8 female
Cancer survivors	30	5 Focus groups (FGD) of 4-8 participants	Nairobi: 3 FGD Uasin Gishu: 2 FGD	23 – 70 years old	3 female groups (n=20), 2 male groups (n=10)
General population	36	4 FGD of 8-10 participants	Nairobi: 2 FGD (1x F, 1xM) Uasin Gishu, 2 FGD 1xF,1xM)-	18 – 70 years old	Nairobi: 1 male group (n=9), 1 female group (n=9) Uasin Gishu: 1 male group (n=9), 1 female group (n=9)
Key informants and stakeholders	13	IDI	Nairobi	-	-

Anonymous audio-recorded data from the individual FGDs and IDIs were transcribed into MS Word files. Interviews that were conducted in Kiswahili were translated into English during transcription by qualified transcribers. An initial set of 45 transcripts was then transferred to Dedoose, a qualitative data analysis software package and coded using an ***a priori*** code-frame that corresponded to the research goals and chosen conceptual framework (HBM). Additional themes were extracted from the transcripts during the review, and initial findings were written into an interim version of the report that was presented to a forum of stakeholders in June 2016. The remaining transcripts were printed, and a manual content analysis was carried out using the same objectives and research questions as guidance. Findings from the qualitative phase of the study also informed the refinement of the household survey tool.

Quantitative household survey

The second part of the study consisted of a quantitative household survey designed to capture some of the different socio-cultural realities in Kenya.

Questionnaire development

The questionnaire was structured (close-ended questions) using: (1) a standardized and validated tool, the UK Cancer Awareness Measures (CAM)[4], (2) the preliminary results from the qualitative phase of this KAP study, and (3) the constructs of the HBM, as the predetermined theoretical framework for this study.

---

[4] The survey instrument (CAM) was developed by Cancer Research UK, University College London, Kings College London, and University of Oxford in 2007-2008. The validated 2008 version was retrieved from www.cancerresearchuk.org/health-professional/prevention-and-awareness/the-cancer-awareness-measures-cam#CAM0. Using questions from a validated instrument has the advantage of increased reliability, validity, and comparability. At the same time, modifications had to be made for a number of questions that were not transferable to the Kenyan context and lingo, for example booking of doctor's appointments, or standard quantifications for the intake of vegatables or physical activity. Due to restrictions in questionnaire length, only a selection of questions of the CAM were used.

For some of the questions – information sources, warning signs, and risk factors or "reasons" for cancer – respondents were asked first for a spontaneous answer and then after with a list of pre-determined possible answers they could agree or disagree with. The final tool was translated into appropriate local languages (Luo, Kikuyu, Embu, Kamba, Meru, Luhya and Nandi) and scripted for personal interviews assisted by mobile devices. An English-version of the questionnaire used for the study can be found in the Annex[5].

Data collection

To capture both urban and rural perspectives, six counties were purposely selected for data collection: two urban counties (Nairobi and Mombasa), three mixed urban/ rural counties (Kajiado, Kisumu, and Nakuru), and one predominantly rural county (Murang'a). While the combination of counties resulted in a largely urban and peri-urban sample, it was still possible to compare differences between urban and rural Kenyans who live in these counties, since rural households were overrepresented in the survey sample compared to the total population in these areas.

The study sample was designed with the technical support of the Kenyan National Bureau of statistics (KNBS) to provide statistically valid results for the overall percentages at a confidence level of 95% and a corresponding margin of error of +/- 5%. It also allowed for the disaggregation of findings by core sub-populations such as gender and locality (urban vs. rural). The sample was drawn from KNBS' National Sample Survey and Evaluation Programme (NASSEP V) frame and was representative of the six targeted counties. A two-stage stratified probability sample design was used with a total of 48 clusters considered at the first stage of sampling (eight clusters in each county). In each cluster, the goal was to conduct an interview in 20 households that were randomly selected by KNBS.

One single eligible household member (18 years and above) was selected randomly for the interview, and callbacks were made at appropriate times when the contacted person was unavailable. The overall target sample was 960 individual interviews, of which 578 were successfully completed, representing a response rate of 60%. The main factors attributed to non-response were: unidentifiable households, vacant/ destroyed households and absence from the household for an extended period.

Fieldwork was conducted in June 2016 using a team of 29 interviewers and six supervisors. The team received thorough and centralized training and participated in a pilot prior to the start of fieldwork.

Data analysis

Descriptive data analysis was carried out using statistical software packages (STATA and SPSS) and graphs were generated using Microsoft Excel. The univariate and bivariate analysis sought to compare frequencies and distributions between different population subgroups, usually gender, counties, and setting (urban vs. rural). For variables were there was a large difference between age groups and people with high vs. low susceptibility, these are presented in the report. Where differences were observed, basic tests were carried out to test for statistical significance and statistically significant results are reported as such.

---

[5] Annex available online: http://www.cancer.org/health-care-professionals/our-global-health-work.html

To adjust the sample to reflect the actual population of the six combined counties, post stratification weights were applied by KNBS. Unless otherwise mentioned, tabulations and graphs in the report are based on weighted data. The ***overall*** statistics are representative of a more urban population, due to the inclusion of Nairobi and Mombasa, which are 100% urban. Figures 2 and 3 detail the urban/rural breakdown for the six counties sampled.

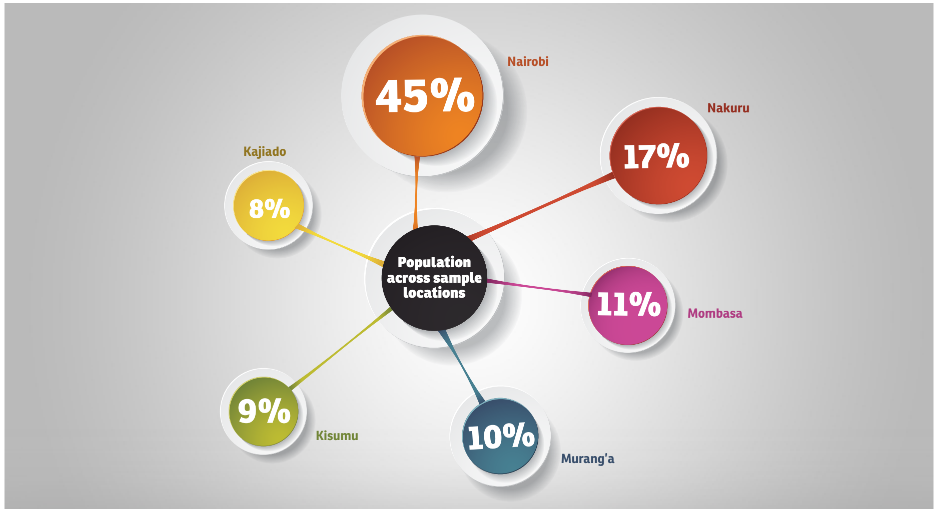

Figure 2: Sample locations

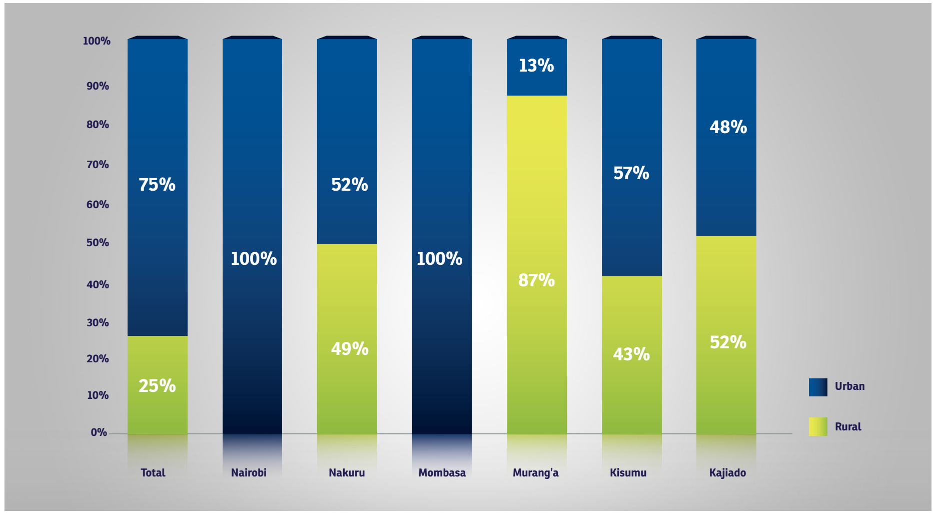

Figure 3: Urban/rural split in sample counties

The pyramid in Figure 4 illustrates the age and sex profile of the population (weighted data). The wider base reflects the predominantly young Kenyan population. Overall, the survey covered slightly more women (56%) than men. Although the population that had only completed primary school was similar in rural (35%) and urban (35%) areas; those in urban areas were twice as likely (50%) to have completed secondary school compared to their rural counterparts (24%).

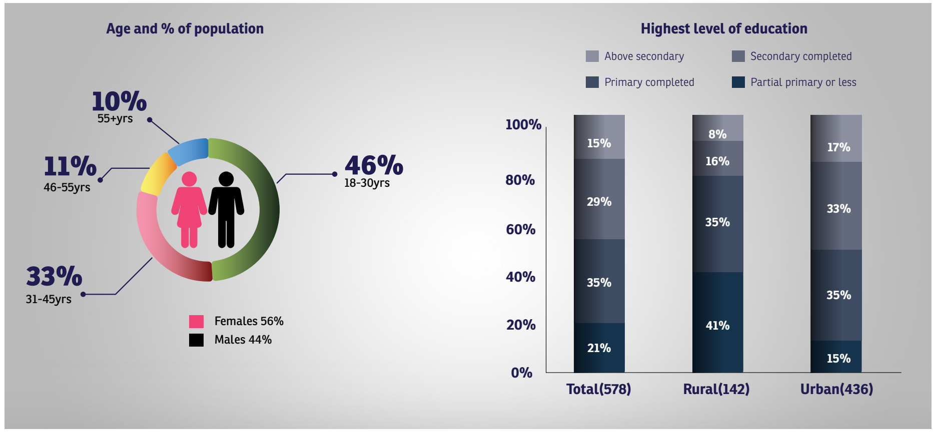

Figure 4: Sample demographics

Many households were dependent on self-employment (47%), either in the formal or informal sector. Close to a quarter (23%) of households were supported through remunerated employment, while about a tenth (12%) were mainly dependent on erratic incomes though casual work or domestic service (see Table 2).

The questionnaire included additional measures of housing conditions and assets to assess the population's socio-economic characteristics, namely connection to the electricity grid, ownership of a TV and ownership of a refrigerator. An assumption was made that the most affluent among respondents were those with a refrigerator, while those with a TV but no refrigerator were in the next group, followed by those with electricity but neither TV nor refrigerator. The least affluent were those without electricity. Close to a third of the population (29%) were in the least affluent segment and 40% were in the second most affluent group. Households supported by remunerated employment were likely to be more affluent than their counterparts. Among the households supported by casual/domestic work, no one owned a refrigerator.

Table 2: Livelihood and socioeconomic status proxy measures

	Total	Farming	Employed	Casual/ domestic work	Self employment own business	Remittances or pension
Main source of household income	100%	15%	23%	12%	47%	3%
SES proxy						
Refrigerator	18%	5%	28%	-	20%	Sample size too small for reporting
TV	40%	13%	39%	36%	51%	
Light only	14%	7%	16%	31%	9%	
No electricity	29%	75%	17%	33%	20%	

Study limitations

This study represents both a broader and a deeper look into knowledge, attitude and practices related to cancer in Kenya compared to any other studies previously carried out in the country. As a new source of information to support evidence-based decision-making, it is important to be conscious of the study's limitations.

First, the qualitative component of the survey, like most qualitative studies, seeks to gain a rich understanding of a broad range of individual experiences; however, the small sample size means that the findings do not necessarily represent all experiences of those who have or had cancer, their caregivers and medical professionals in Kenya. It is possible patients willing and/or able to be interviewed introduced an unrecognized selection bias through a process of self-selection.

The household survey for its part has two major limitations. First, even though the six counties were selected purposively to represent a range of different Kenyan settings and realities, they do not represent the entire country. The inclusion of

Nairobi and Mombasa, the most densely populated areas of the country, meant that the sample was predominantly urban. However, rural households were included in the sample, so the survey does allow for some comparison between the two settings.

The second limitation of the household survey was that the response rate was lower than anticipated by KNBS, due to a combination of factors. One substantial factor was that a relatively large proportion of the randomly selected household respondents were not at home, even when multiple attempts to find them were made. This problem was particularly pronounced in Nairobi. Consequently, it is possible that segments of the population who spend the least amount of time at home due to working long hours or looking for work are underrepresented, especially in Nairobi.

Despite these limitations, this study produced many relevant findings on the knowledge, attitudes, and practices around cancer in Kenya. The next two chapters of the report discuss these findings, with Chapter 2 details the general population focus group and survey results and Chapter 3 focuses on the qualitative research of the community that had experience with cancer. The overall conclusions from the study are discussed in Chapter 4.


SHORT STREET
TWEET AND LIKE
SLAM TO SHARE
ISUZU
289

2

Cancer Knowledge, Attitudes and Practices

The term general population is used to refer to the Kenyan population of all age groups and not specific to those who have experience with cancer. The information about the general population is relevant for stakeholders in charge of community health in their prevention efforts to combat cancer. General population findings can be leveraged to inform community cancer education strategies. In the general population, the study found differences in knowledge, attitudes and practices among people from different socio-economic backgrounds, from urban and rural settings, and from different regions in Kenya. Findings about the general population where obtained from the interviews across all respondent categories, including from the interviews with patients, caregivers and cancer survivors, who reported their experience before the cancer diagnosis. In the following subchapters, results from the qualitative survey are presented first, followed by complementary insights from the household survey where available.

2.1 Cancer awareness and knowledge

Knowledge and awareness

When people in the general population focus groups were asked what they know about cancer, their answers were highly varied. Overall, however, they showed a good amount of knowledge about cancer already exists in the general population of Kenya.

Awareness of cancer and disease severity

First, people knew that cancer is a disease that society fears and that can kill. Participants often conceptualized cancer as a disease by comparing it with HIV, stating, for example, "It is worse than HIV". Although many knew what cancer is, there appeared to be much less awareness of specific symptoms of cancer. In one focus group, the symptom of "painless swelling that persists" was mentioned.

There was a marked variation among participants with regards to their awareness of different types of cancer. Outside Nairobi, many had only heard of breast, prostate and cervical cancers, while a majority in Nairobi knew that it could affect other parts of the body. There appeared to be gender differences in cancer awareness with lung, skin, mouth and brain cancer mentioned in the male group, and liver, throat, and blood cancer in the female group.

Knowledge differences were also seen among urban/rural focus groups. In the Uasin Gishu focus groups, respondents reported less knowledge about cancer compared to residents of Nairobi and more misconceptions were observed. However, most participants in Uasin Gishu knew that cancer is a very serious disease that often kills, as did the participants in Nairobi.

Knowledge of cancer origins and risk factors

Most men and women were aware that cancer is a non-communicable disease. Many participants described cancer as a disease that people "just get" without direct causes. One of the participants, who identified herself as an avid reader, described cancer as an abnormal growth of cells, and as having multiple stages. Another participant also knew that cancers usually present themselves as tumours.

Most focus group participants did not believe that cancer was related to witchcraft, although some responses suggested that the belief still exists and appears to be more common in Western Kenya than in other parts of the country.

Participants had a lot to say about cancer prevention and its risk factors. The general sentiment among interview and focus group participants is that an individual's risk of developing cancer tends to be higher if it runs in the family, to the extent that it appears to be perceived as a hereditary illness by many. This perception is problematic because many of those who do not have a family history of cancer dont see themselves at risk.

Besides genetics, interviewees reported that cancer was also associated with lifestyle in general, and more specifically to an individual's nutritional choices and alcohol consumption. Smoking as a cause was mentioned in the male groups. In Uasin Gishu, a participant attested that some young people colloquially refer to cigarettes as "cancer". In the female group in Nairobi, some additional risk factors were mentioned, including tattooing, drug addiction, or being albino with a greater risk of skin cancer. It was only in the female group in Nairobi that the benefit of exercising for cancer prevention was spontaneously mentioned.

Knowledge of cancer treatment

Often, desirable interventions to halt cancer were discussed from the perspective of participants' experience with information campaigns about HIV. For example, participants mentioned the need to step up interventions and communication efforts about cancer to match the efforts related to HIV.

Many participants were aware that cancer could be treated if detected early. Among both men and women, there were some people who were aware of all the main treatment methods, i.e. radiotherapy, chemotherapy and "cutting", as surgery was referred to. A female participant also mentioned cryotherapy as "freezing of the cells".

Insights from the household survey

Almost all respondents in the household survey had heard about cancer (97%)[6]. Figure 5 show that a majority (67%) reported knowing someone with cancer, with minimal differences observed between gender, age or location. The most commonly recalled risk factors for cancer were unhealthy food (55%), distantly followed by alcohol (11%) and smoking (10%). About 12% of respondents mentioned incorrect causes, which are described in more detail later in the report.

Sixty-two percent of respondents believed that transmission of cancer is not possible, but close to a quarter (23%) were unsure, with statistically significant higher mentions of "don't know" amongst the rural ($p<0.01$) and older population (+55 years; $p<0.05$).

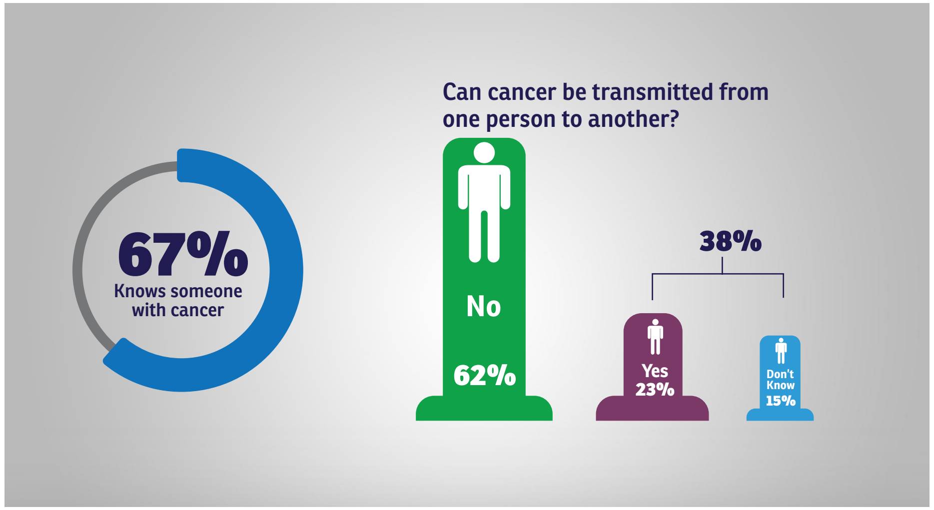

Figure 5: Knowledge of cancer in household survey

Survey respondents were asked if they knew of any warning signs associated with cancer. Figure 6 describes the responses, where the more prominent spontaneous responses were signs that can be detected from sight, such as unexplained lumps (40%) and sores that don't heal (25%). When respondents were prompted about a range of known cancer symptoms, the recognition of other potential signs showed a large increase. Approximately 30% of respondents who ***had*** heard of cancer could not mention any symptom spontaneously, with some variation between counties

---

[6] Those who had never heard of cancer were excluded from subsequent cancer knowledge-related questions.

(Figure 7). In Mombasa, Muranga, and Kajiado the lower proportion of spontaneous mentions was statistically significant when compared to the other counties.

