Access to Cancer Care in Kenya: Patients', Survivors', Caregivers' and Health Providers' Perspectives

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Project acronym: ICCA [Innovation for Cancer Care in Africa]







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Access to health care remains a complex notion with varying interpretations and no universally accepted definition. At least half of the world's population lacks access to essential health services. The literature identifies "6As" dimensions of Access: Accessibility, Affordability, Availability, Adequacy /Appropriateness, Acceptability and Approachability. This paper employs these dimensions in documenting factors that were found to influence access to cancer care in Kenya.

Health and Industry studies were conducted sequentially. The health part of the study reported in this working paper, employed a convergent parallel mixed methods study design which was undertaken in three counties of Meru, Nairobi and Mombasa. A total of 405 patients were interviewed in public sector health facilities, four focus group discussions with cancer survivors and 22 in-depth interviews with caregivers, health workers and policy makers held.

Affordability of cancer services was enabled largely by cash payment with incremental use of National Hospital Insurance Fund (NHIF) from entry in health care up to the first treatment, but the high costs of cancer services were a major challenge. Payments for tests, treatment and indirect costs including transport and accommodation potentially impoverished many patients and their families as well as social networks . Facilities were financially supported by County Government funding, business and non-profit partners, and collaborations between health facilities to reduce indirect costs for the patients. Approachability was facilitated by community outreach services, local networks, awareness and knowledge promotion. However, better linkage between the community and health facility was required, especially for screening services. Availability: 30% of survey participants indicated that something they needed at the health facility was unavailable. The missing items included: medication, tests, treatment therapies, pain relief and essential commodities. Qualitative findings identified additional requirements including oncology staff and equipment. Patients also considered aspects of care that were unacceptable, and mentioned fear, stigma, cultural influences, religious and alternative beliefs. Nonetheless, having information and support from family, friends and other patient's facilitated acceptability of cancer services. Accessibility in terms of distance and time to reach cancer care services located at national referral facilities county or was reported as a challenge for many. Communication, including lack of clarity, mis-diagnosis and non-disclosure of relevant information emerged as an appropriateness concern.

It is important to note that the six access dimensions interact and therefore, may not be addressed separately. When these aspects of access to cancer care are facilitated, then access can be improved. Hence, a holistic health system approach to access is desirable, while emphasis should be put on enhancing diagnostic capabilities at lower levels of care in line with the objective of Universal Health Coverage. Mutually supportive interventions to strengthen access can include wider insurance coverage, extended staffing and improved information. When challenges to any of the access dimensions remain, then access to cancer care is undermined.





INTRODUCTION

This Working Paper presents key findings on access to cancer care from a research project funded by the UK Economic and Social Research Council. It is a collaborative research study conducted in Kenya by the Kenya Medical Research Institute (KEMRI). The research study forms part of a larger project, Innovation for Cancer Care in Africa (ICCA)¹. A collaboration between research teams in Kenya, Tanzania, India and the UK, the broader research project sought to demonstrate the scope for linking industrial and health sector innovation to improve cancer care in East Africa. The objective of the study in Kenya included establishment of practical scenarios that can link innovation in industry and health sectors to widen access to cancer care in Kenya.

BACKGROUND: DIMENSIONS OF ACCESS

Concepts of access

Health care systems around the world are key to promoting health, hence access to healthcare services is central to their performance [1]. Access to health care remains a complex notion as exemplified by the varying interpretations of the concept across authors [1,2]. Some authors have further documented a variety of characteristics of access [2,3,4].

At least half of the world's population lacks access to essential health services. Access levels to health care vary widely from country to country, and even within countries. Access to healthcare is a multidimensional challenge and there is no "one size fits all" solution [5,6]. Improving one aspect of healthcare is often not enough. For example, improving access to a hospital for a cancer patient is only beneficial if there are trained oncologists and nurses on hand with the necessary equipment, medicines and related commodities. Similarly, improving access to a diagnostic test for a disease is only effective if it is accompanied by the relevant awareness in the community and skills and expertise among the healthcare givers. When it comes to the more complex treatments, such as those used for cancer, the level of sophistication required for successful treatment, whether for diagnosis, specialized training or hospital infrastructure, becomes even more pronounced [5].

To date, there is no universally accepted definition of access. It has been defined as the timely use of services according to need and includes the right or opportunity to reach, use or visit facilities and services [1,2,7]. Utilization of health care is often used as an operational proxy for access to health care [7]. Some of the identified dimensions of access in the literature include: availability of services, geographical accessibility, affordability and acceptability. Barriers to accessing health services can stem from the demand side and or the supply side. Demand-side determinants are factors influencing the ability to use health services at individual, household or community level, while supply-side determinants are aspects inherent to the health system that

¹ ICCA website: <u>https://www.open.ac.uk/researchprojects/innovation-cancer-care-africa/</u>





facilitate or hinder service uptake by individuals, households or the community [8, 9]. Access is a complex concept and at least four aspects require evaluation. If services are available and there is an adequate supply of services, then the opportunity to obtain health care exists, and a population may have access to services. The extent to which a population gains access also depends on financial, organizational and social or cultural barriers that limit the utilization of services. Thus, access measured in terms of utilization is dependent on the affordability, physical accessibility and acceptability of services and not merely adequacy of supply. Services available must be relevant and effective if the population is to gain access to satisfactory health outcomes. The availability of services, and barriers to access, have to be considered in the context of the differing perspectives, health needs and material and cultural settings of diverse groups in society [6].

Cancer : Access barriers and facilitators

Cancer has remained a leading cause of disease burden globally with the Globocan 2020 reporting an incidence of 19.3 Million new cases and 10 Million deaths in 2020. The low income countries bear the largest burden with a rising mortality seen in most of these countries. In Kenya, the Globocan data ranks cancer Third as the cause of mortality after infectious and cardiovascular diseases with an incidence of 42,116 new cases diagnosed and 27,092 patients dying in 2020 [10]

Health knowledge has a vital impact on cancer prevention and health outcomes. Patients' knowledge influences their ability to actively participate in the decision-making processes for medical care and treatment choices, and their ability to manage their condition to improve medical outcomes. A general understanding of disease and stage is crucial for cancer treatment decision-making and adherence. Furthermore, knowledge about cancer diagnosis and treatment is a key reason for variation in survival [11]. Access to population based primary prevention early detection, quality diagnostics, treatment and palliative care services remains the goal of the Kenya National cancer control strategy 2018-2020 [12]

Research shows that lack of awareness and knowledge about risk factors, and also about prevention of cervical cancer among women, affect service utilization [13]. Other influences are age, marital status, socio- economic status, cultural and religious beliefs. Stigma attached to discussing reproductive health issues in some communities has been shown to limit young women's awareness of some types of cancer. Understanding individual, community and health system barriers that hinder utilization of cancer prevention services is crucial in designing effective cancer control programs in low- and middle-income countries [13].