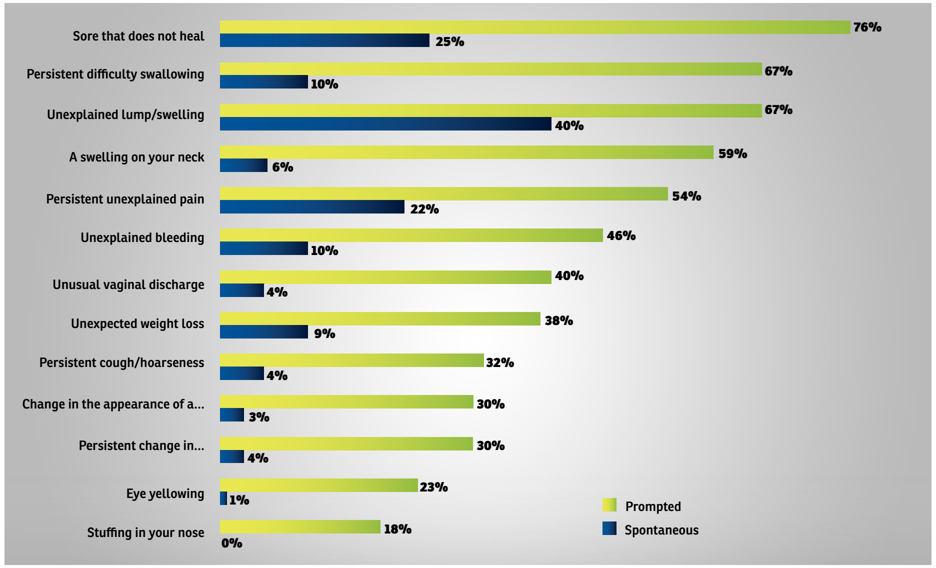

Figure 6: Spontaneous and prompted awareness of possible signs and symptoms of cancer

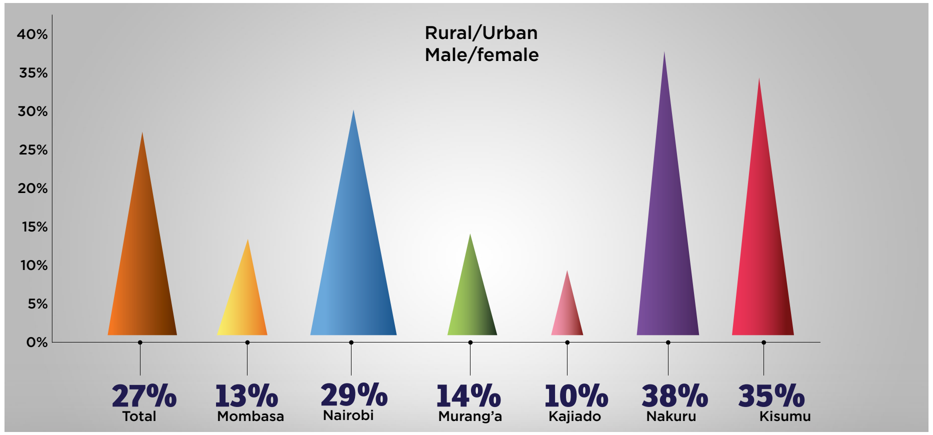

Figure 7: Unable to mention a potential sign/symptom of cancer

Respondents were asked to what extent they agree or disagree with statements about various risk factors for cancer. The answer options, taken from the CAM, included "strongly agree", "agree", "not sure", "disagree" and "strongly disagree". A large proportion agreed that smoking increases the risk (94% and 81% for passive smoking) and 76% agreed that regular consumption of processed meat does the same. Slightly more than half (55%) saw alcohol as a risk factor. In contrast to the qualitative findings, poor nutrition and being overweight were also seen as risk factors by about half of the respondents and having a relative with cancer by only 40% respondents. Respondents were less aware about the relation of physical activity, age, exposure to sunlight, and being infected with the human papillomavirus (HPV) with cancer risk (Table 3).

To gain a more comprehensive picture of the population's view of cancer risk factors, three items were included in the list of prompted possible factors that are not part of the CAM. They were derived from findings in the qualitative research: (1) "use of makeup or other beauty products", (2) "family planning" and (3) the distinction between drinking government-regulated versus unregulated alcohol. Almost three in four (71%) agreed with the statement that using makeup or beauty products increases the risk of getting cancer[7] - significantly more male respondents believed so than female respondents. Two thirds agreed with the statement that family planning methods increase the risk of cancer and less than a fifth disagreed with this statement (18%). Approximately 15% of the respondents believed that non-regulated/'illicit' alcohol increases the risk for cancer but regulated alcohol does not.

Aggregating the various responses provides a snapshot of overall awareness of the risk factors for cancer. About half of all respondents (48%) had eight or more correct responses and 5% had 12 or more correct responses from the list of known risk factors. For this summary measure, no differences were observed between gender and urban/ rural settings.

Table 3: Risk factors of cancer (prompted)

These are some of the things that may or may not increase the chance of getting some cancers. How much do you agree that each of these can increase the chance of getting cancer?	
Smoking any cigarettes at all	94%
Exposure to another person's cigarette smoke	81%
Eating red or processed meat once a day or more (Processed meat includes bacon, ham)	76%
Drinking non-regulated alcohol/illicit brew	71%
Drinking alcohol that is regulated by the government	55%
Not eating enough greens or fruits	53%
Being overweight (BMI over 25)	46%
Having a relative who was affected by cancer in the past	40%
Doing less than 30 minutes of moderate physical activity 5 times a week	32%
Being elderly	31%
Being in the direct sunlight for too long as a child	28%
Infection with HPV (human papillomavirus)	27%
Using family planning methods such as a pill or implant	82%
Using makeup or other beauty products	85%

Information sources

Focus group participants most often referred to radio as their source of information about cancer, which was consistent with findings of the household survey. Participants also mentioned TV as a source for existing knowledge on the disease, as well as friends, "random people talking" and relatives who have cancer. One rural participant had received information from a lady who had come to speak to them in church.

---

[7] While there are a wide array of beauty products on the market in Kenya, some of which are not licensed for sale in other parts of the world, there is no current evidence that use of the products is associated with cancer.

Participants reported having heard requests for financial support for cancer patients on the radio, and one rural participant specifically referred to Radio Citizen, which “has two weekly shows - on Monday and Thursday - where they bring doctors”. A young man in rural Uasin Gishu had learned about cancer on Facebook when a prominent person he follows told his friends and followers about his own experience.

Two focus group participants in Nairobi reported having seen or heard information about cancer in health facilities, either through an education session by a health worker, or on a poster. The messages people talked about were usually cancer specific (e.g. breast or cervical cancer) and often included instructions to get screened regularly.

Insights from the household survey

From the household survey, the percentage of people who reported seeing or hearing cancer information or messages in the past 12 months was similar in rural and urban areas (urban: 86%, rural: 85%). However, rural respondents were more likely to have received information from the radio (76%) compared to urban respondents (42%), which is statistically significant (Figure 8; p<0.01). In contrast, urban respondents were more likely to have received information from television (48% vs. 15% rural).

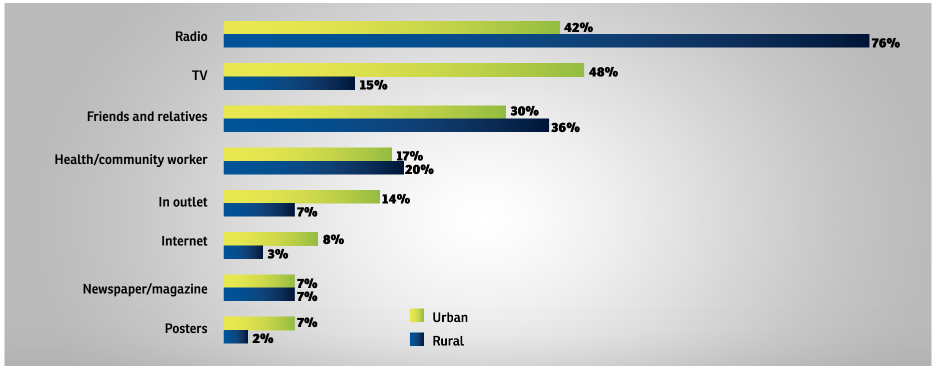

Figure 8: Media reach, rural and urban

Additionally, there were gender differences in media exposure, where more men reported they had seen or heard cancer messages in the last 12 months through radio, television, friends/relatives, print media, and internet, while women had been reached more often through health workers (Figure 9). Of these differences, gender-specific exposure to radio and Internet was statistically significant (p<0.01).

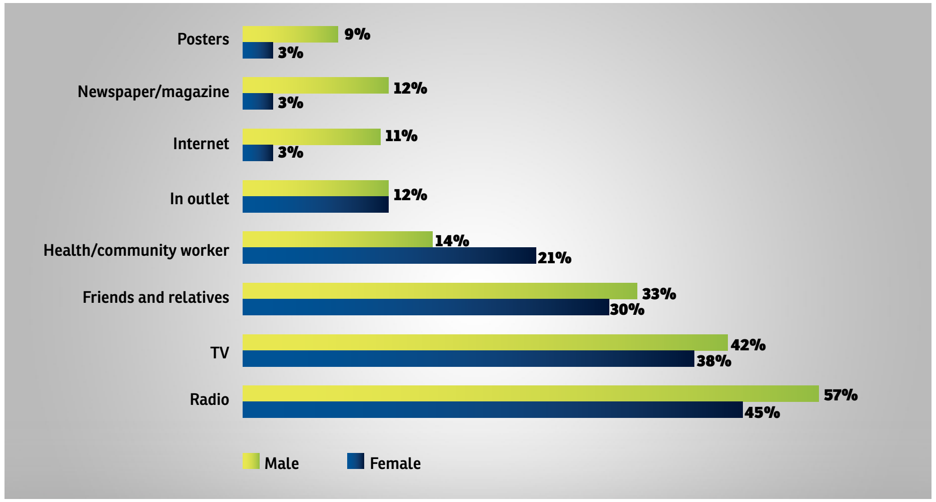

Figure 9: Media reach by gender

Misconceptions, beliefs and myths

Possibly the most widespread misconception regarding cancer found in this study is related to susceptibility to the disease, which is discussed in more detail in chapter 2.2.

People in the study also associated cancers of the reproductive system with sexual behaviour[8]. In the focus groups in Nairobi, sexual lifestyle was also mentioned as a risk factor, where one female participant explained that she had heard cancer risk was related to HPV virus infection. One male participant emphasized that he was at an increased risk for being "a lover of girls". In the rural female focus group, the belief that men who sleep with multiple women "leave dirt" and thus put women at risk of getting cancer was expressed explicitly. Some participants thought that cancer affects mainly women (since they mainly know of cervical and breast cancer), and one misconception that was mentioned was that cancer could be caused by a certain leaf that women use to wipe themselves when using the toilet.

While many had accurate knowledge that elderly people are more at risk for cancer, this also led to the misconception, among some, that it is "a disease [only] for old people". Prostate cancer, in particular, was repeatedly referred to as an "old man's disease". There was also a belief indirectly related to age in the rural women's focus group, where a participant thought that menstruating could help protect against cancer, implying that menopause leads to an increased risk of cancer. Mostly, people said that they know better now than in the past, when they "used to think that cancer is a disease for the old".

Some people in rural Kenya attributed cancer to the lifestyle changes of those who move to the city, including immoral and sexually loose lifestyles, and the use of modern family planning methods. One of the male focus group participants said that he did not think he could get cancer not only because he had a healthy lifestyle, but because of his strong faith, declaring being a born-again Christian and "protected by the blood of Christ". Another participant did not see himself at risk because of his "healthy way of living".

However, upon being asked specifically if they saw themselves at risk of getting cancer, perhaps to some extent because of being in an interview, many of the focus group participants – both female and male – said they did. While they partially attributed this increased susceptibility to scientifically accurate risk factors (smoking, unhealthy food, family members who had cancer, increased cancer prevalence in the population), both groups also pointed to scientifically unproven reasons for that increased risk, such as the increased use of family planning and exposure to products such as make-up or genetically modified foods.

In Uasin Gishu, two female focus group participants associated cancer with accidents and wounds, a view that had also been expressed in Nairobi. Their understanding was that cancer could be a consequence of wounds that do not heal or remain untreated. Open wounds were also mentioned in a discussion around beliefs of how cancer is healed. One participant explained that when herbalists treat cancer, a wound opens up, through which the disease leaves body.

Many other uncertainties and misconceptions in the general population about cancer causes and risk factors emerged during the interviews. Among the misconceptions were:

- Only the consumption of illicit/unregulated types of alcohol increases the risk of cancer
- Implants and pills for family planning can cause breast and cervical cancer
- Stopping to be sexually active can lead to prostate cancer
- Certain hair products cause cancer

---

[8] There is a complex relationship between sexual behaviour and certain cancers, through the intervening factor of HPV infection. It is therefore true that there is an indirect relationship between the two. It is now known that behaviour change around sexual practice is not an effective way to prevent HPV infection; condom use is not fully effective and until widespread vaccination is available in a county most people will carry the HPV infection at some point in their lives. Only HPV vaccination/cervical cancer screening are effective at reducing the incidence of cervical and other HPV-related cancers.

- Modern-day products and technologies such as microwaves, roll-on deodorant, plastic bottles cause cancer

- Food supplements can help prevent cancer

The belief that cancer is a result of witchcraft and/or a family curse is still a reality, especially in rural Kenya, although regional variations exist in the nature and intensity of the belief. As mentioned earlier, participants in both Nairobi and Uasin Gishu pointed to rural Western Kenya as the region where this belief is more common. Less than one percent in the household survey believed in witchcraft or supernatural causes as a cause for cancer; these were too few individuals to confirm such a geographical trend. This belief is associated with victim blaming, whereby the assumption is that the person who has cancer has somehow sinned or otherwise contributed to his/her own trouble. Interviews suggested that beliefs related to witchcraft might be more common in some communities than others. Finally, according to an expert, some churches spread the belief that cancer may be caused by people losing their relationship with God.

The misconception that perhaps caused the most direct harm to cancer patients and their family is the common perception that being diagnosed with cancer amounts to receiving a death sentence. “Death” was among the first things mentioned as coming to people’s mind in all focus groups when they heard the word cancer. Another stigmatizing misconception that appeared in urban and rural groups was that cancer is somehow communicable. This belief is particularly directed at those affected by cervical cancer, as it is seen by many as the possible direct result of irresponsible sexual behaviour. Additionally, members of the male focus group speculated about the increase of cancer risk through oral and anal sex, through blood transfusion, and sharing cigarettes with others.

A misconception that was mentioned only once, but which has an implication for the prevention of cancer if it were to be widely held, was that screening is always for HIV, without any knowledge about the existence of cancer screening. Finally, with regards to treatment, participants in the focus groups and one of the experts suggested that there is still a part of the general population that believes that good quality cancer treatment is only available outside of Kenya – this may be driven by media reports about politicians who were treated abroad, or calls for financial support for overseas hospitalization, as cited by two patients.

Insights from the household survey

When asked about their knowledge of causes of cancer, 12% of respondents named at least one misconception about the causes of cancer, as shown in Table 4. There were no differences between urban and rural settings. Additional misconceptions were present in 1% or less of the population, including phone radiation or the consumption of spicy food.

Table 4: Misconception about the causes of cancer (Household survey)

Family curse or individual curse	3%
Wounds that are left untreated	3%
Using your nails to reveal codes on scratch cards	2%
Poor hygiene	2%
Cosmetic products	2%
Family planning	2%

One survey question was designed to test whether respondents see herbal/traditional treatment or prayers as a viable substitution to hospital treatment for a patient who “doesn’t have a lot of money”. The responses revealed a statistically significant difference between urban and rural respondents. As seen in Figure 10, rural respondents were more likely to say that patients should seek alternative treatment or pray, while urban respondents were more likely to suggest asking the government for help (p<0.01 in both cases).

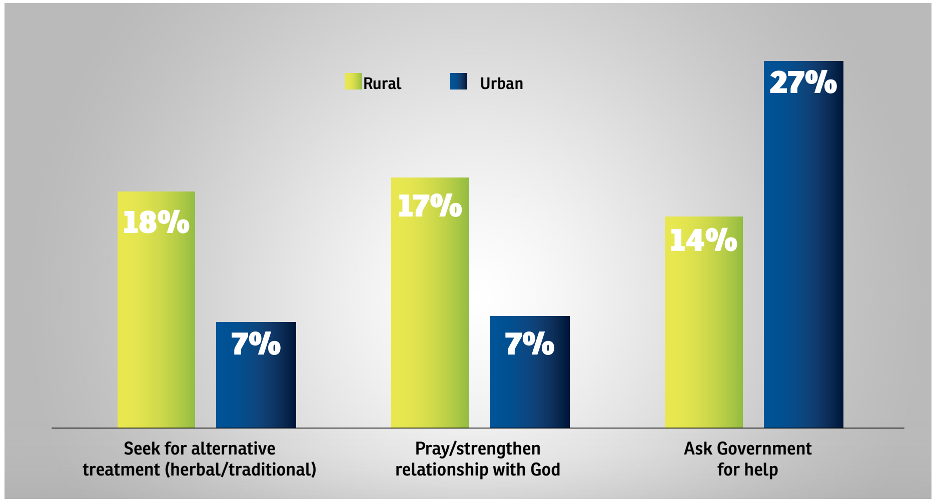

Figure 10: "What can someone who has cancer and who doesn't have a lot of money do to get better?"

Knowledge gaps and uncertainties

When cancer patients were asked to think back to their knowledge before diagnosis, many, especially those from outside Nairobi, said that they had little to no basic knowledge about cancer. Several of the patients said they had never known anyone with cancer before. The self-reported lack of knowledge was confirmed in the general population rural focus group in Uasin Gishu, where participants said they knew little to nothing about cancer – especially what the symptoms were, what caused it, and whom it affected.

There was also a lack of knowledge about the prevalence of cancer and the fact that it can often be cured when detected early. Unsurprisingly, there was some confusion and uncertainty about the curability of cancer. As one of the experts explained, cancer is less curable and more life threatening for average Kenyans than for those in Europe or North America, due to the lack of affordable and accessible treatment options and late-stage diagnosis. Not much knowledge was demonstrated by participants about how much treatment costs other than that it is "really expensive". Overall, participants in the focus groups had fewer questions about what cancer "is" than questions about its causes and symptoms.

There were several gaps and uncertainties in terms of the different types of cancer. Respondents reported that they had previously heard of breast and cervical cancer, but most had never heard of colon cancer. In general, there seemed to be uncertainty around prostate cancer. One of the caregivers explained he had known about leg and stomach cancer but only heard that the prostate could be affected when his relative was diagnosed. One male focus groups participant asked, "What exactly is this 'cancer of men' thing we keep hearing about?" In addition, there seemed to be a lack of knowledge and understanding about cancer screening for men, as many respondents seemed to assume that cancer screening was only for women. However, there were also important uncertainties related to screening for women, about the process, whether it is painful or not, the cost, and where it could be done.

Box 1: Quotes related to uncertainty

> They didn't give birth [women affected by cancer were infertile] because it was said they contracted cancer after having relationships with different men. I don't know whether that is true, if it's another way of getting cancer, of spreading cancer. Having relationships with women if you are a young man or sleeping with men if you are a woman. That can be so, because there is only one pot and this pot holds every rubbish.
> General Population Focus Group. (male)

> I have heard that there is another type of cancer, especially commercial sex workers, they get cervical cancer so much because of having sexual relations with many different men. Another one is, I don't know whether it's proven, especially men if he is married and then he suddenly stops having sex and he stays dry [laughter] that is, lack of playing sex for some time if you are used to it and then you suddenly stop at once, then you are likely to suffer from, it's called what? Prostate cancer."
> General Population Focus Group (male)

> You find in our county hospitals, we don't even have specialists, or cancer oncologists. We don't even have enough medicines, you get referred to Kenyatta from the county and if you are referred to Kenyatta from county and you don't have a relative here, then write yourself out because the cost is too much. Again you are coming to Nairobi whereby we live in a room equally to the size of this table and we share a bedroom with you. You will stay in the village and die from there.
> General Population Focus Group (male)

2.2 Attitude towards cancer: Perceived severity and susceptibility

The HBM was used as the theoretical approach to define “attitude”. According to the model, someone's preventative behaviour is influenced by the perceived threat of a disease they want to avert. The threat is made up by two subjective components: (1) the perceived severity of the illness and (2) the perceived susceptibility of getting it. This chapter explores these two elements, with the addition of stigma, an important theme in Kenya both in relation to cancer severity and patient wellbeing. Subsequent chapters will discuss the other elements of the HBM that are related to specific behaviours.

Perceived severity

In all the focus groups, cancer was described as one of the most severe and frightening diseases in Kenya and a leading cause of death. Participants were aware of the stigma that is associated with it, especially the fact that others see someone who has a cancer diagnosis as having a death sentence, and treat them accordingly. Participants were also aware of the fact that cancer treatment is very expensive.

In contrast to the severity of cancer as an illness, the accounts given by cancer patients and survivors made it clear that the signs and symptoms of cancer were not typically perceived to be serious or to be related to cancer.

Box 2: Quotes related to perceived severity

R1: Apart from death what I have also observed is disability. Either your leg will be cut off, or hand, finger or breast. R2: Death being automatic, when there is cancer in the family, that family is never the same again. The centre does not hold anymore because of the expenses.
General population focus group (male)

R2: It also affects them psychologically and also physically. R9:It also affects them emotionally because you realize the way they feel about themselves, they tend to feel discouraged and maybe at some point they get to be discriminated in the family, so they tend to be emotionally disturbed. R10: You find that maybe one of your legs is cut and in your family you are the person that people expect to provide food in the house so you find things to become hard.
General population focus group (female)

R3: What I know about cancer, is that you lose most of your friends. Once you have cancer you lose friend because they know that you are dead already.
General population focus group (male)

Moderator: What happens when you don't have money for treatment?

R5: This is my home, it will be my home and you will bury me here. Nowadays we don't have harambees for sickness or hospital or bills because people know there is NHIF and they believe everyone has one. But NHIF is not enough, radio and chemotherapy needs a lot of money. [So you start planning], and repenting your sins.
General population focus group (female)

Insights from the household survey

The household survey gauged the perceived severity of eight known cancer symptoms[9] by asking respondents how many days they thought it would take them to seek treatment, from the first time they noticed the symptoms. Figure 11 illustrates the percentage of respondents that indicated that they would seek treatment within a maximum of three weeks for all eight symptoms. There was a statistically significant difference between settings, with a lower propensity to seek health care within three weeks among rural respondents (p<0.01). This difference is reflected in the comparison between counties, with people in Kajiado statistically more likely to seek treatment immediately than the other counties. Compared to men, women reported higher rates of seeking health care within three weeks (44% vs. 39%), however, this difference was not found to be statistically significant. Additional research, both qualitative and quantitative, would be useful to understanding the perceived severity of the various cancer symptoms, as opposed to cancer itself.

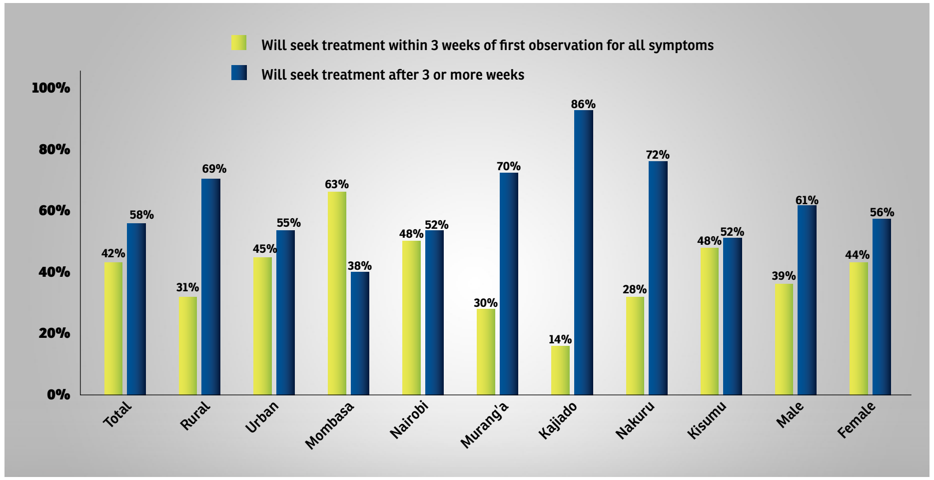

Figure 11: Time to seek treatment after becoming aware of symptoms

---

[9] The symptoms were; (i) unexpected lump or swelling (ii) difficulty swallowing (iii) change in the appearance of a mole (iv)a sore that did not heal (v)unexpected weight loss (vi)eye has become yellow (vii) your nose has been stuffy for very long and never cleared, (viii) a swelling on your neck.

Stigma associated with cancer in the general population

As mentioned previously, among the research participants, cancer was closely associated with death and was perceived to be one of the most severe illnesses that existed. Beyond the expectations around mortality, people reported other tribulations that came with having cancer and had a victimizing and isolating effect on those affected:

- Cost ("I heard many times on radio people who were asking for contributions")
- Morbidity (e.g. amputation)
- Family impact (financial and concerns about the presumed hereditary nature of the disease)
- Stigma ("You lose all your friends - you are seen as if you were already dead.")

These factors resulted in an uneasiness and avoidance of those with cancer in Kenya, which had a strong negative impact on the wellbeing of cancer patients.

Stigma appeared to particularly be a problem in rural areas of Kenya. Beliefs that related cancer to sexual behaviour/promiscuity and the use of family planning as causes of cancer were more widespread in rural areas and were associated with moral judgment and stigmatization of the victims. Another stigma articulated in rural focus groups in Uasin Gishu was the association of cancer with bad smell and rotting. A female participant reported: "When it affects someone you know, you can't enter the house where that person is, because it smells a lot. It's like someone is rotting when they are still alive. (...) If it's the stomach, it will go up to the private parts if the pus will come then it will come out through the private parts. So it's scary". Another participant in the same group confirmed the account by telling her own story of her son who had cancer many years ago and his leg started rotting and the blankets and the whole house started smelling.

Perceived susceptibility

When focus group participants were asked to think back to the time before they were diagnosed, nearly all cancer patients did not recall seeing themselves at high risk of getting cancer. Many said that since there had not been another cancer case in their family, they did not see themselves at risk. Other misconceptions that minimized individual's perceived risk of cancer included their health status ("I was young and strong"), their non-use of certain products ("I never used nail polish and makeup, and didn't pierce my ears"), and their health behaviours. One respondent said that at her age, she "didn't behave irresponsibly anymore", and therefore did not understand how she could have gotten cancer.

Insights from the household survey

In the household survey, a five-point scale was used to gauge perceived likelihood of getting cancer. When asked directly, close to half (46%) said they thought their chances of getting cancer were likely or very likely, while 54% of the population either thought that they were unlikely to get cancer, or they did not know - an attitude labelled as "agnostic" below. A larger proportion of rural residents (28%) indicated that they were unaware about their cancer risk compared to their urban counterparts (17% - statistically significant difference, p<0.01). Regionally, 54% of Nakuru residents reported they had a low chance of getting cancer. This was statistically significantly higher than all other counties (p<0.01) and four times as high as the respondents in Kisumu (12%). Mombasa had the highest proportion of respondents who didn't know if they were likely or not to get cancer.

Figure 12: Perceived susceptibility

When looking at other demographic differences, the data suggest that a higher proportion of older people and the less educated rated their susceptibility as high, however, the differences observed were not statistically significant. A relationship was also found between exposure to cancer messages and perceived susceptibility. Those exposed to cancer messages in the past 12 months were less likely to say that they don't know if they are at risk for cancer (17% exposed vs. 44% unexposed).

Table 5: Perceived susceptibility

Susceptibility by selected demographics		High	Agnostic	Low
Gender	Male	46%	15%	39%
	Female	46%	23%*	31%
Setting	Rural	43%	28%**	29%
	Urban	47%	17%	36%
County	Kajiado	49%	23%	29%
	Kisumu	65%*†	24%	12%
	Mombasa	37%	35%**††	27%
	Muranga	46%	26%	28%
	Nairobi	52%	12%	36%
	Nakuru	22%	25%	54%*
Exposure to cancer messages, past 12 months	No	39%	44%**	18%
	Yes	47%	17%	37%
Education	Below primary	41%	32%*	27%
	Primary complete	57%*	13%	30%
	Secondary complete	43%	20%	37%
	Above secondary	33%	18%	48%*
Age	18 - 30	44%	15%	41%*‡‡
	31 - 45	43%	20%	37%
	46 – 55+	54%	29%*‡	17%

*$p<0.05$ **$p<0.01$, significant difference when compared to other group(s)

† Difference significant except when compared to Nairobi †† Significant difference compared to Nairobi only

‡ Significantly difference to age group 18-30 ‡‡ Significantly difference to age group 46-55

Figure 13 shows that there appears to be a relationship between risky behaviour and perceived susceptibility, as the HBM would predict, with smokers and users of alcohol reporting higher levels of perceived susceptibility, a difference that is statistically significant.

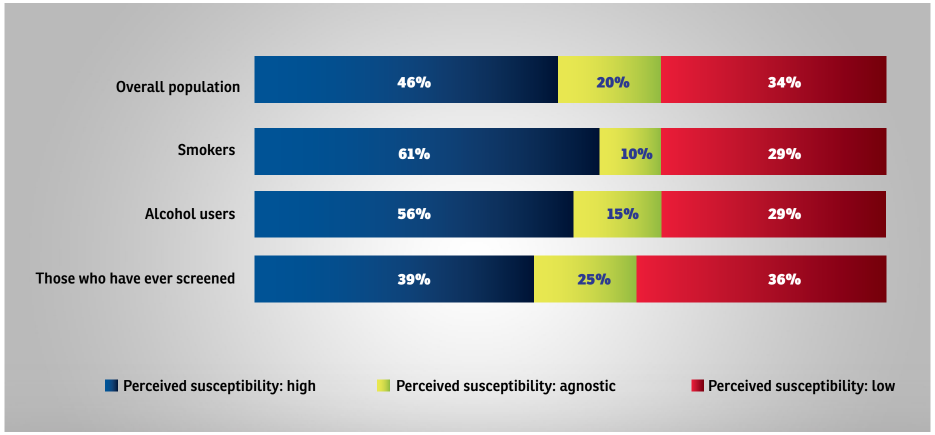

Figure 13: Differences in perceived susceptibility among risk behaviour subgroups

2.3 Behavioural aspects of cancer prevention

Three types of behaviour were investigated as part of the KAP study: (1) leading a healthy lifestyle, including healthy nutrition and reduction of alcohol and smoking as preventive measures; (2) seeking advice from a health professional in the case of chronic symptoms that can be signs of cancer; and (3) cancer screening. Questions related to a healthy lifestyle were explored in more detail during the household survey, while the focus groups provided more insight for the other two themes. In all cases, the constructs of the HBM were used to identify possible priorities for campaigns aimed at influencing behaviour.

Adopting a healthy lifestyle

When asked explicitly in the context of the organised discussion about cancer, focus group participants recognized the benefits of healthy nutrition, specifically in reducing the risk of cancer, as well as the benefits of exercising. Participants explained, however, that it was particularly challenging to change unhealthy behaviours such as drinking, poor eating habits, and smoking because decision-making was often tied to social interactions.

Insights from the household survey

For each of the lifestyle-related health behaviours (nutrition, alcohol and tobacco consumption) three questions were asked in the household survey, one each to assess perceived barriers, benefits, and cue to action.

Healthy nutrition

Most survey respondents were either the main decision-maker, or had an influence over the decision of what to eat. In rural areas, significantly fewer individuals considered themselves to be the main decision-makers compared to people in urban settings ($p=0.01$), and significantly fewer of the men compared to women considered themselves the main decision-makers on the food they consumed ($p<0.001$, Figure 14).

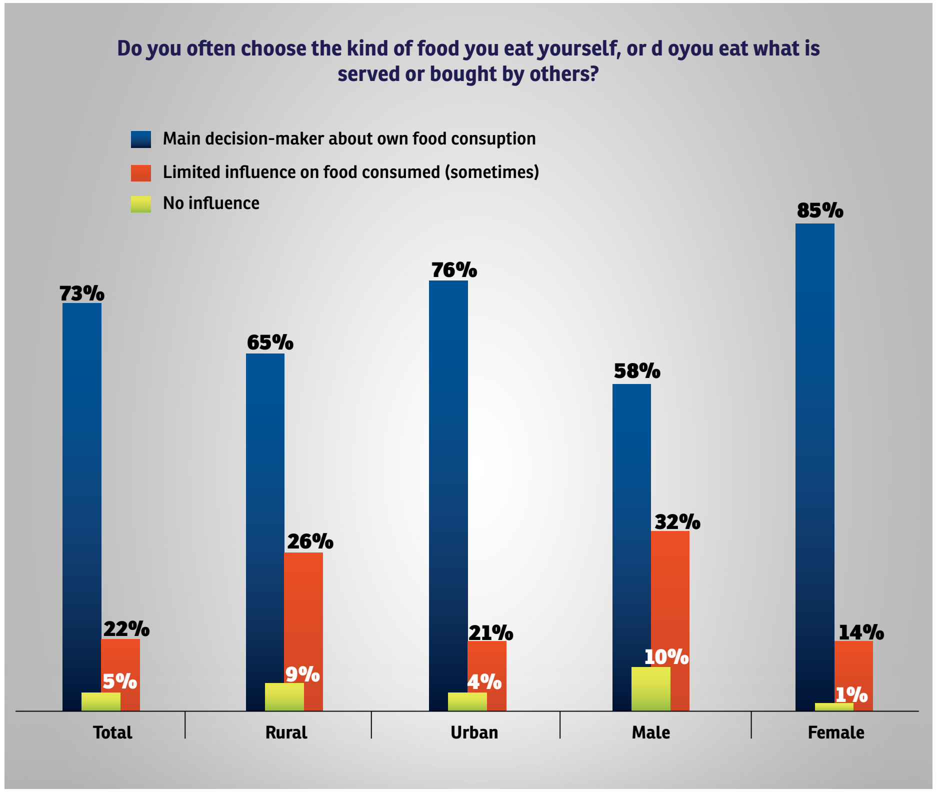

Figure 14: Decision as to what to eat

The statement that eating nutritious traditional food (such as greens and fruits) is good for health and prevents disease was mentioned by almost everyone (94%), but other benefits were mentioned more infrequently. A third of respondents (33%) mentioned the effects of healthy eating on physical looks, with no differences observed between genders, county or age groups. Short-term benefits of healthy traditional foods – reduced cost and good taste were mentioned by only 9% of respondents.

Table 6: Perceived benefits of healthy nutrition

What are the benefits of eating healthy traditional food, greens and fruits for you as a person?	
Better health, prevention of disease	94%
Better body shape/looks/weight reduction	33%
Long life	15%
Nice taste	9%
Saving money	9%
More nutritious/filling	2%

Three quarters of the respondents claimed they were already eating healthy (healthy traditional food, greens and fruits), suggesting that they did not perceive any substantive barrier to nutritious eating.

Among the barriers that were reported, costs were mentioned most frequently, followed by the perceived difficulty to find healthy food (Table 7). However, barriers to healthy eating seemed to be perceived by few people overall, with only 11% or less of respondents mentioning that they had encountered any barriers. The younger respondents (18-30 year olds) were significantly less likely to indicate that they already ate healthy (69% vs. 80% and higher for other age groups, p<0.01).

Table 7: Barriers to eating more healthy traditional food, greens and fruits

I already eat plenty of healthy traditional food, greens and fruits	75%
It's more expensive	11%
Don't like the taste/ prefer other food	10%
Don't know where to get it	7%
Someone else decides for me	4%

Since most respondents claimed to already eat nutritiously, the main reason for wanting to eat healthy traditional greens and fruits was mostly based on their own preferences. A desire to be healthy came second as a reason, mentioned by a much lower proportion of respondents (31%). External cues were related to easy access and availability and a nice preparation and presentation, while peer-influence was mentioned by only 13% (Table 8).

Table 8: What or who sometimes makes you want to eat healthy traditional food, greens and fruits?

Own cravings	43%
Health conditions/own intention to be healthy	38%
When it's sold/available to me in an easy way	28%
When I see a specific fruit/vegetable that I like	20%
When it's prepared in a really nice way (at home/restaurant)	15%
When someone else I know eats these foods	13%

Consumption of alcohol

Of those surveyed, 38% of respondents reported to have ever used alcohol, with higher rates among men compared to women (56% vs. 24%; p<0.01). In terms of county differences, the more traditional Kajiado county and Mombasa, which has a higher proportion of Muslims, recorded the lowest alcohol consumption (23%) and Nairobi had the highest (46%) (Figure 15).

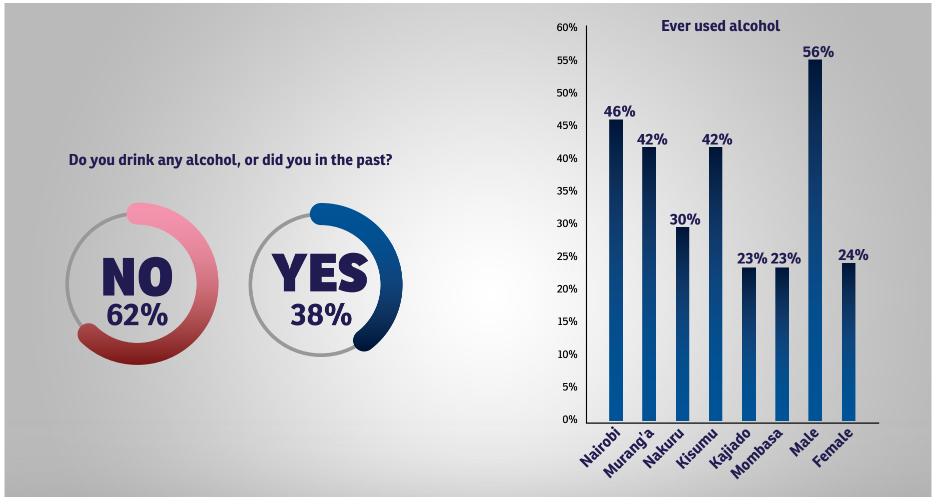

Figure 15: Consumption of alcohol

Among alcohol users, the main perceived benefits of reducing the consumption of alcohol were financial and health benefits, which were mentioned by 58% and 57% of alcohol users, respectively. Men mentioned financial benefits of reducing alcohol consumption (66%) significantly more often than women (43%, p<0.01). Other reasons were mentioned much less frequently and 13% expected no benefits to reducing the amount of alcohol they drink (Table 9). Regionally, all respondents in Mombasa and Kajiado identified at least one benefit of reducing alcohol consumption, but in Nairobi 17% of users did not report one benefit to reducing consumption.