Factors that influence low screening rates, late presentation and utilization include limited availability of screening services and barriers to screening uptake such as inadequate knowledge of screening tests [14, 15, 16]. Other factors include stigma associated with the





disease [15] including: traditions, fear of partner abandonment and embarrassment, all of which hinder disclosing symptoms to healthcare professionals [17]. Evidently, the lack of screening and treatment facilities combined with poverty, poor follow-up, and lack of trained personnel, unaffordable treatments in combination with socio-economic and cultural factors which all operate within an ill-structured health-care system are a major hindrance to access to cancer care [18]. The importance of diagnosing cancer early for survival cannot be overstated, whereby delayed diagnosis of cancer patients in LMICs results in higher care costs compared to if diagnosed earlier. Cancer treatment costs can be reduced through early detection and intervention [19, 20].

Access as applied in this paper

This paper assembles the research findings under the six categories of access widely used in the literature. It then reflects on understandings of access drawn from these findings, and draws out some recommendations for policy. Access as discussed in literature range from four to six dimensions, including: accessibility, affordability, availability, adequacy/appropriateness, acceptability and approachability ("6As"). Accessibility is basically the ease with which the patient can reach the provider's location and includes factors such as geographical accessibility for patients within a timely manner. Affordability implies the willingness and ability of the patient to pay for the providers' charges. It entails direct costs of treatment, as well as indirect costs such as loss of livelihood, aspects of insurance and other ways that people pay for treatment. Examples of the availability of the requisite resources by the provider include personnel with suitable training, technology, equipment, and medication to meet the needs of the patient. Adeguacy/appropriateness refer to the extent to which quality care is available that fits patients' needs. It relates to the appropriateness i.e.the type and quality of services and the manner in which they are provided and how integrated and continuous. Acceptability looks at how acceptable the services or treatment are to the patient. This is often shaped by factors including culture, gender and access to information. These factors are said to determine to a large extent the possibility of people accepting the aspects of the service (e.g. the sex or social group of providers, the beliefs associated to systems of medicine) and the judged appropriateness for the persons to seek care. Finally the approachability element requires that people with health needs can identify that services exist and can be reached It applies to questions about patient knowledge and beliefs, outreach and transparency and information from health providers. [2,3.4].





METHODOLOGY

Study design

The ICCA-Kenya study employed an explanatory sequential mixed methods design [21] to conduct both health and industrial data collection. This paper presents primary data findings from the health facility-based research, which was conducted concurrently, hence a convergent parallel mixed methods study design [19] was applied.

Study Area and Sites

The health research data collection was conducted among selected individuals in three counties: Meru, Mombasa and Nairobi. These counties were chosen due to the high burden of cancer, as recorded in the regional cancer registries, and the perceived varying levels of accessibility of cancer care. At the county levels, public health facilities that provide cancer care were targeted. These included a level six hospital (Kenyatta National Hospital- facility 001), and level five hospitals at the other two counties (Meru level 5 hospital- facility 002 and Coast teaching and referral hospital;- facility 003). In addition a lower level facility was sampled (health centre) in Meru County as was advised by emerging qualitative data.

Patients Survey

The quantitative part of the study comprised a facility-based patient's survey. The survey tools embedded open-ended questions to explore patients' pathways and personal perceptions along their cancer care journey, and included socio-economic detail. The survey tool was digitized into a mobile data collection application (ODK) and data collection was done by use of mobile phones and tablets.

The study had a total estimated sample size of 422 participants which was then proportionately distributed among the three participating facilities as guided by the volume of cancer patients within each facility. Recruitment of study participants was done from the three participating facilities. Health facility booking lists were used to systematically select the potential participants within each health facility. The criteria for selecting participants was: those above 18 years of age, consented to partake in the study and were not too ill to respond to the questionnaire . All completed tools were examined for completeness by the team leaders at the end of each day before onward transmission to a central server for storage and data analysis.

Data management included cleaning and analysis of the open ended section of the patients' pathways data. Deeper analysis of the qualitative survey data was undertaken by selecting a subset of 214 patients for further analysis of themes. The subset was shared between team members. After familiarization with the pathways data, a set of themes was developed collaboratively, addressing the objectives of the project. Evidence from each patient in this subset was summarised by a team member under headings that attempted to separate patients' decision making from facility characteristics and responses. Themes on the patients' side





included: reasons for delay; reasons for re-entry after temporary drop-out or delay; use of alternative treatments; referrals and self-referrals; out of pocket spending and sources of financial support and/or insurance coverage. On the facility side the themes extracted were: human resource and other capacity constraints; constraints relating to consumables and drugs; constraints relating to diagnostic imaging and laboratory testing capacity; and interaction with the private sector for example, out-sourcing diagnostic testing. This set of data was analysed using NVivo11, and these themes are used here to identify key facilitators and constraints on access.

Qualitative study

The qualitative health data sets emanate from in-depth interviews with key informants drawn from the selected counties and National government offices and some key advocacy groups. These were: health workers (including; oncology doctors, oncology nurses, pharmacists, nurses, clinical officers, community health worker), caregivers, policy makers in health and palliative care. Focus group discussions were also conducted with cancer survivors in all three counties. In-depth interviews were conducted at selected venues where the informants felt comfortable, for example at their offices in hospitals or other hospital spaces. A total of 22 in-depth interviews were conducted as shown in **Table 1.** Focus group discussions were conducted at convenient spaces/ rooms in the health facilities or within facility catchment areas. A total of four focus group discussions were conducted in all the three counties.

Category				Total		
	Level 3	Level 5 Meru	Level 5 Mombasa	Level 6 Nairobi	IDI	FGD
Oncologist Doctor (Public)		1		1	2	
Oncologist Doctor (Private)				1	1	
Oncologist Nurse				1	1	
Palliative Nurse		1		1	2	
Nurse	1		1		2	
Pharmacists		1	1	1	3	
Clinical officers			1		1	
Community Health Volunteer		1			1	
Caregivers		2	2	2	6	
Policy makers		1		2	3	
Focus group Discussion		1 (7 Participants)	1 (7 Participants)	2 (15 participants)		4 (29 Participants)

Table 1. Study participants [IDIs and FGDs]

Data was collected using audio recorders, anonymized and backed up for safe keeping. The data was prepared for transcription and translation to English in the case where interviews were conducted in the local dialect or in Kiswahili, especially among the caregivers and cancer





survivors. A team of three transcribers were responsible for the transcription of the audiorecorded data. This process entailed verbatim transcription of the recordings followed by translation of the data into English. The transcripts were written in MS Word and cleaning was done alongside familiarization with the data.

In order to increase the reliability of the findings, the scripts were shared with the research team members who were divided into two groups consisting of two members each to read through, identify and extract information related to the access dimensions in cancer care. Thematic analysis was applied with the six access dimensions (6As) described earlier forming the main themes.

Ethical aspects

Ethical approvals were obtained from institutional ethics review boards at the Kenya Medical Research Institute (KEMRI) Scientific and Ethical Review Unit and Kenyatta National Hospital. Other permits included NACOSTI and written permission obtained from the Ministry of Health in the study Counties. The study participants were also taken through an individualised consenting process for participation in the survey, the focus group discussions or in-depth interviews. The broader project was approved by the Human Research Ethics Committee of the Open University, UK.

STUDY FINDINGS

Survey patients' characteristics

Total respondents were 405 out of the 412 sampled, giving an overall response rate of 98.3%. The socio-demographic characteristics of the facility survey participants are summarised in Table 2.The distribution of participants in Nairobi, Mombasa and Meru was (61.2%), (21%) and (17.8%) respectively. Over two thirds (67.7%) of the participants were female; a majority of respondents (63.2%) were married. Economic activities declared were varied, with small scale farming being the most common source of income at 20.1%. Income levels were low, 91.4% of the participants reporting a combined monthly household income of less than KES25,000 [USD 227], and 65% earned less than KES10,000 [USD 91].

Variables	n=405	%	Variables	n=405	%
County of survey			Source of income		
Nairobi	248	61.2	Small Scale farming	81	20.1
Mombasa	85	21.0	Small business/self-employed	79	19.6
Meru	72	17.8	Casual/informal labour	61	15.1
Gender of the patient			Farming and selling produce	57	14.1

Table 2: Socio-demographic characteristics of the facility survey participants





					In Search of L
Female	274	67.7	Relatives/remittances	49	12.2
Male	131	32.3	Formal employment	37	9.2
Marital status			Petty trade (reja reja)	23	5.7
Married	256	63.2	Others	10	2.5
Single	59	14.6	Welfare/NGO support	6	1.5
Widowed	51	12.6	Income band of the household (KE	S/month)	
Divorced/ Separated	39	9.6	No income	21	5.5
Age groups			Less than 10,000	228	59.5
≤ 25	21	5.2	10,001 – 25,000	101	26.4
26 – 35	52	12.8	25,001 - 40,000	25	6.5
36 – 45	108	26.7	40,001 – 55,000	3	0.8
46 - 55	92	22.7	55,001 – 75,000	4	1
56 - 65	75	18.5	Above 75,001	1	0.3
≥ 65	57	14.1	Religion of the patient		
Occupation of the patient			Christian	382	94.3
Farmer	115	28.4	Muslim	22	5.4
Business	81	20	Traditionalist	1	0.3
Casual Worker	66	16.3	Who the patient lives with		
Employed/Professional	42	10.4	Immediate family	351	87.3
Housewife	23	5.7	Live alone	25	6.2
Fishing	22	5.4	Other relatives	20	5
Unable to work	18	4.4	Friends/Non relatives	6	1.5
Unemployed	16	4			
Retired	12	3			
Student	10	2.5			

EXPERIENCED DIMENSIONS OF ACCESS

The following sections describe access findings from both qualitative and survey health data sets where relevant:

Affordability

Affordability appeared in study findings as an important dimension of access, presenting many challenges for patients, carers and professionals. This section presents participants' explanations of how patients and facilities cater for costs of cancer care (screening, diagnosis, treatment and survivorship), including both direct and indirect costs.





The expense of cancer care services

Generally, cancer care services were described and experienced by the study participants as expensive at all levels of the cancer care spectrum: screening, diagnosis, treatment, and survivorship. A health worker expressed the need to reduce costs for cancer patients:

"...to make it affordable because it's expensive...the screening, the treatment, the investigation the diagnosis, everything is expensive to them and these people are poor". (Health worker, Meru)

Costs of diagnostic tests

Costs of diagnostic tests were a particular challenge. Table 3 shows the costs reported by patients of the range of diagnostic tests relevant to cancer diagnosis, for each event for which the patient could recall the costs. The number (n) is the number of events where this cost was recalled. The table shows the distribution of costs for each type of test (the first and third quartile and the median), since the variation was considerable. So for example, the median cost of a biopsy was KES 5000; however, a quarter of patients paid KES 14,500 or more (Table 3). Imaging, such as CT scanning and MRI, was particularly expensive (Table 3).

	n	25th ^a	Median	75th ^b	Mean (std)	
Cost of tests in Kshs.						
Biopsy	12	3750	5000	14500	9708 (9561)	
Lab test	30	2100	2750	4500	6316 (12876)	
MRI	2	15000	15000	15000	15000 (na)	
Mammogram	3	2000	2000	4750	2916 (1587)	
Ultrasound	16	1800	2000	2530	2147 (704)	
CT Scan	17	8000	8000	15000	10882 (4109)	
X-ray	5	800	1000	1000	920 (109)	
Endoscopy	1	6500	6500	6500	6500 (na)	
Barium Swallow	2	4500	4500	4500	4500 (na)	
n=number of subjects who received the service and paid.						
a= 25th percentile of the service cost, b= 75th percentile of the service cost.						
std= Standard deviation of the service cost.						
na = not applicable.						

Table 3: Costs of diagnostic tests

These are substantial sums for patients to find, especially since many tests were repeated in search of diagnosis. The qualitative interviews and discussions emphasized the expense of these test, and the late presentation that this could cause, as indicated by the following quotes.