Table 9: Perceived benefits of reducing alcohol consumption

What would be the benefits for you to reducing the amount of alcohol you drink? (top mentions)	
Saving money	58%
Better health, prevention of disease	57%
Better body shape/looks/weight reduction	16%
Less fights with my spouse or relatives	15%
No benefits	13%
Less risk in driving / prevention of accidents	4%

Barriers to reducing alcohol consumption were identified by asking the users why they drink, with the assumption that stopping would come at the cost of losing the described benefits. In the case of alcohol, the main motivation participants referred to was the social impact of "enjoying doing it with others", followed closely by the pleasurable feeling or relaxation that comes with alcohol consumption. Fewer than 20% reported any other reason and 8% stated that drinking was a routine for them and/or they were unable to stop.

The motivation to stop or reduce drinking alcohol, in the experience of respondents, was primarily influenced by their own individual decisions, with 43% reporting that no one or nothing else has motivated them to reduce or stop. However, 21% reported that a family member had motivated them and 15% stated their spouse as a motivator, which was consistent across gender and rural/urban setting.

Table 10: Barriers to stop drinking and cue to action

Why do you drink alcohol?			What or who has ever motivated you to stop drinking or to drink less? (top mentions)	
Enjoy doing it with others	53%		Nothing/no one/only myself	43%
Enjoy feeling, relaxes	47%		Other family member or relative	21%
Enjoy the taste	16%		My spouse	15%
It makes me more confident	11%		Price was too high / no more money	11%
Peer pressure[1]	9%		Friend	9%
Stress/anxiety	6%		Pastor/religion	6%
It is a routine for me/can't help it	8%		Other	5%

Consumption of tobacco

Only 15% of survey respondents had ever smoked, sniffed, or chewed tobacco. There are, however, substantial gender differences, with 30% of men having used tobacco compared to 4% women ($p<0.01$). Murang'a residents recorded the highest incidence at 25% followed by Nairobi at 17% (Figure 16).

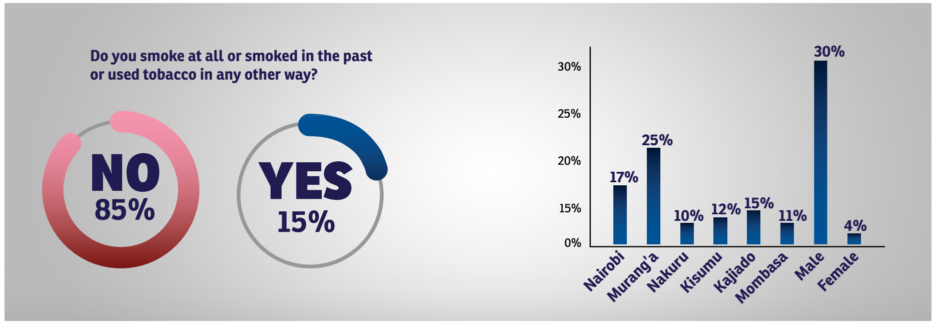

Figure 16: Tobacco use

---

10 Peer pressure was operationalised in the questionnaire as any statement that suggests that 'others would look at me strangely if I didn't'.

Nine out of 10 tobacco users mentioned 'better health' as a benefit to quitting tobacco and half of them also recognized the positive financial implications (Table 11). The other options (better breath/smell, fewer fights with family, increased sense of taste) were not perceived as substantial benefit.

Table 11: Perceived benefits of quitting smoking

What would be the benefits for you to stop smoking?	
Better health, disease prevention	**90%**
Saving money	**51%**
Better breath or smell	13%
Less fights with spouse or relatives	11%
Increased feeling of taste	4%
No benefit	2%
Other	4%

For tobacco consumers, the main reason given for continued smoking was the enjoyable feeling experienced by smokers (53%) followed by the social aspect (37%). Compared to alcohol consumers, more tobacco users said that they "can't help it" and it is difficult to stop tobacco use.

In terms of motivating factors for quitting tobacco, persuasion by a family member (40%), friend (21%), or spouse (14%) were the strongest cues likely to trigger a reduction in tobacco use. Other motivators, such as advertisements and price, were mentioned as motivating factors for fewer than 10% of tobacco users (See Table 12).

Table 12: Barriers to quit smoking, and cues to action

Why do you smoke (or did you smoke) and what makes you keep doing it?			What or who has ever motivated you to smoke less? (top mentions)	
Enjoy feeling (relaxes, distracts)	53%		Other family member or relative	40%
Enjoy doing it with others	37%		Friend	21%
Enjoy the taste	17%		My spouse	14%
I can't help it /It's difficult to stop	17%		Internal motivation only	8%
Peer pressure	9%		Religion	6%
Other reasons	6%		Advertisement	5%
			Price was too high / no more money	5%
			Doctor or healthcare worker	5%
			(For health reasons	30%)

Health seeking behaviour

Based on patient interviews and survivor focus groups, a typical reason why people with a potential cancer symptom did not seek healthcare for their symptoms was that they usually attribute the problem to something else. Early cancer symptoms were often relatively unspecific and people said that when they first experienced symptoms, such as night sweats, shortness of breath, persisting backache, coughing, swelling, skin discolouration, weight loss and acidity, they made no mental connection to cancer.

People suffering from different types of cancers had different reasons to not suspect cancer as a reason for their symptoms. For childhood cancers, one survivor pointed out that many children spend most of their time with nannies, so parents may not have been aware of their child's symptoms at all. Women sometimes incorrectly attributed symptoms to menopause or use of family planning methods and did not consider cancer as a possible explanation. Men sometimes attributed symptoms to their own drinking habits. The male respondents in a Uasin Gishu focus group explained that alcohol "disguises disease" and people attributed pains and aches to hangover instead of other health conditions.

Financial barriers also inhibited health care seeking for potential cancer symptoms, particularly the costs of diagnostic tests, for which there are no standards, at least not known to the general population. There were enormous price variations and no way for most patients to find out if the test was necessary and the cost justified. Significant time and financial costs were also associated with referrals to higher-level facilities in other cities, which could have further acted as a barrier to care.

As such, many people with symptoms, especially in rural areas, explored alternatives to seeking appropriate care. This included home remedies, praying, and local healers. The use of traditional healers was more prevalent among participants in Uasin Gishu than in Nairobi, where many of the rural respondents had a positive attitude towards traditional practitioners due to tradition, but also because the traditional healers were perceived to be good-hearted and flexible with payments. Some traditional healers only asked for pay when their interventions were successful and could be paid in kind – for example with cattle or chicken. Most importantly, their treatment was seen by many as having a chance of success.

Another barrier was a perceived lack of quality at more mainstream health facilities and providers. Some participants reported being given painkillers or antibiotics and "sent away" each time they sought care in a health facility, while others simply did not trust the health system very much and felt that there were too many young and inexperienced doctors. One expressed sentiment was that one must go abroad to receive high-quality healthcare.

There was also an element of fear that stopped some people from actively seeking diagnosis. Some reported fears of not being able to afford expensive treatment, and that the treatment itself may be lethal. The fear of being stigmatized by a serious illness was also expressed. Similarly, respondents said that certain cancer symptoms were embarrassing to talk about, particularly cervical, prostate, and breast cancer.

Rural area interviewees reported some specific issues around fears and embarrassment. Most prominent was that someone with cancer symptoms might be accused of being bewitched, with two rural participants who indicated that they were initially under suspicion. Also in the rural areas, seeking healthcare was seen more as something that was a private affair and not discussed among married couples, possibly because of potential shame and consequences due to extramarital affairs.

Perceived benefits and cues to action for health seeking behaviour

The obvious benefits of seeking care were getting rid of symptoms and relief from the worry of a possible serious illness. This was often related to prevention or treatment of diseases or symptoms other than cancer. Several respondents, particularly urban female participants, reported active health seeking and stated that it did not require much effort to see a doctor. One participant said that she always seeks care if there are small signs and symptoms of illness because "I love myself, and I want to preserve my body". Another patient recounted that she decided to seek care because she expected it to help her "survive and continue to provide services to her children and other people."

The qualitative research identified two main cues to seeking care: (1) the symptoms worsen to the extent that a health professional is sought, or (2) a close family member or a friend convinces them to seek care. Examples of new or worsening symptoms reported include: unbearable pain, unexpected bleeding, vomiting, and backaches becoming stronger and accompanied by swelling, skin and discharge discolouration, and increased tumour size. One gentleman reported that his trigger to see a doctor was an experience during a bus trip to Nairobi, when he had to stop the vehicle to urinate, yet nothing would come out and his fellow passengers started complaining about the long time it took him. Another survivor's cue to visiting a doctor, before her diagnosis, was the growing conviction that her growth was abnormal.

Family members and friends encouraging health checks was a common theme. Most of the female cancer patients said that it was their husband who had prompted them to get checked. Others sought healthcare because a friend, parent, neighbour, or child encouraged them to do so. A military officer recounted a story that when his men told him that they did not understand his commands anymore, he decided to be checked. Participants from the general population corroborated these experiences of the patients and survivors, in saying that especially for men, it often takes a friend's encouragement before they decide to see a health professional.

Insights from the household survey

Survey respondents were presented with a list of statements about why they may delay seeking treatment in cases where they think symptoms could be serious (Table 13). Cost was reported to be the main barrier to seeking prompt treatment (58%). Despite the wording of the question, that it was about symptoms that respondents think could be serious, the second-most common response was a perceived lack of seriousness of the symptom (36%).

Table 13: Barriers to seeking health care

What are some reasons why you might delay going to see the doctor		Summary categories
I wouldn't want/be able to spend the money needed to see a health professional	58%	Costs **58%**
Illness is seen as not serious	33%	Not priority/serious **36%**
I have too many other things to worry about	4%	
I would be too scared	11%	Fear of the process of the consequence **21%**
Too weak to go to a doctor	4%	
I would be worried about what the doctor might find	8%	
Outcome might negatively affect marriage	1%	
Use herbal medicine	3%	Self-medication **13%**
Self medication/use pharmacy	11%	
It would be difficult for me to arrange transport/the facility is too far	13%	Transportation **13%**
I would be too busy/not have time/to go to the doctor	12%	Time **12%**
It would be difficult to make an appointment with my doctor	5%	Health provider availability **5%**
The waiting times are usually too long	5%	
I wouldn't feel confident talking about my symptom with the doctor	2%	Health provider rapport **6%**
I would be worried about wasting the doctor's time	2%	
My doctor would be difficult to talk to	2%	
Hospital won't help	1%	Mistrust of health system **2%**
No trust in health system/fed up/tired	1%	
Lack of spousal consent	1%	Spousal consent **1%**

There were differences in reported barriers between counties. While in most counties cost was the main barrier, only 18% of respondents from Kajiado reported cost as a barrier. Instead, Kajiado respondents reported a higher percentage of fear of the outcome and transportation as barriers, compared to the other counties. Transportation was a larger barrier in rural areas compared to urban (25% vs. 10%). Supply side barriers such as provider availability, rapport with the provider and mistrust of the system appeared in both settings, but were generally mentioned infrequently (Table 14).

Table 14: Reasons for delaying seeking medical attention by region

	Rural	Urban	Mombasa	Nairobi	Murang'a	Kajiado	Nakuru	Kisumu
Cost	62%	57%	52%	57%	65%	18%	67%	79%
Not a priority/ serious	35%	37%	44%	37%	43%	33%	39%	13%
Fear of outcome	17%	21%	23%	19%	16%	41%	19%	13%
Transport	25%	10%	12%	8%	10%	29%	21%	18%
Self-medicate	14%	13%	22%	8%	13%	20%	19%	11%
Health provider availability	3%	6%	11%	4%	1%	5%	5%	-
Health provider rapport	3%	6%	6%	8%	1%	11%	3%	1%
Time	9%	12%	7%	12%	4%	13%	14%	17%
Mistrust of health system	2%	2%	3%	3%	-	1%	4%	-
Spousal consent	1%	1%	1%	1%	-	3%	-	-

In contrast to many of the qualitative responses, nearly three quarters of the survey population claimed that they would seek prompt treatment (74%) even in the presence of embarrassing symptoms (Table 15). Another 36% reported they would talk about it with a close family member or a friend, indicating they could be prompted to seek treatment. Very few respondents said that they would seek information about such symptoms, either on the Internet or via other sources.

Table 15: If you had a symptom that you (or other people) can be embarrassed about, what would you do?

See a health professional as soon as symptom noticed/ not embarrassed	74%
Talk about it with a close family member	20%
Talk about it with a friend	16%
Try and buy medicine from a pharmacy	10%
Wait until it got bad before seeing a health professional	8%
Try to find written information about it (internet and others)	2%

Cancer screening & early detection

There were limited inputs among the focus group participants on the perceived benefits of cancer screening. Some participants in the female focus groups in Nairobi, recognized the benefit of screening in enabling early detection of the disease for successful treatment. Others saw a more generic benefit to screening as 'knowing what your condition is' and 'becoming knowledgeable about your health'.

The main reported barrier to seeking screening services was fear or discomfort related to the screening process itself in both urban and rural areas. For example, in the case of cervical cancer screening, one participant reported that other campaign beneficiaries had warned her that it was painful and she ended up going back home without doing the screening. Another focus group participant spoke about her own experience of discomfort and she said she would never present for screening again. This fear of the screening process appears to have been a major factor that stopped people in rural areas from attending screening sessions, even if they were free. In particular, the need for women to undress and be exposed appeared to be such a major threat that they literally ran away when they heard that a group of people were coming to screen.

Cancer screening also brought out fears related to cancer itself, such as emotional distress, stigma, financial, and lifestyle consequences. One male focus group participant attested that "truth kills" so it is better for your own health not to know. Some of this fear stemmed from experiences or fears related to HIV testing; the strong association with stigma extended to other illnesses.

In the urban focus groups, the perceived cost of screening services was also identified as a barrier, especially screening for men, which was thought to be less likely offered for free compared to breast and cervical cancer screening. Finally, in the male focus group in Nairobi, two participants suggested that the fear of embarrassment in relation to the symptoms of prostate cancer was another reason that people do not go for screening.

Cue to action for screening

In urban settings, the primary cue to action for screening was the announcement of free screening camps. The second most frequently mentioned cue in qualitative interviews in Nairobi were recommendations by doctors during an otherwise unrelated health consultation or from announcements in hospitals. People with relatives who had cancer were also more likely to get screened, both because of additional knowledge and feeling more susceptible. Cues to action did not necessarily act in isolation. One of the female cancer survivors, whose cancer was detected during a screening campaign, had gone for screening after three consecutive triggers: her father had been diagnosed with cancer, which prompted her to read up and learn more about cancer, and then the announcement of a free screening camp made her decide to attend.

Insights from the household survey

Figure 17 details the proportion of the survey population that had ever gone for cancer screening, with 17% having ever gone for cancer screening. Women were three times more likely to have gone for cancer screening (25%) than men (7%, $p<0.01$). Among those who consider themselves at risk of getting cancer (high susceptibility), there were a somewhat higher proportion of people who had gone for screening than among those with low perceived susceptibility -– however the difference is not statistically significant (20% vs. 14%).

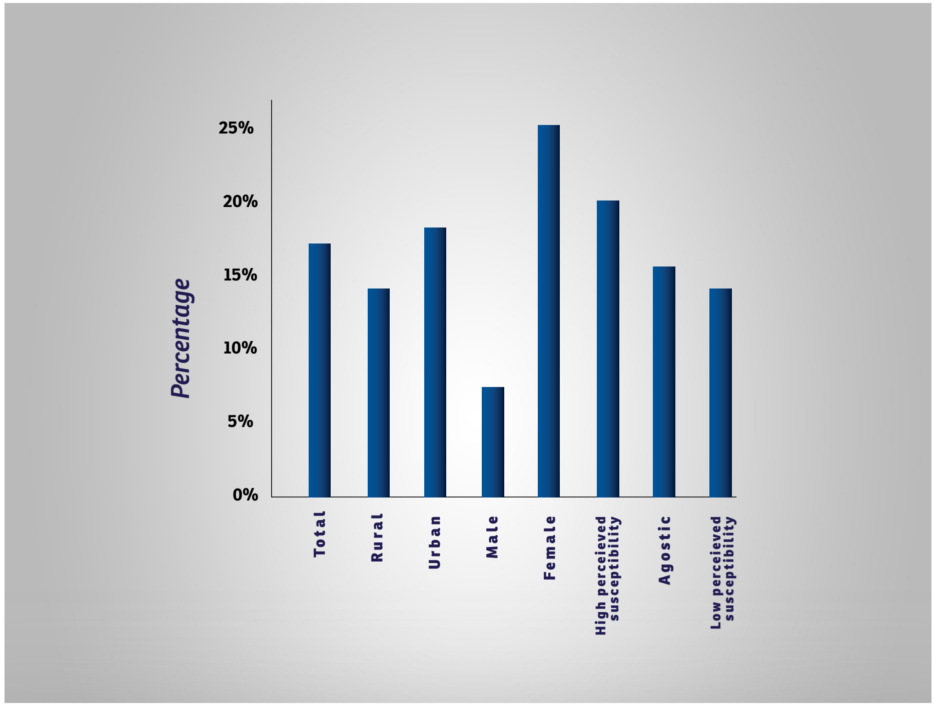

Figure 17: Have you ever gone for cancer screening?

The benefits of cancer screening mentioned by the household respondents are listed below[11]. There were no statistically significant differences between the segments (gender, setting, counties). The most common responses were detecting cancer early (71%) and taking care of myself and my health (70%).

---

[11] It is possible that responses may have been partially primed by the previous questions, given that the question about screening came at the end of a 30-minute interview about cancer awareness.

The most common perceived barriers to screening that emerged during the household survey included that respondents had never thought about screening (37%) or perceived their health to be good (35%). Physical barriers such as lack of facilities (14%) and costs (8%, $p<0.05$) were significantly more pronounced in rural areas. Lack of time as a barrier was almost exclusively mentioned by the urban dwellers ($p<0.01$). Those who rated their susceptibility as low were significantly more likely to give good health/no need as a reason for not going for screening, which is in line with the assumptions of the HBM.

Table 16: Barriers to cancer screening

	Total	Rural	Urban	Male	Female	High	Agnostic	Low
I have never thought of it	37%	32%	38%	38%	35%	35%	41%	36%
I don't need it / I'm healthy enough	35%	37%	34%	44%	26%	33%	28%	41%
It's not available anywhere around here	14%	23%	12%	13%	16%	12%	21%	13%
I don't have enough time	10%	1%	13%	8%	12%	8%	9%	12%
It's too expensive	8%	13%	7%	8%	8%	7%	8%	10%
I've never heard of it	7%	12%	5%	7%	6%	6%	7%	7%
I'm scared of the results	7%	5%	7%	4%	9%	7%	2%	9%

Nine out of ten people claimed that they would participate in a free and nearby cancer screening event. Those who rated their susceptibility to the disease as high were most likely to state they would go for screening (96%, compared to 86% among those with perceived low susceptibility). Marginally more people in rural areas reported that they would participate in free screening events than their urban counterparts.

Other events or cues that respondents said would trigger a decision to go for cancer screening are listed in Table 17. Generally, people reported that they would go for screening if they experienced signs or symptoms of cancer (27%), indicating a misunderstanding of the role of screening for prevention, as opposed to a diagnostic procedure for persons with symptoms. About a fifth (21%) of respondents reported that they would participate in a screening event if they had a concern, which could include a symptom or family history. Another 22% would go for screening if prompted by a health provider.

Table 17: Cues to participating in cancer screening (>10% responses)

When I see the signs or symptoms of cancer	27%
Doctor/healthcare worker	22%
Concern for own health, without apparent symptoms	21%
Friend	15%
Spouse	15%
Advertisement on radio	15%
Community health workers	15%
Advertisement and explanation on flyers or pamphlet	10%

Communication channels

Nearly all the participants interviewed in focus groups and individual patient and caregiver interviews expressed a strong preference for using interpersonal channels to communicate cancer-related messages to the general population. Urban participants in Nairobi emphasized the role of schools for educating and sensitizing children about cancer at both the primary and secondary level. In the rural setting, churches were mentioned as a particularly useful venue to share information. In addition to schools and churches, Chief's Barazas, community health workers, hospitals, ***chama*** meetings (women's savings groups), and Huduma centres (newly established government service points where citizens obtain services like renewals and registrations) were also suggested as channels for face-to-face communication on cancer and other critical population health issues. Additionally, focus group participants and experts suggested social events that could foster interpersonal communication around cancer awareness and knowledge. These could include plays presented in road shows or group events by local politicians, events and concerts for youth, and even funerals. One-on-one conversations were also a critical communication tool mentioned, as well as door-to-door campaigns like those used for malaria and polio.

Despite the emphasis on interpersonal communication, mass media was also seen as a valuable communication channel. The leading medium was radio because it has the farthest reach in all age groups, geographies, and socio-economic classes. Vernacular stations, in particular, were seen as a means of reaching large population groups and radio was seen as much more cost-effective than TV. Nonetheless, TV also has a wide reach, and in addition to talk shows (vernacular or on the main national TV stations), edutainment formats such as a series were seen as a way to pass messages in a more easily digestible format. For specific segments of the population (young, mid- and upper- socioeconomic status), new electronic channels including social media (Twitter, Facebook) and mobile phone applications were also considered important.

Print media as a communication channel for the general population was mentioned only by the expert stakeholders, not by patients or representatives of the general population. Such printed media could include flyers as a complement to interpersonal communication, posters, and billboards. One of the experts pointed out that print on clothes can be an efficient means of stimulating conversation and therefore has a potential multiplier effect - this includes messages on tie-around cloths (lessos/kangas) especially in the coast region, and on t-shirts.

2.4 Analysis and Recommendations for Cancer Communication Strategies

This section provides a synthesis of key insights obtained from a combined examination of the qualitative and quantitative findings in the general population and their implications for a community communication and education strategy.

Both the household survey and the focus group findings suggest that the Kenyan population is generally aware of the existence and the severity of cancer. What is much less recognized is the potential severity of signs and symptoms that may indicate cancer. **Most of the signs and symptoms are not well known as potential signs for cancer and not seen as something severe by much of the general population.** Per the HBM, increasing the perceived severity of these symptoms is an important component to trigger a change in behaviour for health seeking and early diagnosis.

Almost all cancer patients reported that cancer had caught them completely by surprise. One patient noted that the very high perceived severity of the disease may create the expectation that someone would be able to recognize cancer if they had signs or symptoms. This demonstrated a potential "downside" to the high-perceived severity of cancer that people preferred not to see themselves as susceptible, effectively using denial as a protective mechanism. **As such, not taking symptoms seriously –** or mistaking them for symptoms of more benign illnesses and not taking them seriously early enough **– was the most common barrier to health seeking and early diagnosis.**

There was a disconnect between the reports of cancer patients, who almost universally stated that they did not ever think that they could get cancer before they were diagnosed, and the statement of many focus group participants in the general population and 46% of the household survey respondents who saw themselves as "likely" to get cancer. It is possible that in a prompted, organised context many people intellectually knew and stated that they could get cancer, but this knowledge did not correspond to a continuous internal awareness. Based on the narratives of patients, it was not uncommon for Kenyans to believe that cancer only affected "people in whose family it runs" or "people who use make-up, or have irresponsible sexual behaviour".

The interviews with cancer patients revealed another widespread reason that cancer diagnosis was often delayed; health professionals made an incorrect diagnosis by not conducting diagnostic tests or ordering incorrect tests. Based on the stories of cancer patients and survivors, **misdiagnosis appears to be a substantial problem** because people with symptoms often do seek advice from a health professional, yet the advice they get is inaccurate. Late diagnosis of cancer is therefore caused both by a lack of knowledge both in the general population and by health professionals.

The most frequently mentioned knowledge gap found during the general population and patient focus groups[12] was an understanding of what causes cancer. There may therefore be a need to sensitize the population to the important risk factors, but also to the fact that there is usually no way of attributing the onset of the illness to a single specific cause.

For those who have personal experience with cancer, either diagnosed themselves or their loved ones, there are strong negative emotional associations to cancer and an expressed strong need to talk about it during the focus groups. In contrast, those without personal experience with cancer associated it with death and suffering but did not respond emotionally. The high level of emotions around cancer likely contributes to the experience of stigma and avoidance that cancer patients reported after receiving their diagnosis. As such, **communication and education on how to interact with cancer patients to make them feel encouraged, rather than victimized, would benefit the cancer community.**

Healthy people should be encouraged to talk about cancer more openly. People currently talk about cancer "with a whisper" and behind the back of those who are affected. To break the taboo and promote knowledge within the population, everyone needs to be encouraged to talk more freely and learn about it.

Everyone who knows someone with cancer should be encouraged to stay in touch with them and be positive and encourage them to keep fighting and accept the fact that they have cancer. Conversely, those who have a relative or friend with cancer need to be careful and restrictive about giving advice, especially when it is about seeking alternative/herbal treatments or decisions related to treatment.

Finally, the urban population can be encouraged to help dispel beliefs related to witchcraft in their rural community, particularly in regards to cancer.

Another important issue that emerged was the uncertainty and fear related to the process and the outcome of cancer screening, especially in rural settings. Some statements during the focus group discussions suggested there might be active avoidance and fear related to cervical cancer screening, and some additional research may be warranted to understand this phenomenon in rural areas and whether it extends beyond Uasin Gishu. One possibility is that cancers are currently caught at later stages which has resulted in people thinking screening clinics are set up to diagnose women rather than as a way to prevent cancer or ensure early detection for timely preventative treatment. If this can be confirmed with additional research, messages should emphasize that screening can help healthy women stay healthy to help calm fears. Similarly, this emphasis should be used for HPV vaccination campaigns for girls.

In the household survey, 22% stated that they would go for screening if prompted by a health provider. Promotional screening campaigns could therefore be supplemented by the reinforcement of the same messages during regular medical consultations. Similarly, encouragement by family and friends /family) were also strong cues for cancer screening. As such, **one campaign approach would be a call to action that exemplifies a brother's keeper mentality and encourage screening not just for themselves but their loved ones as well.**

---

[12] Subjectively held knowledge gaps weren't explored in the household survey.

Leading a healthy lifestyle is a complex proposition to promote and it is necessary to focus on healthy behaviours that lead to a substantial risk reduction and require a manageable change in knowledge, attitude, and practice. The most well-known strategy to reduce the risk of cancer globally is the avoidance of smoking and other tobacco use, including the increasingly popular shisha.

The most recent national prevalence estimate for smoking stands at 15% among men; however, the household survey of this KAP study found 30% of men said that they had ***ever*** smoked or chewed tobacco. Enhanced education and prevention initiatives around smoking are critical, and campaigns to reduce alcohol use, particularly among men in both rural and urban areas, are also an immediate priority.

With regards to cancer prevention, a focus on nutrition could be a good starting point to increase the proportion of people, currently 55%, who understand unhealthy eating is a risk factor. Findings suggest that making healthy foods readily available and openly displayed is likely to increase their uptake further. In contrast, increasing physical activity was mentioned infrequently among experts and in focus groups, despite it being a known strategy to reduce the risk of cancer. This may be due to the perception that people in Kenya move enough through walking and working, especially in rural areas.

Insights on targeting communication campaigns

In terms of targeting communications campaigns, the data suggests that a different focus and messaging strategy is needed for rural and urban populations, and that some targeting is also valuable when addressing different genders and age groups. The household survey found large differences in terms of perceived susceptibility between counties. Table 18 shows the main insights with regards to targeting key population subgroups.

Table 18: Key differences between subgroups for targeted communication efforts

Variable	Subgroups	
Setting	**Rural**	**Urban**
	More respondents said that they know little to nothing about cancer and were agnostic about susceptibility. More misconceptions about cancer. Transport is more of a problem. One third considers themselves not to be the main decision maker for their own nutrition (mostly men). In case of illness, there is a greater inclination to use herbal practitioners or resolve to pray alone. Isolation of cancer patients and stigma associated with the smell that can result from untreated cancer symptoms. Greater tendency to delay health seeking.	More respondents considered themselves as not susceptible to cancer.
Gender	**Female**	**Male**
	Large fear of the discomfort and outcome of screening, especially for cervical cancer. Often play a key role in prompting their spouses and children to seek care. Often key decision makers for food choices.	More likely to smoke or to consume alcohol. Often unaware about prostate cancer screening. May take longer to seek health services for symptoms.

	Youth	Middle aged and elderly
Age	Mostly use and prefer traditional channels of communication (interpersonal and radio), but are more likely to also use the Internet and social media.	No suggestion to specifically target the elderly. The preferred channel is interpersonal communication by outreach workers and in social settings (church, Baraza), followed by radio.
County/Region	Several factors varied between counties, which should be taken into consideration when deciding on a communication focus for each: ● Counties varied in the extent to which the population feared the outcome of screening -- In Kajiado, 41% of the respondents expressed more fear than 20% on average in the other counties covered in the survey. ● There was a large variation in perceived susceptibility to cancer -- In Kisumu, 65% saw themselves as susceptible and 12% not, compared to 22% and 54% respectively in Nakuru, while Mombasa had the highest percentage of the population who said they didn't know. ● There were differences in the perception of cost and transport as barriers to seek healthcare --In Kajiado, cost was seen as less of a barrier, but transport was mentioned more frequently than elsewhere.	

Communication messages

Signs and symptoms: In addition to making symptoms more known in the general population, messages should be crafted in such a way that they address those who know someone with symptoms. Findings show that the decisive cue to action for cancer patients was often the encouragement of someone close - a spouse, a friend, a neighbour - who stimulated or even pushed patients to seek healthcare. An important message for people with symptoms, and their relatives, is that they are allowed and expected to ask additional questions about their symptoms and possible cancer diagnostic tests, as misdiagnoses are common (see also chapter 3).

Perceived susceptibility: When addressing the perceived susceptibility of cancer, it is important to understand that while exposure to cancer-related messages reduced the number of people who were agnostic about their susceptibility, it led to an increase in the number of people with both high and low perceived susceptibility. That is, cancer-related messages did not necessarily ensure people understood that their susceptibility is high, which an effective cancer message should communicate. Any messaging – even for fundraising – should therefore contain an element of reminding people that they could be diagnosed with cancer at any point in their life – that everyone is susceptible.

General information: The concern that many respondents (in both the qualitative and quantitative study) felt that they know too little about cancer was mostly related to the causes and risk factors. While it is important to ensure that people understand that there are many different types of cancer, including those in unexpected parts of the body, there is no need to go into detail about different kinds of cancer when addressing the healthy population, but focus more on known risk factors, range of signs and symptoms and what the public can do to stay healthy.

In the interviews with patients (Chapter 3) it was evident that the biggest burden for cancer patients was the high cost of treatment. It is therefore recommended to combine the message about general susceptibility of cancer with messaging that encourages people to join the NHIF or another medical scheme and take measures to be financially prepared for a medical emergency, even while they are healthy.

Screening: Messages to increase participation in cervical cancer screening must address the distress some women in rural communities associate with exposing their private parts, as well as the discomfort and pain that some women report experiencing during screening. These messages may best be conveyed through interpersonal communication. Omitting these facts could have a reverse effect of deteriorating trust in people who provide screening services and advice on preventive measures.

Alternative therapies: An important message is that the use of traditional practitioners and self-medication should never delay the seeking of advice and diagnosis in a health centre or hospital, even in cases where patients come to see them after an unsuccessful experience in one of these institutions.

Prevention: With regards to cancer prevention, the survey results showed that there is general acceptance about the benefits of healthy eating so a focus on nutrition could be a good starting point for population-based prevention messages. While many older survey respondents perceived that they already ate healthy foods, the younger generation was not convinced they ate as well, possibly suggesting a shift in the types of foods being consumed and their availability, or a more widespread inclination among younger groups to question their eating habits. Communication on nutrition should emphasize the need to eat less processed meat products and other processed foods, lowering salt intake, and reverting to more traditional foods, particularly greens. Cooking and eating together with family should also be encouraged.

For smoking and other tobacco use, the perceived barrier to quitting among survey respondents was related more to pleasure (e.g. enjoyed the feeling) than to addiction (e.g. can't help/ it's difficult to stop). This might be because many of the tobacco users among the respondents were not heavy-regular smokers/chewers or because they were unaware they were addicted. The predominant cues to stop smoking were of social nature, with pressure from the spouse or other family members mentioned by 61% of respondents as the main reason to stop smoking. Thus tobacco control campaigns linked to cancer should incorporate family or relatives' endorsement and persuasion. Campaigns aimed exclusively at health risks may not be as effective as findings suggest that smokers are already aware that smoking is associated with an increased risk of cancer. Cancer-related tobacco control messaging should also be coordinated with existing effective policy efforts being implemented in Kenya such as tobacco tax increases, graphic warning labels on tobacco packaging and advertising bans.

Any communication targeting reduced alcohol consumption needs to acknowledge the perception found among survey respondents that this behaviour change may come at a cost in terms of social interactions and reduced pleasure of consumers. A large proportion of survey respondents (43%) said that a decision to reduce drinking would be solely based on their autonomous choice suggesting that testimonials of individuals who have reduced drinking out of their own choice could potentially be effective. However, 31% or respondents also said pressure from a spouse or family member could be a factor so including messaging targeting family or peer endorsement could also be beneficial. The survey also showed that financial savings was the main perceived benefit of drinking less alcohol (mentioned by 58% of all those who drink) and could therefore be an emphasis of messaging to encourage reduced alcohol consumption.

Priorities for cancer-related issues in the general population

After a review of findings across the different respondent categories, the recommended priority areas for community education efforts and general population communication campaigns are: (1) correct perceptions of individuals who underestimate their susceptibility to cancer, and increase the understanding of cancer signs and symptoms that, if ignored, can be dangerous and lead to a more severe condition; (2) to reduce the stigma that is associated to cancer patients being seen as "almost dead" and encourage open communication about the disease with everyone, including with those affected; (3) to explain risk factors and causes of cancer and (4) to address the fear of screening and outcomes for early detection.

Channels of communication

Based on the lower level of overall knowledge, the suboptimal health- and treatment-seeking behaviour and the fears related to screening, we recommend prioritizing communications campaigns in rural Kenya in a context of limited resources. The preferred communication channel in rural Kenya is interpersonal communication, including through churches, chief's Barazas or door-to-door campaigns, as well as communication in schools, ideally as part of the regular curriculum. For mass media, the radio should be used, as it has a higher reach than TV has in these parts of Kenya. Since there is still a level of trust in the services of traditional/herbal practitioners, these practitioners might be used as messengers and/or given a specific role such as providing advice on nutrition in the fight against cancer. TV should only be used to target the urban population and Internet and social media channels have a reach that is nearly equal to newspaper (both far below electronic media and interpersonal communication).

Messengers

Two thirds of the population covered in household survey said that they knew someone with cancer. While this could well be used as an entry point for the design of messages, it also means that cancer patients and their caregivers can be important messengers to promote the uptake of a healthy lifestyle and early detection, and possibly to help reduce stigma.

Several of the interviewed experts identified survivors as good conveyors of health promotion messages. Survivor stories are powerful, they help reduce stigma and the messages they convey are more credible by the fact that they come from experience. Prominent cancer survivors, such as Dr. Anyang' Nyong'o, can represent ideal messengers because they reduce stigma and represent a certain authority.

Working with other 'cancer champions' who are not directly affected and who might have limited in-depth knowledge related to cancer can have a strong short-term impact and receive the required media attention, but at the same time this should be used with caution and always with an agenda and proper content to avoid creating a short-lived buzz with potentially reduced credibility. With that caution, young people were recommended as cancer champions in view of the Kenyan demographic – this could be athletes, musicians, or TV personalities such as Churchill of the popular TV show ***Churchill Live.***

Community health volunteers were also recommended as cancer awareness messengers. Conversely, the best interlocutors and experts in mass media (radio, TV) are doctors, as they were seen as the most credible information sources for health-related information.

For interpersonal communication, an expert recommended matching communicators with their audience – for example, young people should be talked to by a young health professional in an informal manner, or Muslim women on the Coast should be addressed by someone among them. A repeated recommendation was the use of pictorial messages.

Targeting

Women should be the principal targets of prevention messages around nutrition decisions, screening opportunities for the most prevalent cancers of the cervix and breast, and HPV vaccination for their daughters to prevent cervical cancer. While alcohol consumption reduction and tobacco messages should ideally be aimed at the whole population, males would benefit from some targeted risk factor messaging given the high use of both among men. Men should also be the main recipients of messaging on prostate health, and they should be the focus of communication encouraging men to ensure female family members are screened for cervical and breast cancer and receive the HPV vaccine.

Communication campaigns and education strategies should be regionally targeted. Risk behaviour varies between counties (with big differences in the levels of alcohol consumption, for example), and so does the perceived susceptibility of getting cancer.

When addressing policy-makers, communication about cancer should emphasize the extent of suffering through personal stories to complement numbers, science and epidemiology. Policymakers not only need the data to understand resources that can be saved but can also gain the support of their constituents by prioritizing cancer and health for their constituents.

Languages

In terms of language, there was a general agreement among different types of respondents that it is necessary to provide information in Kiswahili, as well as vernacular languages based on the area of the intervention. Vernacular languages for communities where cancer is most prevalent should be prioritized. The use of local languages Kenya is not just a matter of different words, but also a matter of adjusting the messages to the local culture.

Some experts and focus group participants suggested that for the youth in Nairobi, communication should also be available in Sheng language. The terminology utilized should be very simple.

3

The cancer experience in Kenya

The following chapter focuses on the experience of those affected directly by cancer, either because they are suffering from the disease themselves, or are involved in providing care for a patient. The first part of the chapter describes the reality as it was experienced by cancer patients. Cancer patients were operationally defined as individuals in Kenya who have been diagnosed with any form of cancer by a medical professional[13] and who have not yet completed their treatment. Cancer patients were interviewed for this report at KNH and MTRH. These patients originated from all over Kenya, as KNH is the only public health facility that offers radiotherapy, whereas chemotherapy is limited in the public sector to MTRH, KNH, and Mombasa County Referral Hospital[14]. Treatment in public facilities still entail high out-of-pocket costs; however, is it less expensive than treatment in private sector facilities, which is used by a small fraction of the population in Kenya. Interviews with caregivers provided additional information about the experience of patients.

3.1 Findings

What it means to have cancer in Kenya

The journey to the correct diagnosis

The interviews with patients showed that by the time someone becomes a cancer patient in Kenya, they have often experienced a long journey in seeking healthcare from various health professionals, sometimes including traditional or herbal healers. Many have been given several alternative diagnoses – such as ulcers, amoebae, hemorrhoids, typhoid and malaria – and many have consumed painkillers, antibiotics, and other treatments.

In the journey to the correct diagnosis, many patients have spent a substantial amount of time and money undergoing multiple diagnostic tests and treatments. When they are finally sent for the decisive test, such as a biopsy or endoscopy, the price can be overwhelming – examples of KES 30,000 and KES 75,000 were given[15], with a considerable price variation between providers. Several patients and survivors could not understand why they had to visit three or four different health providers before the correct diagnostic test was ordered. Further frustration was expressed by patients who had to repeat tests because their prior health providers refused to give them their patient files when they wanted to seek a second opinion.