"...But even for a patient who cannot afford, 4500 for a lab test, it is a mountain" (Health worker, Meru)





"... We know laboratory tests are not cheap, doing a biopsy might cost a couple of shillings, to be able to do. Doing images for us to be able to stage² patients including CT scans, MRI, Ultrasound, be it even chest x-ray also costs money, so all these are coupled with the patients' economic disadvantage makes them present late..." (Health worker, Nairobi)

"The cost of tests to be done for diagnosis were too expensive" Male patient 74 Nairobi "The surgeon asked for tests including ultrasound of the prostate, colonoscopy, blood tests, rectal examination. I was told to do the tests in (a level six private hospital...) went home to look for money". (Male patient, age 80, Nairobi)

Treatment costs

Treatment costs were also said to be expensive. There is relatively little detail on treatment costs, since treatments were also covered by NHIF, and patients were at different stages of treatment when interviewed. However, Table 4 illustrates the reported costs of surgery, chemotherapy, and radiotherapy, and therefore the importance of insurance cover to aid in payment of these treatments' options.

Table 4 . Reported payments for treatments (KES)

	n	25th ^a	Media n	75th⁵	Mean (std)	
Treatments						
Brachytherapy	1	30000	30000	30000	30000 (na)	
Chemotherapy	9	10000	13800 0	36000 0	222922 (277430)	
Chemotherapy & Radiotherapy	1	18000	18000	18000	18000 (na)	
Injection	2	800	1100	1400	1100 (300)	
Mastectomy	1	11000 0	11000 0	11000 0	110000 (na)	
Radiotherapy	14	12500	90500	10000 0	67264 (45649)	
Surgery	1	15000 0	15000 0	15000 0	150000 (na)	
n=number of subjects who received the treatment and paid.						
a= 25th percentile of the treatment cost, b= 75th percentile of the treatment cost						
std= Standard deviation of the treatment cost						
na = not applicable						

Findings from the qualitative study expressed and confirmed the difficulty patients experienced in payments of treatment due to high costs tied to these services

² To stage a patient is to establish the stage to which the cancer has progressed.





... There is one chemo that I know which is very expensive, which is 700,000 it is called rituximab, I usually see on the approval, in fact before they issue in the pharmacy they should be very sure that NHIF has approved (Health worker, Nairobi).

"...for some patients that I have seen they actually have to pay more than three hundred or four hundred thousand every 3 weeks, so that is quite high for most of our patients unless you have quite a good insurance, yes. (Health worker, Nairobi)

"It reached a point I had no money to continue with chemotherapy treatment. I used to buy the drugs." (Male patient age 50 Nairobi)

"I did not have money to follow up treatment after being referred to (Public, level 6 hospital). (Male patient, age 70, Nairobi)

"I was expecting maybe I might get financial support but I wasn't given any. I also was prescribed pain medication at a private wing of a public level 6 but I could not afford it." (Female patient age 41 Nairobi)

"The results showed that I had bladder cancer stage 1. I was told to start on chemotherapy. I was booked for the therapy. But I stayed [waited] for two months as I was looking for money to start on chemotherapy." (Male patient, age 44, Mombasa)

"There were a lot of delays in initiation of treatment. We faced a lot of financial challenges because not all drugs were available...we had to get into our pockets to pay for them. The tests done were so many and costly. (Female patient age 56 Nairobi)

Those patients who could afford however, were compelled to seek services in private hospitals. '...we went to a public facility level six and we stayed for like 2 months, just looking for ways of entering the place. Since this facility normally has so many people, we were told that we will be called. We followed the line, and we were told we would be called. That is compulsory. I wanted it to be faster, my mum to feel well so that we can go back home. So, we went to ... [a private hospital in Nairobi].' (Caregiver, Meru)

Cancer Screening services

All services within the cancer care spectrum were experienced as expensive and this included cancer screening services that are critical for cancer prevention.

'People are encouraged to go for screening but when they start enquiring you are told you have to pay x amount or y amount and a lot of them just shy away from it because of the cost. I can do a lot more with that money. I have children to feed, I have this, and I have other costs.' (Cancer survivor, Nairobi)

Cancer Survivorship

Discussions with cancer survivors illustrated that affordability challenges continued after patients finished treatment for cancer. Such costs included rehabilitative commodities, such as colostomy bags, that were required by some patients.





"When you are sick, someone is taking care of you... but now they look at you, they say 'si alishapona?' [Meaning 'didn't she/he get well?']. You know when you are sick they can fundraise for you, they can take you to hospital but the moment the disease is not there, you sort yourself." (Cancer survivor, Nairobi)

Indirect Costs

Treatment could be delayed or stopped also because of indirect costs such as transport and accommodation.

"We see patients who do not even have transport to come to the hospital to be seen, let alone being able to pay for the investigations... (Health worker, Nairobi)

"... People don't finish radiotherapy courses as they have challenges with accommodation". (Health Worker, Meru)

This was also the case regarding accessing outreach and screening services:

'And you see most people where they are, sometimes transport, coming to hospital is also an issue...those who are actually coming are the ones who can actually afford to have that fare to come to the hospital. There are others who want to come but they don't have the fare.'(Health worker, Mombasa)

Payment modes

Cash Payments

A high proportion of care was paid for in cash, from patients' or others' pockets as indicated in Figure 1. Affordability of this type of expense for particular patients, when not covered by insurance, depends on several factors: their income, their scope for fundraising, and the cumulative cost that they incur, that is, whether they run out of funds at some point in their pathway. Figure 1 shows the mode of payment at particular milestones for cancer patients: their first visit (entry into health care); their initial tests for cancer (entry into cancer care), their diagnosis, and their first treatments.

Figure 1 shows the dominance of cash payment for cancer care across the patients' pathways, including the services accessed while seeking diagnosis. It also illustrates how the mode of payment changed for these patients at the different milestones in their pathways to treatment with a sharp increase in insurance use at first treatment. Patients were asked to describe their pathways to diagnosis and treatment, event by event. Figure 1 shows, at each of a set of significant events, the mode of payment used for each non-zero payment A patient may have used more than one method of payment at any milestone (for example, insurance may have covered an element, and out-of-pocket (OOP) payment the rest) so at each event, the percentage of each type of payment may add to more than 100.







Mode of	Entry into	Entry into		1st
payment	health care	cancer care	Diagnosis	treatment
Cash	93	90	91	71
NHIF	9	16	18	56
Other				
insurance	0	1	1	2
Other*	1	1	1	1



Figure 1 indicates the milestones to cancer diagnosis and treatment that were reached as the patients experienced more and more events (symptoms and actions). Up to the point of entry into the healthcare system, a patient may not have experienced many events and even the severity of the events might not be very alarming. As a result, the patients may have visited a healthcare facility for treatment of the event (e.g. fatigue, pain etc).