While the problem of misdiagnosis and mistreatment was equally pronounced among patients in both hospitals, the accounts of patients interviewed in Eldoret suggested that patients in Western Kenya and those who live in rural areas typically take longer to begin seeking care. Similarly, more patients in MTRH recounted having first tried herbal medicine than in KNH.

Receiving the diagnosis of cancer

Based on patient accounts, at the time of their cancer diagnosis, only a minority of cancer patients in Kenya were told by a health worker in an appropriate manner, including an explanation of the meaning of the diagnosis and treatment while together with a relative. Few were offered counselling at the hospital and the majority reported that they were handed an envelope or sent for treatment without explanation, or that they were told in a matter-of-fact manner while alone with the doctor. While breaking the news, health professionals were said to have used language such as "your breast will have to be removed", "your leg will be amputated" or "there will have to be an operation to remove your rectum".

A few cancer survivors in Nairobi and Eldoret recounted experiences where the patient was not told they had cancer, but rather the doctor told their relatives and left the decision on how and whether they wanted to break the news to the family. In one case recounted by a caregiver, the doctor told the family not to let the patient know. Another story involved a patient whose diagnosis of prostate cancer was withheld from both him and his family until the day he passed away. In another story, the wife of a patient was not informed about his condition due to her own

---

[13] There are cancer patients who are not aware of their illness, as they may not have been told by their doctor or relatives. There may be cancer patients who were diagnosed through medical imaging alone, even for cases where a biopsy would be clinically required (according to one of the key informants). Cancer patients interviewed for this study had all started treatment. Many of the insights about the experience of cancer patients were derived from the interviews with cancer survivors. There is no clear line that separates cancer patients from cancer survivors.

[14] Source: Website of the Kenya Network of Cancer Organisations (https://kenyacancernetwork.wordpress.com/cancer-care-providers/), accessed in July 2016.

[15] About USD $300 to $750.

physical weakness. Some patients were made aware that they had cancer but not always the stage of the disease.

Some reported that doctors had used technical language and avoided the term cancer, unless a patient insisted on an explanation. Some survivors also reported that doctors immediately emphasized how much money they needed to raise and which hospitals they could be admitted to.

For many patients, their diagnosis came as an unexpected shock since they had no family history of cancer and did not consider the possibility that it might happen to them. The initial emotional reaction was often the impression that they had just been given a death sentence. For those who were aware of cancer, diagnosis was often followed by an immense worry about the financial consequences of seeking treatment for cancer and the consequences about surgical interventions such as mastectomy, colostomy, or an amputation. Survivors recounted in the focus groups how these concerns were mixed with anxiety about the distress this would cause to their families.

For a few patients, the cancer diagnosis was less severe. Some elderly patients reported that they took the diagnosis without fear. Additionally, those who had already suspected a potential cancer diagnosis could digest the news better.

Disclosing diagnosis to others

After diagnosis, patients faced the question of whom to tell about it. There were many worries surrounding this decision and the most prevailing concern was that people would start seeing them as a "walking dead person". Parents did not want to expose their children quickly to the difficult reality. One of the patients interviewed had never told her children about her diagnosis while others waited a long time before they disclosed their diagnosis to family members because they didn't want to burden them. One concern was that people would start distancing themselves for fear of having to contribute financially to treatment. As a result, some patients said that they avoided telling those who they thought would not be able to help anyway. Other patients and survivors reported that they were forthcoming about their cancer from the beginning, believing the disease was not their fault and there was no need to hide it. Some stated that they wanted other people to learn that having cancer did not automatically mean that they were dying.

For married people, the first person that most patients disclosed their diagnosis to was usually their spouse. Other family members who were told include siblings, parents, and children, followed by other relatives, such as cousins, uncles and aunts. In addition to family, most employed patients had to tell their employers. In some cases, employers became a critical source of support, while in other cases, patients lost their job soon after they disclosed their diagnosis. Whether to family, friends, employers, or others, the main reason patients gave for disclosing their diagnosis was the need for support.

The financial burden

Per the interviews, the greatest challenge for cancer patients in Kenya was dealing with the financial implications of the disease. Money problems were the one major issue emphasized by nearly every patient and caregiver interviewed at KNH and MTRH. Paying for the drugs, which were frequently out of stock in the hospital and needed to be bought outside from private pharmacies, was sometimes described as very difficult, leaving some patients unsure of how they would pay for the next chemotherapy session. Many survivors and patients reported that it took them a long time until they could start treatment, as they first had to raise the required funds. For those with a lack of income or support, undergoing treatment meant skipping meals and sometimes going without food for more than a day, and/or sleeping on the ground or in the hospital waiting area because there was no accommodation in Nairobi or money to return home overnight. Because of the illness, patients had to stop or curtail work, meaning that the high cost was compounded with lost income.

To raise the necessary funds for cancer treatment, patients often depended on the support of others, including their immediate and extended family, and other friends and acquaintances who might contribute varied amounts of money sporadically, often in amounts of KES500 - KES2,000[16]. For those with assets, such as property and cattle, they or their family members were often forced to sell these to cover treatment costs. Another strategy was taking on loans, which was a further burden on patients and their families. In addition to the costs of treatment, for those with dependents the possibility of not being able to provide for the family, such as not being able to pay school fees, was an additional worry. The knowledge of being a financial burden to family was tough, but those who did not receive much support from their family felt sad or bitter about being abandoned.

Box 3: Learning about the diagnosis

> They never involved me even what I got, I was just sleeping on the hospital bed, I got a doctor saying, and "I think he's the one who is suffering from colon cancer" I never knew. I was just napping there, so the doctors came and surrounded me. One doctor just said, "Can you wake him up?" the other told him, "I think he's resting, let him just continue to sleep.
> **Patient/survivor**

> When I got cancer, the doctor just said, "You have cancer," and when I started crying he was like, "Why it is a big issue and you already have HIV?"
> **Patient/survivor**

> They told it was Kaposi Sarcoma and I didn't know what that meant so I insisted they tell me what it meant and they told me it was cancer...but even before they told me that I had asked them it was cancer and they said no, they told me not to worry and he tried to tell me something about soft tissues.
> **Patient**

> They told me to come for the results after two weeks. Of course you will go alone because in your mind you are only going for your results and you trust the person that is going to give you the results...you know we human beings trust the doctors so much and whatever they say you must do. When you get to his office: *"Hi Mum" - "I am okay" - "You have come? These are your results. Your eye has to come out, you have cancer of the eye" - "What? Does cancer also affect the eye? "- "Mum I have given you the results; you have cancer of the eye. Take this letter, go look for money."*
> **Patient/survivor**

> I went then the doctor had opened the door. They had already communicated with this other one. When the first thing she says when I entered, "Have you been told both of your breasts are going to be removed?" before I even sat down. I just banged the door, I went. I never went to her office for counselling. So I walked away, that was around 9.30, 10am.
> **Patient/survivor**

> When he went to Kenyatta and he was diagnosed with Prostate cancer. Unfortunately, we were not even told, the close family. But a cousin of ours is a doctor. He knew but he didn't want to tell us because it had already reached stage four. But we would go to Kenyatta we'd find him tied on the bed, in much pain. So we would ask, "What kind of disease is this that it's so painful, that he has to be tied on the bed?" we could ask but our cousin was not telling us, then the doctor would tell us, "Let your cousin tell you, because he works there," but he didn't tell us. Until the day he died.
> **Patient with a relative who died of cancer**

> I received my result in a paper. It was just an envelope folded like this, I still have it, and I've framed it because it's very nice. I just got a paper that said, histology report. CA, adeno-carcinoma of the colon with I don't know what, what. I didn't know what it was, I got a letter. Nobody called me, nobody told me. I just picked up a report from the lab.
> **Patient.**

Stigma

The experience of stigma is a reality for all cancer patients. The greatest difficulty for a patient is that most people seem to think that someone who is diagnosed with cancer is ***as good as dead***. "People see you and grieve," as one survivor put it. As a result, survivors reported that they had been careful with whom they informed about their situation because they did not want discouraging sentiments of grief. Regardless of whom they told, though, there was no escaping the gossip surrounding their illness. As one survivor explained, cancer is associated with "everything bad" in society and even politicians on TV would say things like "we have to rot it out like cancer".

The burden of stigma was shown to be particularly high for patients with cervical cancer, prostate cancer and colon/colorectal cancer, because of the taboo and stigma associated with sexual organs and the rectum. Cervical cancer was also said to be associated with immoral sexual behaviour by some. Contributing to the stigma, the financial cost of cancer has social repercussions as well. Survivors and patients recounted how people had started avoiding them because of the fear that they would be asked to contribute or feel guilty about not having contributed enough. In the female discussion group in Eldoret, an association of cancer with bad smell and rotting was mentioned, and a participant observed that people tend to avoid houses with a cancer patient because of these factors. This further suggests that cancer patients in rural areas are at risk of isolation.

Witchcraft as a perceived cause of cancer did come up in some of the discussions with patients in Nairobi and Eldoret, but they mentioned it less than other cancer stakeholders and experts. One survivor from Western Kenya had to live with her family attributing her eye cancer to witchcraft and to her move to Nairobi, where they presumed she led a life of loose sex or prostitution. Survivors and general population participants told stories about cancer being seen as a family curse, or as a sign of a lost relationship with God, but patients did not typically talk about this kind of stigmatization as their own direct experience.

---

[16] USD $5 to $20

Stories of stigma varied for individual patients and survivors. A female patient of cervical cancer in MTHR found it difficult to understand that she was afflicted with the illness, as she would have expected it to occur among younger women who sleep with multiple men and "accumulate dirt". Two respondents, a cancer survivor and a patient, recounted stories of being abandoned by their husband, leaving them and their children upon learning of their diagnosis with the rationale that they needed to find a wife who can bear more children or they feared the financial impact and potential contagion. Another two patients recounted how they waited a long time before they disclosed their illness to their spouse due to similar fears.

Effects and fears related to cancer

The most obvious fear reported was the fear of death and the anxiety of patients who feared they would not see their children grow up or the cancer would recur or spread further. For patients who required surgery, there was fear of amputation or removal of an organ. The fear was often mixed with disorientation and confusion, where patients said they did not understand what would happen, what they needed to do, and what cancer meant for them. For some survivors, the situation was initially seen as hopeless and death as impending. Self-esteem was also negatively affected, particularly in young people facing mastectomy or prostate cancer.

Patients and survivors also gave accounts of the severe pain and discomfort caused by the illness and the treatment. Chemotherapy and radiotherapy came with strong side effects including hair loss, the discolouration and sometimes loss of nails, continuous nausea, weakness, and an inability to eat. Additional side effects included the limited capacity to perform daily tasks such as cooking, walking, or washing. Survivors in Nairobi recounted the pain and disorientation resulting from these physical effects and caregivers explained how these effects on the patients made their task more challenging. However, compared to the financial and social burden, the physical effects seemed less of a concern.

Logistics

Based on the accounts received, the limited resources and functionality of the health system made the process of receiving treatment and care for cancer difficult from a logistical point of view. All patients and caregivers interviewed in the national referral hospital recounted their experience of drug stock-outs and the hardship associated with "chasing" the drugs at private pharmacies, where they were more expensive, often unavailable, and often not available in incorrect dosages.

Patients found the admission process to a referral hospital was confusing and unfriendly. Additionally, many reported that the queues were often so long that some patients preferred to "suffer at home". Most patients from outside of Nairobi found it difficult to deal with lack of accommodation because sleeping in a hotel was typically unaffordable and all resources needed to be used for the purchase of drugs and transport.

Support

Moral, financial, and logistical support from within and outside their family was said to be of critical importance for cancer patients. The closest supporters and caregivers were spouses, parents, children, or siblings. In-laws also played an important role and the support of cousins and uncles was often vital. Often, no clear distinction could be made between the different kinds of support, where people who helped with transport and accommodation were often the same who also provided financial support, and closer family members who helped financially were also the ones who provided nursing care and moral support. More than one patient explained that their boss at work had been supportive and helpful. People who already had experience with cancer were particularly understanding, including neighbours, acquaintances, survivors, and volunteers previously unknown to the patient. The very few who were made aware of and used support groups described them as beneficial. Chapter 3.2 provides a more detailed description about what it means to provide support, as well as the challenges associated with it.

Box 4: Financial burden

> The biggest challenge we have right now is that we are so worried about her...even the other day she was crying and saying that " I use a lot of money on treatment yet I have children in school. How will they go back to school when schools open"? At times she cries and says "God take me away so that my child will find help" but we told her not to say such things and that God is the provider.
> Caregiver

> There is no one else who can take care of her if not me and my mother. We have sold all our cows and goats, we have nothing for now, so we are just hoping on God to help us to get the money to help her until she gets well (...). You are told you have the disease and the doctor wants a lot of money which you may not have. But we took heart and told our God to help us and he has. Even right now we have paid everything we had, we did not eat anything yesterday and today...we even don't know how we will get to Muranga. We have spent all the money we had here.
> Caregiver

What patients know and don't know

For many patients, a defining characteristic of cancer was that it is a "disease that catches someone unaware", and that can affect anyone. Many patients knew that cancer is curable if detected early and that having it in the family increases risk. Several also mentioned that nutrition and a healthy lifestyle is important to prevent cancer and to prevent their cancer from spreading. Patients and survivors were aware that some people do not know that cancer can be cured or about the importance of a healthy lifestyle.

The primary knowledge received from doctors was related to treatment, but it was provided inconsistently. Patients and caregivers said that they were told what treatment would be administered to them and what side effects they should expect, especially hair loss and nausea. Other potential side effects, such as the loss of nails or skin burns were often omitted according to the patients' accounts.

Several patients complained that they had received little to no information about radiotherapy apart from the instruction not to wash the marked area on their body with soap and that the machine was used to "burn" their cancer. Some providers referred to "cancer virus" or "cancer germs" and patients did not realize that this was an incorrect explanation.

Misconceptions

The qualitative findings suggested that there are many misconceptions that can arise at the time of the diagnosis. Survivors and a health worker recounted stories of patients from rural areas who themselves had initially believed that they had been bewitched. Another survivor narrated how she initially thought her husband might have infected her with cancer. Early on after the diagnosis, some patients were unaware of how long and complex the process of treatment would be and one said that she thought she would take treatment only once. According to the research participants, there were still patients who continued to believe that cancer could be cured through prayers alone, or through herbal medicine –until the symptoms were so severe that they passed away.

The more persistent misconceptions were related to the cause of cancer, where many patients expressed a belief that there is nothing you can do to prevent cancer, since it comes from within the body without direct external cause. A female cancer patient suspected that her use of family planning methods might have led to her breast cancer. There was generally more mistrust and fear of surgery as compared to chemotherapy and radiotherapy, and a few believed that it promoted the spread of cancer. This appears to be related to a belief in the general population that cancer is associated with wounds and accidents (see Chapter 2).

In Eldoret, there were patients who expressed confidence in the potential of herbal/traditional medicine, but not as a substitute for their current treatment. One patient said that in the "old days", healers knew how to treat cancer, but that this knowledge had since been lost. Another person testified that she had witnessed someone with cancer that had been healed by a traditional healer.

Patient questions and uncertainties

The painful questions that survivors had after they received their diagnosis included: How much longer do I have to live? What is the chance that my cancer can be cured? These questions were often not adequately answered and led to other uncertainties related to the impact of the disease. A young survivor recounted how he had asked himself if he could ever play sports again and if he would ever be able to perform sexually again.

Other open questions early after being diagnosed were whether the treatment would be effective and why patients were still coming for therapy many years later. There was also uncertainty expressed by several respondents about what herbal treatments and supplements might work or complement their treatment. Several patients recounted that they had received insufficient information about chemotherapy, radiotherapy, side-effects, and generally about the cost and duration of treatment.

Among the patients interviewed in Nairobi, a few felt that they had sufficient information about cancer; however, more typical was a great interest in learning more about the disease. In several cases, the respondents expected the interviewers to share more information about cancer. Patients often said that they knew little or nothing about the disease beyond basic knowledge about their own diagnosis. Most patients said that they would like to receive additional instructions related to the management of their diseases and they expressed a wish for detailed guidance about which foods they should consume or avoid and what else they can do to participate in the fight against cancer. Some required additional information about alternative places to receive chemotherapy. Survivors with a colostomy said that they had felt much unprepared for the operation and for the management of the stoma.

The most frequently mentioned questions many patients struggled with during their illness were around reasons for the disease. For example, they would ask questions like "Why did I get cancer?" "What is the cause?" and "How did it start?" Patients were disturbed and puzzled that they got the disease when there was no family history of it, or that they got it even though it is not communicable. Others believed that the disease mostly affected elderly people and therefore questioned their diagnosis because they were not old.

Another uncertainty expressed by multiple patients was related to the expected inclusion of cancer treatment in the benefit package of the National Hospital Insurance Fund (NHIF). Some patients wondered why this had not yet come into effect, despite being announced for April 2016[17].

Two critical knowledge gaps

In addition to patients who experienced uncertainty, there were gaps in practical knowledge that became apparent during this research. First, hardly any patients in KNH and MTRH were aware of the existence of support groups, with "No one ever told me" as the most common response after learning of them. Other support programmes offered by NGOs or private organisations also had limited reach. This suggests that improved communication to patients when they come for therapy or clinics could increase the impact of already existing initiatives at a relatively modest cost. However, the access to support groups for the many patients outside Nairobi is limited.

Second, patients often did not know that they had a right to get more detailed information about cancer and its management and that they could ask as many questions as they needed about the prescribed and alternative treatment options. It is likely, however, some health professionals, due to their lack of time and heavy workload, have discouraged inquisitive behaviour and alternate solutions. More effective patient counselling need to be put in place.

---

[17] The public national hospital insurance fund in Kenya currently covers roughly 20% of the population, mostly those who are in formal employment and their families, as it is a mandatory scheme for employees. Until recently, only inpatient costs ('bed costs') were covered in the insurance scheme, but outpatient coverage and an updated benefit package is being rolled out in 2016.

Treatment adherence and healthy nutrition

For patients in treatment at the time of the interview, there were hardly any doubts about the perceived benefits of it. Nearly all patients reported an improvement of symptoms after starting their treatment. Apart from a relief of symptoms, adherence to treatment came with a strong hope of being cured for many patients, and resulted in a lessening of fear. Several patients said that taking the treatment was the only option they had.

Perceived barriers to treatment adherence

Barriers that patients perceived as obstacles to treatment adherence included the following:

- **Affordability and access to treatment**: Costs drove some patients to consider less expensive alternatives and stopped some from starting or continuing treatment. In Eldoret, some patients reported that they had tried herbal medicine as they waited for their appointment or until they had raised enough money. In addition to the unaffordability of treatment, there was also a challenge of physical access (e.g., chemotherapy was only available in a few public centres, and radiotherapy only at KNH in Nairobi). The wait times at KNH were very long and could range from weeks to months, depending on the waiting list and equipment downtimes.

- **Influence by other people and alternative treatments**: Based on the interviews in Eldoret and at KNH, most cancer patients received advice from family, acquaintances or friends, often unsolicited, about possible alternative treatments, usually herbal medicine. Often the advice was accompanied by warnings about the danger of surgery and explanations that the high cost of regular medical treatment was not affordable or justified.