As the events multiply, the patient may achieve the next milestone while on symptoms management, possibly, because the symptoms were getting severe. As a result, NHIF starts being utilized somewhat more and the relative use of cash reduces (possibly because the patients are getting treatment from higher levels of healthcare which are NHIF accredited and the severity of the symptom is payable by NHIF). Cancer diagnosis is a key milestone and early diagnosis is in the interest of the patient.

As the cancer gets diagnosed and treatment is started, sharply more of the patients had utilized NHIF. The use of cash fell relatively to insurance, but cash payment remained widespread. Only 1% of patients had used other insurance at these later milestones. However, most people in the Kenyan population do not have an insurance cover. Many patients had paid some money by cash and the rest by NHIF. Recorded waivers and sponsorship were only 1% of the totals.





Affordability – and notably access to insurance – are therefore important factors in determining access.

Milestones	Ν	1 st quartile*	Median	3 rd quartile*	Mean
Cumulative out of				•	
pocket cost					
Entry into Health care	333	350	1,500	4,500	6,578
Entry into Cancer care	315	3,150	8,450	20,300	26,588
Diagnosis of cancer	302	8,920	19,425	39,500	44,925
First treatment	122	34,300	69 <i>,</i> 850	112,850	130,184
Cumulative Indirect cost					
Entry into Health care	397	60	200	500	510
Entry into Cancer care	401	300	800	2,300	2,111
Diagnosis of cancer	400	800	1,925	5,550	4,419
First treatment	313	2,000	4,800	10,500	8,640
Cumulative Insurance					
cost					
Entry into Health care	13	1000	1,500	9,000	47,958
Entry into Cancer care	23	2500	10,000	30,000	38,887
Diagnosis of cancer	25	7500	17,700	30,000	49,358
First treatment	68	13,000	28,700	68,288	50,560

Table 5. Cumulative expenditure up to a particular milestone, by patient (KES) and type of expenditure

Notes: N: number of patients recalling at least 70% of OOP payments; number of patients recalling at least 70% of indirect payments; number of patients able to provide details of some insurance payments made on their behalf.

*25th percentile of the expenditure, **75th percentile of the expenditure

Table 5 shows that the median expenditure by patients who made out of pocket payments up to and including their first health facility visit was KES 1,500. The table also shows the wide distribution of these payments across patients. By the time they reached a cancer diagnosis, these patients had spent out-of-pocket a median of KES 19,425; a quarter had spent KES 39,500 or more. By the time patients reached first treatment, median OOP spending had risen to KES 69,850 and a quarter of patients had spent KES112,850 or more. In addition, patients had made cumulative indirect expenditures such as transport and accommodation. By diagnosis, the median indirect expenditure was KES 1,925 and by first treatment, when more travelling may have been required his had risen to KES 5,550.

Some patients – but only small numbers, see "N" – were aware of the cost to insurers of their care. The final four rows show these cumulative reported insurance payments (mainly NHIF payments) up to each milestone, but care in interpretation is required given the small numbers of patients able to report these data. These figures greatly understate insurance costs of cancer treatment.





Qualitative findings from focus group discussions and in-depth interviews concur with the findings on cash payment, as cash was said to be the main payment mode for cancer services. This was often facilitated by fundraising from family, friends and other acquaintances, and selling property.

Fundraising was said to have enabled, and still to enable many patients to manage cancer care costs:

"...I had friends, like my college mates who formed WhatsApp groups and they fundraised and my colleagues also sent the contributions to me. So that is how I survived, and I used approximately like around 400,000 to 500,000 around there" (Cancer survivors, Meru).

Fundraising however does come with its own challenges and was sometimes seen as a burden where social relationships are affected and some patients abandoned by family due to financial burden.

When asked about support from friends, the following was the responses-

"Especially on the side of finances, that one, they run away, because of the burden, the patient has to be brought daily." (Health worker, Nairobi)

"I feel like it is just disturbing them, there is no other support...Even if they know it is very difficult, the problem is yours and your family." (Health worker, Nairobi)

Selling property was also common, and could be very detrimental to the family.

"Many people have sold a lot of things at home. When you get cancer, you and your family will get poor". (Health worker, Meru)

National Hospital Insurance Fund payment method

The existence of NHIF was described as a major facilitator of cancer care, allowing cancer patients to afford care as presented below:

"NHIF Reduces cost of treatment in comparison with pre-NHIF costs". (Cancer survivors, Meru)

"It is very much affordable because we have actually introduced most of our patients to this NHIF, the insurance thing, so most of our patients are covered with NHIF, so with NHIF they are able to cater for everything including the surgery, the investigations and everything plus if need be chemotherapy, they are okay." (Health worker, Mombasa)

The survey findings presented in Figure 1 indicated that about 9% of patients had made payments at entry into formal health care through NHIF, and more (25%) of patients had made payments at first treatment by NHIF, enabling patents to afford the treatment expenses.

Qualitative findings concur with the survey finding that most patients when they first seek cancer care services at the health facilities often do not have the NHIF cover. However, the health workers help them on board as expressed by the following quote

"If you come and you are diagnosed with cancer, the first thing we tell them is to have an NHIF card, because we do educate them that the process is long and it is expensive, and you cannot always be paying cash. You can pay for six months, but we educate them so





that when they start on radiotherapy and chemotherapy, they can be using NHIF so that by second session it would have matured. It matures in a very short time.' (Health worker, Meru)

A health worker explained that with NHIF, the patients are admitted at the hospitals to make it easier and affordable with NHIF which covers all the inpatient costs at the hospital

"...Most of our patients, actually they have NHIF, because they are of low social economic status, so mostly they use NHIF, go through authorization of NHIF then the CT scans, X rays, are just done as inpatient" (Health worker, Nairobi)

Having the NHIF caters for care at both public and private hospitals making it easier for the patients:

"NHIF is also accepted at some private facilities, so even if the CT machine is broken at this facility, one can still use cover when sent elsewhere" (Health worker, Nairobi)

'We are a private hospital not for profit but obviously you know, but despite that we have a lot of mix population because we have a very robust welfare, patient welfare system. And then NHIF is also very supportive, with all that happening I think we have a mix of clients, we have very poor patients as well who cannot afford anything but are provided everything from either hospital or NHIF and we have very high end clients as well. But in general if you ask me we have a good mix of everyone.' (Health worker, Nairobi)

NHIF was also seen to come with a number of limitations as expressed in Table 6.³

Table 5. Challenges faced with use of the NHIF

Most patients don't have NHIF	"many patients don't have NHIFand from statistics we know thatit is only 15 percent of patients who have NHIF cover despite being as low as 6000, so we see patients who present very late and like statistics out there show 80% of patients present to the hospital with advanced disease" (Health worker, Nairobi).
Approval/Ti me Delays by NHIF	1. " NHIF had so many delays. One had to follow up so closely for them to approve the treatment." (Female patient age 56 Nairobi)
	A study participant expressed that she did not have an NHIF cover and so was advised to wait until its maturity by the doctor. This was because they could not afford the costs of surgery (Male patient, age 55, Meru)
	A patient informed that chemotherapy cycles for her started late as she was awaiting NHIF to be active in order to cover the cost of chemotherapy (Female patient, age 37 Meru)

³ As in the main text: italics show verbatim speech; non-italic text is interviewer summary.





	" You must have money to do the tests because if you rely on NHIF, yes they will pay for you but it will take some time, so it makes the process of diagnosis slow even to start on treatment. So you have to look for cash if you really want to get the diagnosis on time and to be started on treatment. So I had to pay for all those tests, it was expensive." (Caregiver, Mombasa)
NHIF doesn't cover all costs leading to treatment interruption	'if you are going to get cancer treatment, don't think NHIF is going to pay everything, NHIF is going to support you like 50 or 40 per cent, but what about the other percentage? Like me now, if I go to the hospital I need to have 650 shillings' consultancy, I went there maybe we need blood count, I need to pay. Me personally I didn't finish my chemo, why? Because I never had the money for blood count.' (Cancer survivors, Meru)
S	"sometimes there are tests that you go for, for instance MRI, when you go a Private facility, level six they tell you it is 35,000 and NHIF pays for you 15,000 so 25,000 has to come out of out of your pocket. Getting that money is a challenge, and that is why there is a delay (Cancer survivors, Mombasa)
	"Sometimes we get challenges because you hear patients say NHIF cover is finished and then now the patient is stranded and doesn't know what to do, those are some of the challenges. Maybe they should look into that cover, maybe to expand it, something like that." (Health worker, Mombasa) A patient said they were in the middle of chemotherapy but NHIF exhausted:
	catering for the medical costs of chemotherapy". (Male age 50 Nairobi)
NHIF would cater for oversea s expenses but not any more	"Like when I went to Bangalore in India, there was a patient with prostate and when he went to his doctor, he was told to go to Bangalore in India. And before that, you were given NHIF and the headquarters paid that country but these days the doctors have refused. (Cancer survivors, Meru)

A majority of our study participants and informants expressed that in one way or another even with the NHIF, they find themselves having to pay cash for some things. This has had an impact on families as the disease is now associated with: poverty, treatment adherence challenges when a treatment is skipped or delayed, and the disease is seen as a business as outlined in the following sections.

Cancer care cost associated with impoverishment

Many study participants expressed that cancer care was associated with poverty as it necessitates many to leave their work whether employed or self-employed, sell property, animals to generate cash.





"...that person needs to leave their family and you know, leave their businesses or their source of income behind and put up in Nairobi" (Health worker, Meru)

"Another challenge is when you get this cancer, you leave your work, and you become so poor. And when you become very poor even food at home becomes a challenge.' (Cancer survivor, Meru)

"Yes [there was something I did not get], I needed money to pay for treatment. All I had, pigs and cows, were sold to access treatment at X Medical Centre. By the time I came to public hospital level six, I had nothing to sell." (Male age 60 Nairobi)

"Many people have sold a lot of things at home. When you get cancer, you and your family will get poor." (Health worker, Meru)

*"I think if the government helps cancer patients, we will not die early. But if we sell our property, even our children will not have anything and it will be expensive". (*Cancer survivor, Meru)

As these quotations attest, cancer care payments are impoverishing. The lower the patients' incomes are, the greater their risk of impoverishment. We can measure that risk in several ways.

Our data from the patients' interviews include self-reported monthly household income (Table 2). Table 7 divides the households of the patients interviewed into four roughly equal income bands, from lowest to highest. Most households were on low incomes.

 Table 6. Median total OOP payments for cancer care compared to median annual household income of patients, by household income bands of patients.

Household income band (Ksh/month)	N*	Median total OOP payments	Median annual household income	Median burden of OOP payments (% annual income)
<3000	100	34,200	13,200	193%
3000 & <9000	107	34,300	72,000	47%
9000 & <15000	91	39,500	120,000	26%
15,000 upwards	90	43,775	240,000	14%

* Number of patients providing data for household income

Table 7 shows median cumulative OOP expenditure according to these four household income bands. Patients from the poorest 100 households interviewed are shown to have spent, shockingly, a median of 193% of their declared household income out of pocket on cancer care. Cancer payments can therefore impoverish already low income households.

Table 7 shows that the median burden of total OOP payments on household income was much lower for patients from households with higher incomes. Column 4 shows the median declared annual income of patients in each band, while the final column shows the median percentage burden of OOP payments, calculated for each household as total OOP payments divided by





declared annual household income. As income rises, the median percentage of annual income spent on cumulative OOP payments falls sharply. The OOP payments for cancer care are thus sharply regressive.

The survey data summarised in Figure 2 shows that there is a high risk of catastrophic health expenditure (CHE) among cancer patients and this risk was evidenced in all the study sites. CHE is now generally defined as expenditure on health greater than 10% of a household's budget (income or expenditure). On that definition, in 2015, 5% of all Kenyan households were found to fall into that category (<u>https://www.who.int/data/gho/data/themes/topics/financial-protection</u>). Among cancer patients interviewed, 82% had made catastrophic expenditure on this definition, having spent over 10% of their declared annual household income out-of-pocket on cancer care by the time we met them (Figure 2). Although this total spending had been made by some households over more than one year – creating an over-estimate of the annual burden – conversely, not all patients could remember all their spending, implying an underestimate.



Figure 2 throws into relief the catastrophic expense imposed by cancer.