- **Fear of negative consequences***:* Some patients who had been advised to undergo surgery had heard that surgery could have adverse effects, such as promoting the spread of the cancer ("when it's touched, it spreads further"). For the elderly, there was often a fear, especially among caregivers, that they may not recover from the operation. One health professional and some survivors also reported that severe side effects could be a barrier to adherence.

- **Inefficiency of treatment:** In some cases, patients expressed a doubt that surgery or other treatment would have the desired effect. According to one expert, there was also a risk of patients ceasing treatment once their condition improved, as they might see less of a need for it.

- **Denial and fatalism**: A survivor said that she had mentally denied her cancer immediately after the diagnosis, which led her to delay treatment for months. On the opposite extreme, there were accounts of patients who believed that they would die anyway so there would be no point in incurring large costs for treatment. Family members who were concerned with financing the funeral and other regular expenses sometimes openly or tacitly supported this attitude.

Box 5: Knowledge gaps

> At first I was afraid, I wondered why me?" Then I recalled that I have never heard of that disease at our home and wondered where it might have come from and what I was going to do.
> **Patient**

> When we are on the queue you hear other people say they have been treated and are cured and they are coming for clinic... some have been coming for clinics for the past 15 years. They still come for clinics to be checked. Others say its 7 years of them coming for clinic and they are going about their business well. I am wondering: will mine take me to the grave or I will be cured?
> **Patient**

> I also have an issue with how cancer treatment is charged, I've always asked myself, who dictates how much an oncologist should charge, because they're crazy figures, my brother calls them satanic figures. They'll tell you figures that you cannot – it's only in a doctor's room that you do not bargain. So daktari amesema, ni million moja. So you start fundraising, you don't even think daktari can we make it lower? "Daktari amesema.
> **Patient/survivor**

> I have not heard about [support groups], no one can tell you anything here at Kenyatta [KNH], because these private doctors want to syphon money from us, they charge a lot of money.
> **Patient**

> I asked the doctor about this yesterday. I think a month ago I heard over the TV, radio and it was even gazetted that the government was going to allow cancer patients to use their NHIF cards, do you understand? (...) They said chemo patients would receive a certain amount of money and the radio patients would also receive a certain amount, they had said it would start in April. But the month is almost gone yet we have not seen or heard anything, no one has addressed us on that issue.
> **Patient**

Self-efficacy for treatment

Since the sample of interviewed patients and survivors mostly included people who had been successful in adhering to treatment[18], it was not surprising that they showed high self-efficacy for treatment adherence. A few of the patients saw the main reason for this as their own strength and ability, while others emphasized the importance of a strong family support system. A survivor and a caregiver related how their discovery of nutritional supplements was helpful to get through treatment, reporting that it helped with the absorption of nutrients.

Treatment cue to action

The principal cue to action for all the interviewed patients was the doctor's prescriptions and instructions. Beyond this, family members and friends provided an additional important cue when they expressed their support, and encouragement. Sometimes these people also provided additional useful information or helped patients ignore unsolicited advice and warnings of others. A decisive cue to action was also given by "the pocket", when patients could start their treatment because they had raised enough funds to afford it.

Perceived benefits, barriers and self-efficacy for healthy nutrition

While all patients and caregivers were aware of the need to eat well, many said that they would like to see a more comprehensive list of recommended or discouraged foods. In addition to healthy foods, patients and caregivers were also aware of the need to drink enough water. One patient explained that healthy food and low stress levels were needed to obtain a sufficient count of white blood cells, which was required for chemotherapy. Patients understood that there is a general health benefit of eating well and following the doctor's instructions.

In general, apart from some uncertainty about which vegetables are recommended and perhaps a lack of understanding by other household members who routinely prepare food, there appeared to be no major barriers to the preparation and consumption of healthy food. One patient said that in addition to eating healthy herself, she also instructed her children to follow the example. In the survivor's group, a participant acknowledged that in Nairobi, sometimes hunger can drive one to make a poor dietary decision when one is offered unhealthy food.

Coping Strategies

Most patients who had lived with cancer for a while eventually learned strategies that helped them cope, but it took time and they were often unaware of additional coping mechanisms available to them.

---

[18] Patients who experienced less difficulty with treatment may have introduced a selection bias by being more willing to be interviewed. This bias was less likely for caregivers and survivors than with patients.

Numerous patients and survivors reported that the single most important step cancer patients must take is to accept the fact that they have cancer. Without this, the management of the disease and the fight against it is less likely to be successful. For one survivor, accepting herself was an integral part of accepting the cancer as part of her life. For others, the acceptance of death as a part of life was the basis of their ability to fight for their life. One patient in Eldoret expressed it as follows: "If I had worries, I would already be dead."

Almost all patients stated their belief in God and frequent praying were core tenets of their strategy to live with, and battle the disease. Their belief in God and the mental acceptance of having the disease were closely linked. Prayer also provided immediate relief from fear and silenced negative thoughts. Several patients recounted how they found ways of giving themselves strength through maintaining a strong belief that the cancer would ultimately be cured, believing in their own capability and power to defeat the disease. For some it helped to re-frame cancer as "a disease like any other" rather than being the deadly threat that they first perceived it to be.

Members of a support group interviewed in the survivors' focus groups strongly underlined the central importance the group had played in their lives. They suggested that other patients should be given a similar opportunity and expressed their willingness to help in increasing the visibility of the group. Some of the patients at KNH explained that it was helpful for them to have conversations with other patients who were there for treatment or consultations.

Activities that help reduce stress were also mentioned as an important element of being able to cope with the disease. Unknown to many cancer patients[19], support services, such as massages, yoga, and complementary medicine were available at the Faraja Cancer Trust in Nairobi at no cost.

Even in the absence of support groups, social connections and conversations with other people who have experience with cancer are important in helping with coping.

Barriers and self-efficacy for coping

Accepting cancer as part of their life was said to be difficult for many newly diagnosed patients and it took time to reach that stage. What made it harder was the fear of seeing others in the family being scared and overwhelmed. Patients who suffered from the financial and physical burden of prolonged treatment, especially when they felt alone and abandoned, sometimes reached a point where they were close to giving up internally.

Information seeking and communication channels

Apart from their lived experience and observation of what happens to their body, cancer patients said that they mainly acquired knowledge about their illness and its treatment from doctors and, to a lesser degree, nurses. Those who had lost a relative to cancer in the past derived a good part of what they knew from this experience. Treatment and clinic days provided an opportunity for the more sociable among the patients to exchange knowledge with other patients. For the few who were aware of and had joined a support group, the group was an invaluable source of information and practical tips, both during the meetings as well as via WhatsApp and Facebook groups. Some of the younger patients also used the Internet as an information source. For one participant, this posed a dilemma as the information he found was not fully in line with his own treatment experience or with the information provided by the doctor, yet he did not feel entitled to ask the doctor about it.

Many patients also reported having received information through mass media, especially radio and TV, such as a regular program on Inooro radio and ***Hope Channel***, a faith-based TV station. One survivor narrated a story she read in the Standard Newspaper about colon cancer, which motivated her to get in touch with the doctor interviewed, who led her to a support group that positively impacted her life. Of the 16 patients interviewed at KNH, one mentioned that she had seen "booklets, which I tried to read**"**, and a member of a support group talked about pamphlets in a waiting room for radiotherapy during treatment in a private hospital.

Another existing information source mentioned were volunteers who occasionally addressed patients waiting for treatment.

The key messages received from the doctor, as recalled by the patients, were usually instructions related to preparing for chemo- or radiotherapy, and healthy living (e.g., good nutrition, reduction of stress, sufficient water intake and avoiding direct sunlight). They also received instructions to attend clinics as scheduled.

Active information seeking

About half of the patients interviewed at KNH said they had never actively looked for information, and many said they would not know where to look for it. At MTRH, this number was even lower. Of those who had sought additional information, most asked their doctor or other health workers. One option sometimes used was to ask questions to doctors in other hospitals or in another town. Fellow patients were also actively approached for their experience and knowledge. Other resource persons for information included parents, children, or other relatives and friends. Only one patient mentioned that she had actively looked at and obtained print materials. For young patients, the Internet was an important source of information, accessed sometimes via mobile phones and almost always using Google to search for topics. One patient explained that he always read the full insert of the drugs that he got, and usually searched for more information about the drug on the Internet. A survivor described how he had used mostly YouTube as a source of information about his condition, as he had not been in the mood to read. Another male survivor recounted how the doctor had explicitly asked him not to seek information from the Internet, as it often has a European/American perspective, which cannot be translated to the Kenyan context. The doctor told this patient to use him as the sole source of information, but for this patient, it was difficult to ask the doctor questions.

Recommended communication channels

Patients and experts emphasized the need to communicate through interpersonal channels with cancer patients. While doctors were already the primary source of information and could be engaged in a strategic way to communicate specific messages and content, two other interpersonal routes identified were support groups and individuals who could be present during waiting times before treatment and clinic sessions. Individual peer counsellors could also be used in other occasions to have one-on-one sessions.

One of the experts talked about a positive experience overseas, where patients could read short information leaflets and write down their own question as a preparation before seeing a doctor, who was then able to respond to their specific queries. A similar modified approach could be considered for the national referral hospitals.

Experience with health professionals

The following perspective on the patient experience with health professionals, primarily doctors, is based only on the qualitative interviews with patients, caregivers, survivors, key informants and a small selection of health professionals. It cannot be considered an objective representation, but rather a sample of perceptions and experiences that are insightful and may help serve as a guide to improving cancer care and control.

As mentioned earlier in the report, according to the experiences of cancer survivors, their symptoms were often not initially recognized as cancer symptoms and often led to misdiagnosis, delays in treatment and inappropriate treatments. To mitigate these challenges, one survivor made a strong case that doctors should consult more with each other, rather than operate in isolation. One interviewed oncologist agreed, saying that doctors needed to establish and maintain relationships with health professionals beyond their institutional boundaries and with other types of institutions such as hospices. There was also a concern that young doctors were not always aware of the services offered across various facilities and occasionally made incorrect referrals, leading to unnecessary and costly trips for patients.

One expert also spoke of health care professionals' limited knowledge of correct cancer diagnostics and a fairly common practice of diagnosing cancer based on imaging alone, before having conducted the required pathological tests. Most doctors and health professionals reported being unaware of the 2013 Kenyan national guidelines for cancer management, which had not been widely distributed in counties.

A more indirect, yet important knowledge gap existed among medical professionals, including oncologists, with regards to the potential efficacy of herbal medicine. While there is limited scientific knowledge about herbal medicines, even seasoned professionals indicated that some traditional treatments might have positive effects or provide symptom relief. One of the survivors recounted substantial relief when he was seeing an herbalist in Tanzania as he awaited treatment in the hospital. Unfortunately, according to several other respondents, there were also many examples of herbalists or local healers who claimed to be able to treat cancers with entirely ineffective products, often for substantial amounts of money. Doctors need to be open to discussing what types of traditional treatment a patient might be considering or using to provide guidance on what evidence exists and ensure it is not doing harm.

Patients and survivors often perceived that health care providers sorely lacked communication and empathy skills. The interviews showed that the few patients who had been told in advance that a biopsy was being taken to test for cancer were later able to cope with the news of a diagnosis better and accept cancer more easily than those who had never considered the possibility until the day they were confronted with the diagnosis. Survivors and patients clearly believed it was more advantageous for doctors to be forthcoming about a diagnosis, that they should avoid technical jargon but should use the word cancer, and that they should be better trained on how to be more sensitive in communicating information about treatment options that are particularly scary, like surgery that involves removal of body parts.

The language that some of the cancer patients at KNH used when talking about their disease suggested that doctors or nurses had used language to simplify cancer when they explained it to their patients that might have driven misconceptions.

For example, several patients talked about treatment descriptions from their doctor like driving out “cancer germs” or “the cancer virus”, which could otherwise “jump to other parts in the body”.

Caregivers and family members

For the purpose of this chapter, a caregiver is defined as someone who provides physical, emotional, spiritual, financial, or logistical support to a cancer patient[20]. Much of what is described in this chapter also concerns close family members who may not consider themselves to be ‘caregivers’. The experiences of caregivers interviewed at KNH and at MTRH were similar, with a few exceptions that are mentioned.

Providing care for a cancer patient in Kenya

Based on the accounts of cancer survivors and key informants, families of cancer patients, especially for elderly patients, often knew the diagnosis before the patient, and in some cases decided not to let the patient know in an effort to protect him or her. One caregiver reported that she had been instructed by the doctor not to tell the patient, since the patient might not take the news well. One cancer survivor recounted the story where a doctor only informed the whole family of her grandfather's prostate cancer after the passing.

Caregivers often played a central role in the difficult process of breaking the news and having to tell their loved one about his/her diagnosis. Sometimes, however, the patient was left to tell his/her own family themselves, which was often distressing for both sides. The emotional reaction of caregivers upon learning about their loved one's cancer was described as being comparable to the reaction of cancer patients themselves. According to survivors, caregivers played a central role in helping them accept their diagnosis, a critical aspect of their coping ability.

In terms of self-efficacy, many of the caregivers interviewed at KNH expressed confidence that they had what it takes to provide support and care to the patient, and several of them said that they did not need additional help. A roughly similar proportion of the participants said that it was indeed a struggle that no one had told them how to do it or that more help from other family members logistically

---

[20] Adapted from the definition provided on www.cancersupportcommunity.org/ It became clear during the research that the term ‘caregiver’ is used broadly in the Kenyan context and assumes different meanings, depending on context. It can include volunteers who provide support to people they didn't previously know as well as close family members, health workers, relatives, neighbours or domestic employees.

and financially would have made it easier for them to manage. Many mentioned it is sometimes overwhelming and an emotional battle.

The quality of the communication with the doctor affected caregivers as well. One mentioned being unable to understand technical terms such as "platinum resistant cancer[21]", and was uncomfortable when a doctor told them, for example, that they were dealing with "cancer of the unknown[22]". In some cases, caregivers acted as important intermediaries between doctors and patients, especially when consent/dissent for an operation was at stake. One of the survivors related the experience of his father, who was first discouraged, and later convinced by a relative to consent to surgical castration.

Box 6: Communication gaps

> We didn't [tell him], we thought he would receive the treatment and then we would tell him later. But we decided to tell him because he was wondering what disease it was and why we are not telling him - so it was like we were torturing him. The doctor who told him was a Kamba, and he told him "old man, you have this disease but don't worry.
>
> Caregiver

> The challenge was in the first place, getting admitted. The doctor has told you that your grandmother must be admitted today, this is urgent. When you go you are sent to the wards, the ward sends you to records so my biggest challenge was at the records. You go there, your file is misplaced. You are told your file isn't there. You go to wards and they send you back to tell the person there to look for the file. When you go there you are chased. You are told, "This is not your work, and you go there and wait for your file at the ward." They take you round. For my grandmother to be admitted, it had taken a long.
>
> Caregiver

Elements of care giving

Giving care to a cancer patient involves multiple people, but one person usually takes a central role, typically a spouse, parent, or child. The description of the caregiver activities below is a composition of accounts given by several different caregivers and survivors.

Many caregivers helped with the financial aspect of cancer treatment through various strategies: personal remittances, asking others for contributions, selling assets including land and cattle, obtaining funds from ***chamas*** (micro-savings groups), and approaching NGOs or philanthropic organisations. The funds raised were usually used for the cancer treatment and related costs, as well as to cover other expenses for the children of patients who had lost their income, such as school fees.

Another key function of caregivers was the provision of moral support. Caregivers talked to patients, listened to them, and showed love. They provided reassurance, and encouraged patients to accept the disease and fight for their health. Those who could often went for counselling together with the patient and some liaised with church and prayer groups. Caregivers needed to be strong and tried to avoid being overly emotional in the presence of the patient to make him/her feel comfortable and reduce anxiety.

Every patient needed logistical support, especially for travelling to the hospital to attend clinics and receive treatment. This involved accompaniment, organisation of transport (usually public transport), looking for drugs when they were out of stock at the hospital, organising for or providing a place to sleep in Nairobi, and sometimes helping facilitate the presence of loved ones.

On other days, caregivers provided nursing care by preparing food and supervising its intake, washing the patient, monitoring compliance with the medication, providing support towards the management of side-effects, dressing wounds and changing medical devices such as catheters or stoma bags. They also helped in the household with washing and cleaning or hired someone to do so.

---

[21] Platinum-based chemotherapy is a new treatment modality for breast cancer and platinum-complexes had been established for a long time in ovarian cancer. Phenotypes that are resistant to these complexes have emerged. (Eckstein, Niels: Platinum resistance in breast and ovarian cancer cell lines. Journal of Experimental & Clinical Cancer Research, 2001 30:91).

[22] The patient probably dealt with a case of 'cancer of unknown primary' and was not explained by the doctor in depth. Sometimes it's not clear where a cancer may have started. When cancer is found in one or more metastatic sites but the primary site cannot be determined, it is called a cancer of unknown primary (CUP) or an occult primary cancer. This happens in a small portion of cancers. (http://www.cancer.org/cancer/cancerofunknownprimary/detailedguide/cancer-unknown-primary-cancer-of-unknown-primary)

Challenges associated to giving care

The barriers to providing support and care were considerable for caregivers faced with competing needs on both their time and finances. Like patients, most caregivers reported they were suffering from the financial toll of cancer. Selling assets and being subjected to a continuous financial drain put caregivers at risk of compromising their family's savings. Drugs were reported to be very expensive, leading to fewer resources being available for other critical expenses, like children's school fees. Both the costs incurred and the time spent with the patient were said to have social consequences, including marital disagreements. Those caregivers who were not immediate family of the patient faced additional pressure if they wanted to provide this type of support and care.

Many of the interviewed caregivers took the responsibility with a sense of acceptance but most acknowledged that it was not an easy task. There were worries and fears about what he/she would do without their spouse if the patient died. They had to endure watching a loved one suffer from the illness and/or treatment side effects and/or deal with the hesitancy of their loved one openly discussing their cancer due to stigmatization.

Challenging tasks described by caregivers included monitoring the patient's intake of food, dealing with frequent vomiting, and "seeing everything" (for example when a daughter had to change her father's catheter). Some caregivers explained that the intense and often all-encompassing time requirement and mental commitment, over and above routine tasks like work, family responsibilities or school, resulted in exhaustion.

A caregiver's time, money and energy were often depleted. Accompanying the patient to chemotherapy could easily take up to two days for those travelling from remote areas and caregivers often spent the night with the patient on the seats and floor of the hospital waiting area. Chasing drugs when they were out of stock was difficult and taxing for caregivers and sometimes involved visiting multiple pharmacies until the right drug and dose were found. In addition, patients and caregivers complained about long waiting periods for treatment and other health services, including queues at the hospital pharmacy or to receive test results. One caregiver described how a patient had to stay in a hospital for a week as he was waiting for his blood to be screened.

One caregiver at MTRH, who had learned about her husband's cancer just a few days prior to the interview, was worried about his bad physical shape and his inability to walk properly. Her most pressing need at the time of the interview was to find blood donors to allow him to undergo surgery. She was preparing to travel back to her village in search of donors.

Being close to a cancer patient also exposed caregivers to their own fear of death and disease. This fear was sometimes compounded by other emotional reactions, such as the memory of another family member recently lost to cancer or another tragedy. In sum, the role of care giving was a crucial and difficult one. As one rural participant stated, "As a caregiver, you can die of stress".