Figure 2. Percentage of patients who had spent over 10% of annual household income on OOP cancer costs (catastrophic health expenditure)

Cancer care costs linked with availability associated with adherence to the treatment: It was expressed that cancer treatment therapies work best when fully adhered to. However, financial delays can affect the treatment adherence of the patient:

...treatment with chemotherapy is effective when there is adherence and the ability of drugs, but when there is a time when some people only depend on NHIF and there is





a time when we need some drugs, and they are out of stock. And when you ask them to buy for that cycle as they are waiting for the hospital to supply, they cannot afford it so they are passed like two or one month, the adherence is not consistent.' (Health worker, Meru)

*Cancer Perceived as a business*_partly due to the nature of the treatment – you have to have multiple tests to diagnose and plan treatment, so it's not a one off cost as expressed:

...when I first received news about my status—when I go elsewhere and talk about my cancer status people become afraid. They also say that cancer has become a business, because of the many tests that one has to undergo and therefore someone becomes overwhelmed because of financial (Cancer Survivor, Nairobi)

Facility aspects:

Some of the facilitators that enhance affordability of the cancer services at the health facilities as described by the study informants are: allocated funding from County and partners, and collaboration on treatment between health facilities and facilities networks.

<u>County Funding and partners providing funding to facilities:</u> Another facilitator for cancer care at facility level for some counties was the prioritization of cancer by the county in collaboration with some partners to put aside funds that would support activities at health facilities:

"The main source has been currently from the county as well as the facility improvement fund, but of late when AMPATH came in as a partner it's really been supporting us with some of the drugs".(Health worker, Meru)

<u>Collaboration on treatment between health facilities to reduce indirect costs.</u> Travel and accommodation in search for treatment can take a toll on some patients and sometimes impede the care process. However, with facilities collaborating to reduce these costs enables affordability of care

"Yes, because I come from Meru and Texas⁴ is far and you know I cannot go and rent a house in Nairobi because it is expensive. So I used to prefer Nyeri because I go and I get injected and I return home after the injection. But if you go to Texas, you will have to sleep there. You will sleep there then tomorrow you start the journey and that is a lot of expenses" (Cancer survivors, Meru)

Facilities' networks to support expenses: For those who cannot afford, sometimes health facilities try to work with other local institutions/networks to support patients

"Those who drop out of treatment due to accommodation costs are linked with a social worker who tries to help them find means and also with their church to see if there's any way in which the church can support them". (Health worker, Meru)

⁴ A private facility that offers cancer care services





Approachability

The findings in this section include efforts made by the health facilities to ensure that communities are able to identify services for cancer care [i.e. screening, diagnosis, treatment and palliative services] and some of the reasons or factors that facilitate or impede people's ability to identify the services provided as expressed by our study participants.

Facility efforts

<u>Outreach services:</u> health workers expressed that outreach services by the facilities are conducted at the community level and sometimes utilizing current structures like the churches as presented in the following quotes.

"... yes, we are able to reach the community, like now last year we went to Nyeri county, we had an outreach ...in Nyeri hospital where we screened more than a 1000 patients (Health worker, Nairobi).

Oncology nurses expressed independently, about talking at their church about cancer and big demand for them to keep providing information in this way. (Health workers in Meru and Nairobi)

...The church also—we usually try to hold outreaches in the churches so that we can be able to get the services to the community. (Health worker, Nairobi)

Use of Local networks:

Working with community health workers and asking sub-chiefs to call *barazas* to share a health message.

'These are also our entry points in the community, there are even the churches and the normal gatherings that the community has. We like using them in sharing the messages that concern them.' (Policy maker, Meru)

<u>Awareness and knowledge promotion</u>: health workers informed that different months have been set to bring awareness on the different types of cancers.

"…for example October is breast cancer month" (Health worker, Nairobi)

Another way to boost awareness is the incorporation of screening services into existing services "Cervical screening and breast exam education are incorporated to some extent into maternal and reproductive health clinics" (Health worker, Nairobi)

The focus group discussions and interviews revealed that despite the facilities efforts to boost awareness as expressed by the health workers, more is needed as there is still limited awareness, knowledge and misconceptions about cancer as presented in the following quotes.

Health workers in all the study sites emphasised on the need for strong demand for more information and education on symptoms of cancer. And even with the facilities' efforts put up to enhance approachability, findings highlight areas of improvement as expressed in the following quotes.

It was not always known where one can receive screening services as in the following quote: "Also a question because when you say about screening some of these cancers like the blood cancers where do we go for blood cancer screening?" (Cancer Survivors, Nairobi)





Knowledge of where to source services not known to all:

"Not many people know where you can get these services, especially people in the rural areas, they don't know which hospital to go to, they don't have information" (Cancer Survivors, Nairobi)

Awareness still needed

"I would say that even today we have not gotten help. Like I had been told to drink something, and there is no awareness to people. Some even fear mentioning the word cancer. ... Therefore I request that awareness be done in the rural areas. People will die of cancer there because they do not even know". (Cancer Survivors, Meru)

"...awareness and education is lacking in the community. When you go to the community and reveal your illnesses they tend to get more shocked than you, so it will be very nice if the community was given more information on the illness. (Cancer survivors- Mombasa)

Not all facilities conduct outreach services

"...the so-called screening, we don't do it as an outreach thing, we do it here. We bring people here, so getting the message sometimes to people is also difficult. And you see most people where they are sometimes transport, coming to hospital is also an issue. Even our numbers, you know when we are looking for big numbers, we don't get those numbers, we just get some numbers.' (Health worker, Mombasa)

Referral- Linkages between community outreaches at churches and health facility for screening was often missing

".... another barrier for screening is that after you have told them about screening, they come to the hospital. Maybe you were in a church and you have talked about cervical cancer, or prostate cancer. People will come to the hospital, and they will say they have come to be screened. They will meet different people, and they will tell them there is no screening here. We are not screening. So most of them come and they get frustrated, because we do not have a specific place where you can tell them to go and get screened there. Only women, who we tell them to go and get screened in MCH or family planning clinic where we can screen them for cervical cancer, and the breast. But for men, most of them go back, because we do not have a specific place for screening". (Health worker, Meru)

Availability

Availability here refers to the extent to which health resources are sufficient to enable the provision and receipt of care. In this section we consider availability in relation to facilities and technology, drugs, medical devices and other commodities, and a health workforce with appropriate skills.





Decentralisation of treatment

Table 8 shows the level at which survey respondents sought and obtained care, by county where the patient was interviewed. Although the facility surveys targeted patients/ study participants at level 5 and 6 hospitals, which provided specialised oncology services, experiences on lower level health care by the patients were captured. The table shows the level of the health system at which patients first approached a health facility for a response to their symptoms ("point of entry"). Of the respondents captured here, 2 % were screened, 31% started at a level 2 or 3 facility; and a majority went straight to a level 4 hospital or above.