Knowledge gaps and uncertainties of caregivers

As they provided care, caregivers seemed to have acquired basic knowledge related to cancer, such as the importance of early detection, how cancer can spread, and the need for a healthy lifestyle as well as basic nursing care. However, many knowledge gaps became apparent during the interviews. Knowledge on the logistics related to treatment and care were often lacking. This included smaller issues like where to make the payment in the hospital, but also more substantial tasks like finding additional financial resources and support, finding an affordable place to sleep in Nairobi, and figuring out how to manage a patient who cannot walk anymore. In relation to treatment, caregivers were often initially unaware of the treatment duration and costs and whether the treatment was safe or clinically sound. Specific gaps were noted on the process of chemotherapy, radiotherapy and surgery. One question for many caregivers was, whether the treatment would provide a durable or only a temporary cure.

A frequently mentioned uncertainty with regards to the provision of care was related to diet, specifically what exactly a patient should eat. Many caregivers expressed the desire for more detailed information and instructions that go beyond eating healthy foods such as "greens". There was also a question about supplements to boost the patient's strength. Additionally, caregivers often asked about the cause of their loved one's cancer and whether it could be due to their diet, even though they did not drink any alcohol or smoke. Beyond diet were questions on whether family planning methods caused cancer and what could be done to prevent cancer.

Most caregivers were unaware of additional sources of information related to cancer or cancer care, and they had never heard of the existence of cancer support groups. Caregivers were often unaware of the importance of also taking care of themselves and of the need to develop coping strategies to deal with the physical and mental burden of their responsibilities.

Information seeking and communication channels

As with patients, the primary source of information for caregivers was doctors, followed by nurses. In addition, some caregivers got information and knowledge from a past cancer experience in their family, relatives who were health professionals, or other patients and caregivers in waiting rooms. With one exception, caregivers did not talk about having received information through media or print material. One caregiver had received a brochure from KEMRI about foods to feed the patient. The messages caregivers received from health workers were mostly related to cancer treatment, side-effects of the therapies (loss of hair, appetite, alertness, and potential irritability), and basic instructions related to giving care. Younger caregivers used the Internet as a valuable source of information. "I made Google my friend", one caregiver stated. At MTRH, all caregivers interviewed reported that they were unaware how to seek information themselves.

When asked about their preferred communication channels, there was a strong emphasis from all categories of research participants on the importance of interpersonal communication for caregivers, just as it was for patients and the general population.

Box 7: Caregiver quotes

> The biggest challenge was that, I reached some point and got confused because some of the relatives and friends would advise that I go for the operation; others would tell me not to and that that will be the end of her life when operated on. Some people would give you examples, 'Did you see that woman yesterday, and she didn't stay one month after being operated on and then she died.' That got me a little bit confused. They gave me other solutions of herbal medicine. That was difficult for me.
> Caregiver

> It's God that is taking care of me, I have a child in school, I also have my brother-in-law, the last born, he was supposed to go to school last year but because of lack of funds he is not yet gone to school, the lady is with me and she helps me look for treatment money for the old man...my mind right now is very far because its only one week to schools opening and pay a lot of money.
> Caregiver

> See you see they had really come down though they were still high because the range is up to 35. So we were told she's a platinum and I told them what I know about platinum is a high level because I know there are cards there is silver, bronze, gold and platinum, platinum is the highest. So me I asked the doctor is that what you mean? That is what you mean that she is a high level resistant and she said yes and they said we have to change the medication now
> Caregiver

> Taking care of a cancer patient is a very difficult task, because when the patient is seriously ill, it will have to take the whole family to take care of the patient because you cannot manage when you are alone. You have to wash that person and there is the smelling, you have to carry him and there is the crying because they are in pain. So even the whole homestead...you are stressed, there are some who will even die because of the cancer patient because of the stress they have.
> Female population focus group participant (Uashin Gishu)

Analysis and Recommendations

Insights about behaviours to promote

During the interviews with the different types of respondents, several practices and behaviours emerged that would be beneficial for patient wellbeing, and could be considered as topics for communication materials or support campaigns.

For patients it was important to talk openly about cancer and maintain social relationships to avoid isolation and reduce stigma. Members of support groups and survivors who now volunteer as caregivers reported that they had to overcome fear of shame and humiliation to help pave the way for the removal of the taboo and generate a friendlier social climate. They suggested that patients could benefit from learning how to communicate with those in their social group that cannot afford to help financially about other positive forms of support they can provide. This would help reduce avoidance and detachment of those who feel uneasy or guilty for not contributing financially. Overcoming the fear of talking about cancer could also be improved if patients and caregivers are encouraged to be inquisitive and ask questions to health workers about diagnostic tests, treatment options, and price comparisons. This would also better prepare them for what to expect, create more transparency, and ultimately prepare the ground for better doctor-patient communication.

Cancer patients and survivors are themselves a memorable and credible source of information that can promote health seeking behaviour and a healthy lifestyle. Many of the patients interviewed pointed out that they are already doing this and expressed an active desire to be further enabled to spread more information. Finally, patients could be helped and encouraged to come together to advocate for lower costs and helping each other in the sourcing of drugs. In Kenya, where prices are both unaffordable and unstandardized, there may be a good opportunity for survivors, patients and caregivers to collaboratively make a difference through organised action and crowd sourcing of information.

For caregivers, Cancer patients and health professionals have pointed out that a strong support system improves clinical outcomes and helps patients to cope psychologically. What has become clear from these interviews is that caregivers themselves would benefit from additional support and guidance. During the interviews, a range of additional recommendation emerged that would aid caregivers, including:

- **Avoiding sympathy, pity or commiseration**. Cancer patients need someone with "a strong heart" who encourages them, gives them positive words and invites them to fight. People who sympathise and express their concern and sadness sometimes can do more damage than good. The tendency of relatives or friends to sympathise out of helplessness and ignorance is common enough that patients and survivors said they avoided these social contacts.

- **Attending to the patient to avoid seclusion or loneliness.** This was particularly salient at MTRH and among rural respondents. One respondent suggested ensuring that the patient has good clothing, as they had observed neglect in that respect.

- **Being inquisitive**. Since information is often not readily available and doctors are busy and struggle to communicate appropriately with caregivers, caregivers need to ask questions. Obtaining information will have long-term benefits for the patient, making their life easier and better prepared for what is to come. Asking health professional questions in the presence of the patient is particularly helpful.

- **Bringing only healthy food to patients as gifts when he/she is admitted in hospital or at home.** Well-meaning relatives and friends are sometimes inclined to bring unhealthy items such as chocolate or sweets to generate a moment of happiness. This is counterproductive and nutritious food would be a better contribution.

- **Talking about cancer**. One of the greatest psychological burdens of cancer patients, and their families, stems from the fact that cancer is still a taboo and seen as a death sentence. Caregivers and family members can contribute to the alleviation of the taboo and stigma by talking to others about cancer in an informed way. In the words of one cancer patient interviewed at MTRH, caregivers should "be free" to talk about cancer and not be rumour-mongers.

- **Practicing a healthy lifestyle as a caregiver, by adjusting diet, exercising, and reducing stress.** It is essential that caregivers take care of themselves to retain the strength to fulfil their crucial role in treatment and care.

Health workers at primary and secondary levels of care, including those in private practice, should be encouraged to further increase their own knowledge of cancer signs and symptoms, to consider cancer as a possible diagnosis, and to recommend screening and prescribe correct diagnostic tests early on, rather than using empiric therapy[23].

Doctors who diagnose cancer should appropriately disclose to the patient what they found and what it means. Sending patients with the results to the referral facility without explaining their diagnosis, or by telling only the relatives can have harmful consequences. The findings of this survey showed that some patients who were primed about the possibility of cancer were later able to better digest the diagnosis, as they had already had time to mentally prepare. Doctors should therefore be encouraged to explain it to their patient when they order a cancer test.

Finally, doctors should be enabled to better convey information about cancer to patients and caregivers. This includes communication about testing and screening, 'breaking the news' to patients and their families, and preparing them adequately for what they should expect.

---

[23] Empiric therapy or empirical therapy is therapy based on experience and, more specifically, therapy begun on the basis of a clinical educated guess in the absence of complete or perfect information (https://en.wikipedia.org/wiki/Empiric_therapy).

Insights about messaging

Insights about messages to patients and caregivers were derived both from direct recommendations by experts and from those affected by cancer, and from the recurrent themes that emerged across various interviews.

At the time of diagnosis

The first piece of information, given together with the diagnosis, should be that cancer is not a death sentence and can often be treated and cured. For patients who are diagnosed at a late stage or for types of cancer with little or no hope for cure, careful and balanced information about the implications and the different routes to increase quality of life need to be given at that stage. Both patients and caregivers should be encouraged to ask questions to their health providers.

Immediately after this, patients as well as their families and caregivers, need to be provided with sufficient information about the implications of their illness, including a general understanding of the different treatment options, their benefits, and potential side-effects based on the stage of their cancer. Written material should focus on practical information, including a list of health facilities that provide chemotherapy and other treatments and contacts for support groups and volunteers. It should also talk about how the cancer will affect mobility, the ability to work or carry out household tasks and other meaningful activities. Caregivers need basic advice on how to support a patient through encouragement rather than commiseration.

It is also important to provide basic information about the causes of cancer, as the question about "why" and "why me" was the one that appeared to disturb most of the cancer patients interviewed. Any myths also can be dispelled at this point, such as cancer is not a curse, it is not caused by family planning, it is not communicable, and is either curable or, in some instances, treatment can at least prolong life, reduce suffering, and increase quality of life. Finally, patients should be given guidance and support about how to disclose their diagnosis to their families and friends.

Acceptance and coping

Several survivors and experts suggested that survivors and public figures who talk about their own cancer experience can provide immense help for patients to cope with their diagnosis. A message about the critical importance of accepting cancer as a reality rather than denying or resisting it may also accelerate some patients' ability to reach the point of acceptance. Since faith has shown to be a central tenant of most patients and caregivers ability to cope, a good strategy would likely be to develop a catalogue of relevant and helpful excerpts from the Bible, Qur'an and other holy texts as per the patients' beliefs, along with sermons and reading recommendations.

After the diagnosis: Practical reference and guidelines

- Contact information and directions to find support organisations, including support groups and centres and hospices, as well as where they can obtain help to start a support group if none is available in the region where they live,
- Practical tips and information for specific cancer types, for example where one can get stoma bags for patients and survivors of colon cancer,
- A long-term overview of money required to go through treatment and follow-up care, and fundraising strategies to assist families, alongside with the options and rights they have for NHIF coverage.
- Practical guidelines for nutrition with a list of locally available healthy food and preparation methods,
- A list of pharmacies that sell cancer drugs with phone numbers, and indicative prices for drugs and treatments,
- Additional information about therapies and their side effects, particularly radiotherapy, for which some patients felt uninformed,

- Information on evidence-based, complementary treatments, what is known and not known about herbal treatment for cancer, and what can or cannot be used by a patient,
- How to find affordable accommodation, and
- Detailed explanation of risk factors and lifestyle strategies to mitigate the risk of getting cancer, which patients can use to inform others.

Specifically for caregivers:

- What to expect in terms of the emotional challenges and mood swings of the patient,
- How to provide moral support to the patient, including talking, listening, turning to one's faith, avoiding stress and messages of encouragement,
- Guidelines for nursing care, such as dressing of wounds, feeding, or handling pain,
- How to look after themselves as caregivers and avoid burnout.

Close family members and caregivers, as well as more extended circles of relatives and friends should receive messages about how to create an enabling environment for a cancer patient by being positive and talking about it openly, without perpetuating myths, and with caution in regards to unsolicited or ill-founded advice. Anecdotal evidence from the interviews also suggested that families could benefit from learning about strategies on how to efficiently share tasks and collaborate, so that no one single person gets overwhelmed and everyone can maximize their contribution.

Communication channels

Most patients expressed a wish to be given information interpersonally, and only few among them referred to print materials. This could partially be because they have not been exposed to such materials. Some of the caregivers recommended the use of print material (pamphlets or books), used in combination with expert advice. Checklists, guidelines, instructions and reminders can also be of great support.

Herbalists and traditional healers might also be a good channel to pass on information about nutrition, especially in rural areas where people appreciate and seek the help of these practitioners more than in urban areas.

For communication related to healthy lifestyles and screening, patients themselves can become a valuable channel to transmit information and persuade their caregivers, family and relatives, who in turn can further pass on this information to others. After many years of HIV related communication and education campaigns, findings suggested that many Kenyans would rather talk about HIV and AIDS over cancer, thus demonstrating both the current fears particular to cancer and the potential for cancer campaigns to improve communication and reduce myths and stigma associated with it, like has been possible with HIV.

All communication materials, especially interpersonal communication, need to be provided in Kiswahili and in as many vernacular languages as possible. Language needs to be simple and medical terms and jargon should be avoided as much as possible. Verbal communication can be complemented with written materials, but even pamphlets need to integrate a feedback mechanism, perhaps by indicating a working phone number.

Some patients referred to mass media as potential information sources, especially radio, and TV. The preferable format would be weekly shows. For young patients in the city, online videos can be a valuable channel preferred over written materials, although it would have a limited reach to a relatively small group of patients.

Experiences in the past showed that there is a risk that organisations develop print material and do not budget for the dissemination of it, with the consequence that it never reaches the intended audience. A promising strategy may be for various cancer organisations to plan communication efforts jointly and to not commission any written materials without having a budget in place to disseminate it, ideally with an interpersonal communication strategy.

Insights related to health professionals

One priority area for health professionals is sensitizing them on cancer signs and symptoms that warrant diagnostic testing or referral. Improvements in this area could substantially increase early diagnosis of cancer in Kenya as would continued medical education for general practitioners, clinical officers and nurses.

As described in this research, patients were sometimes not informed of their cancer diagnosis. From the qualitative research, it was difficult to estimate how often this occurs in Kenya overall, but it appeared to be common enough to be taken seriously. This is partially attributed to lack of time, the difficulty of the subject, and concerns about scaring the patient.

For doctors, it seems therefore important to provide guidelines about communication messages and techniques at the time the diagnosis is made, and afterwards. Key messages include:

- A patient who has been diagnosed with cancer needs to be referred for counselling and should be given contact information for support groups on the day they learn about the diagnosis.
- Doctors are among the most influential people in the life of a cancer patient and have a unique opportunity to have a positive impact on their well-being by mentally preparing them for what they should expect, and by reducing uncertainties and fears. Patients who are 'primed' about the potential of having cancer before diagnosis can accept it more easily when it turns out to be the truth.
- When cancer has been confirmed, patients should be asked to come to the doctor's appointment accompanied by a relative or a close friend, as this prompt has the added benefit of the patient having some lead-time for mental preparation ahead of a serious diagnosis.
- While explaining the diagnosis to the patient and family, benefits of treatment should be highlighted for those who can be treated.
- For cancers at a very advanced stage with little hope for survival, providers should explain that there are healthcare options to reduce symptoms and control the pain.
- Doctors should use simple, every-day language when communicating about the diagnosis and the illness.

The most appropriate channel of communication for health professionals to transfer complex knowledge and skills related to diagnosis and communication is the development and promotion of an updated curriculum as well as short courses for in-service training and continuous medical education (CME) modules to enable the acquisition of the required skills in sufficient depth.

Trainings should focus on how to recognize cancer symptoms and correct cancer diagnosis and management, including a good understanding of which institutions offer what and at what cost. Most importantly, trainings should include a module on how to communicate with cancer patients from the pre-diagnosis stage to the post-treatment phase.

In the short term, print and digital media, if disseminated appropriately, could be beneficial.

Underlying issues

The study findings indicated that underlying challenges in Kenya's healthcare system, as well as societal patterns that are unrelated to cancer, strongly influence the experience of those affected by cancer. These issues cannot be addressed with disease- or patient focused campaigns or communication materials alone. The absence of universal health coverage, for example, means that there is a lack of access to healthcare for a large part of the population, especially for diseases like cancer that are expensive to treat. For those who find ways to pay for the treatment, there are still shortages of equipment and specialists, resulting in long waiting times and increased costs. This extends to the added time and expense related to travel and accommodation, which result in more stress with potentially negative health outcomes. Another challenge in Kenya is an absence of regulation for the pricing of drugs and treatments, which results in large variations between service providers and a lack of predictability.


RIMACTANE for optimal T.B. therapy cuts both time and costs
ARI
2007
JANUARY
FEBRUARY

4

Conclusions

This KAP study provides rich insight into the reality of those affected by cancer in Kenya. Many of the findings confirm what stakeholders and experts already knew, including: being a cancer patient in Kenya is extraordinarily challenging, the financial burden is often overwhelming, social stigma around cancer is a problem, and substantial social and structural improvements are necessary to improve the lives of cancer patients and their families.

For the general population, five priority areas for a community education strategy for cancer awareness emerged:

1. Increasing the perceived susceptibility of cancer in the population,
2. Increasing the perceived severity of cancer symptoms
3. Decreasing the fear of cancer screening,
4. Reducing stigma associated with a presumed "death verdict" of cancer patients, and
5. Making risk factors of cancer (e.g., unhealthy eating, tobacco, alcohol consumption) more salient in promoting a healthy lifestyle.

The household survey found stark differences in perceived cancer susceptibility, lifestyle-related risk factors and preferences in media use. The analysis found that in addition to the five priority areas, there is need to focus on outreach to rural Kenya and to target messages based on setting, gender, age and county.

The in-depth interviews were designed to probe deeper and to better understand the reality and needs of cancer patients and caregivers. The results showed that while many of their challenges cannot be addressed with communication alone, they would greatly benefit from practical information related to financing, treatment, nutrition, pharmacies and drug prices, hospital navigation and low-cost accommodation. There was very little knowledge among patients about support groups, free activities, and benefits provided by cancer support organisations. Making this information accessible to all cancer patients in Kenya immediately upon their diagnosis, along with messages that help patients cope with their illness and its social repercussions, would be a great improvement. It is probable that if the various cancer organisations in Kenya combined their efforts for communication and information with that goal in mind, they could have a transformative impact.

Both the general population and those affected by cancer preferred interpersonal communication to disseminate cancer awareness information. There was a repeated and emphatic call to include cancer-related messages in the schools, churches, chief barazas, and health outreach campaigns aimed at the general population. For patients, the waiting area for treatment was identified as an ideal opportunity for interpersonal communication.

Doctor-patient communication at the time of the diagnosis was identified as a critical weakness in focus groups with cancer patients and survivors. There is a need for doctors to enhance their knowledge and skills about communicating a difficult diagnosis. Doctors should be the ones informing the patient about diagnosis in a clear and understandable manner, and offer assistance to the patient at the outset.

Outside the domain of communication and information, three additional priority intervention areas to improve the situation for cancer patients were identified:

6. Supporting initiatives to achieve universal health coverage so that catastrophic health expenditures can be reduced and eliminated;
7. Strengthening efforts to set up and maintain more cancer support groups for patients with different types of cancer in more regions of Kenya, so that all patients have an opportunity to join a support group; and
8. Increasing the cancer diagnostic capacity of health professionals across the country, which involves the development of curricula and integration of cancer-related modules in pre-service and in-service training.

Since the adoption of the 2011-2016 National Cancer Control Strategy, the cancer control community in Kenya has taken concrete steps toward implementation. The National Cancer Institute of Kenya was formally established in 2012. In 2014, national cancer control stakeholders gathered in Naivasha to identify cancer control and research priorities, opportunities and synergies. Four priority areas of action, or "tracks" emerged from this meeting, each organized under different working groups: Track I, Clinical research and capacity building; Track II, Cancer registries and pathology; Track III, Cancer awareness, community engagement and stigma; and Track IV, National health care systems / infrastructure, delivery and access to care. More specifically, Track III also aimed to "understand cultural beliefs and identify key drivers to stigma through community leader engagement and KAP assessments". It is our hope that the results of this KAP study will be used to strengthen these efforts.