The moment in each patient's pathway captured as "entry into cancer care" marks the point where investigation for cancer was first raised. At that point, 89% of respondents were at a level 4 hospital or above; 6 (2%) went to private laboratories in Kenya, or were abroad.

	All Counties	Nairobi	Mombasa	Meru
	n (%)	n (%)	n (%)	n (%)
Point of entry				
Screening	7 (2)	3 (1)	1 (1)	3 (5)
Level 2	77 (22)	42 (20)	23 (29)	12 (20)
Level 3	30 (9)	20 (10)	9 (12)	1 (2)
Level 4	139 (40)	86 (42)	28 (36)	25 (41)
Level 5	78 (23)	44 (21)	15 (19)	19 (31)
Level 6	10 (3)	10 (5)	0	0
Abroad	3 (1)	0	2 (3)	1 (2)
Entry into Cancer				
Care				
Screening	3 (1)	2 (1)	0	1 (1)
Level 2	27 (7)	12 (5)	8 (9)	7 (10)
Level 3	7 (2)	3 (1)	4 (5)	0
Level 4	137 (35)	93 (37)	20 (24)	24 (35)
Level 5	160 (41)	77 (32)	48 (57)	35 (51)
Level 6	55 (14)	54 (22)	0	1 (1)
Laboratory	3 (1)	0	3 (4)	0
Abroad	3 (1)	0	2 (2)	1 (1)
Diagnosis				
Level 2	25 (6)	13 (5)	6 97)	6 (9)
Level 3	5 (1)	2 (1)	3 (4)	0
Level 4	118 (30)	73 (31)	15 (18)	30 (43)
Level 5	144 (37)	66 (28)	46 (55)	32 (46)
Level 6	86 (22)	85 (36)	0	1 (1)
Laboratory	10 (3)	0	10 (12)	0
Abroad	5 (1)	0	4 (5)	1 (1)

Table 8. Facility levels and point of care by county where patient interviewed





First treatment				
Level 2	8 (3)	3 (2)	2 (2)	3 (5)
Level 3	1 (0)	1 (1)	0	0
Level 4	45 (14)	19 (11)	9 (11)	17 (30)
Level 5	113 (36)	13 (8)	68 (84)	32 (56)
Level 6	140 (45)	137 (79)	0	3 (5)
Abroad	4 (1)	0	2 (2)	2 (4)

Note: patients for whom level of facility at each milestone could be identified.

A key moment for all patients was the moment when cancer was confirmed. 89% of patients captured were diagnosed at a level 4 hospital or above; 3% were diagnosed at private laboratories and 1% abroad. The concentration at hospital level may be due to the likelihood for availability of the required diagnostic equipment and access to laboratory analysis in these facilities. However, 7% of patients are recorded to have been diagnosed at lower levels 2 and 3. Further investigation showed that all but one of these diagnoses was at a private facility: these facilities have diagnostic capabilities or linkages, but they are classified in government lists at level 2 and 3.

Most patients who had reached first treatment when interviewed had been treated at higher level hospitals. The small number of exceptions were treated in private facilities currently classified by the government at lower levels (3%). Just 4 (1%) had started treatment abroad. The availability of screening and key diagnostic procedures, chemotherapy, and palliation at level 5 County hospitals was important in facilitating access to care. At facility 001 (level 6), radiotherapy was also available and patients had access to further specialised treatments

Available services

Table 8 indicated point of care for diagnostic and treatment services which can be an indication of where these services are available. It is noted that study participants access these services mainly at the higher level facilities (about 81% accessed first treatment) that is level 5 county hospitals and level 6 national hospitals. Although the facility surveys targeted patients/ study participants at level 5 and 6 hospitals, which provided specialised oncology services, experiences in lower level health care by the patients were captured. The availability of screening and key diagnostic procedures, chemotherapy, and palliation at level 5 County hospitals was important in facilitating access to care.

Screening and diagnostics:

Mobile screening programmes were ran by facilities 001 and 002. At facility 002, screening was conducted every two weeks in different parts of the county, with the aim of covering all subcounties (Health worker, Meru)

The support of county administrations was reportedly important in enabling screening. One health worker at facility 002 noted:





`...the county has really improved...they have taken it really seriously. It is actually a challenge to them but...they are putting the effort [in].' (Health worker, Meru)

At one of the counties it was noted the facility had 'pretty much the basics that we ever require' for diagnosing cancer, meaning that although sometimes referrals were required for diagnosis, 'most of the things that we require are already available in the hospital' (Health worker, Meru)

Tumour marker tests were also available, the importance of being able to provide comprehensive diagnostic services and to then refer patients for appropriate further care within the same facility was emphasised as explained in the following quote.

"...one of the things I did was to talk to...the chiefs and the lab people so that we can do most of the tests ... here [instead of having to] take them out... Tumour markers are very expensive to do them out but they are done here at a considerable amount of money so that the patient can get diagnosed and be treated...for diagnosis we are very fast ... if they are seen in this department. But if they are seen in [other departments in the hospital] now they have to go round and round, they go here, they are sent here, x-ray seeing a doctor can take even a month or two, and then you know the more you delay, the more you delay treatment... [If we identify a patient with breast cancer]the surgeon comes here and reviews the patient, maybe next day the patient is...taken to theatre, so there is no delay for that because we also have a surgical oncologist here.' (Health worker, Mombasa)

Accessing diagnostic procedures at facilities 001, 002 or 003 may depend on patients being referred from lower tiers of the health system. While some challenges related to availability of skilled personnel in health centres are discussed below, one health worker at facility 002 did credit workers at lower tiers with the capacity to make necessary referrals:

...they are able to have a high index of suspicion, which is a good thing, and they are able to do basic investigation then they are able to refer.' (Health worker, Meru)

One interviewee also described efforts to support colleagues at lower tiers or in Counties which did not at the time have such a high level of capacity to provide cancer care:

"...even now places like Kilifi...they have been referring most of their patients here. This is another county now and they have actually started to build their own unit now. But [we have] had some few seminars with those people there at least to put them in the picture on how to go about it, so when they have a case of any form of cancer they just tend to refer, we just tell them to refer direct not to handle or mismanage the patient in any way." (Health worker, Mombasa)

Availability of drugs, medical devices and other commodities

One interviewee involved in procurement felt that the general availability within Kenya of drugs and other products that they regularly ordered was not a major problem:

'[Country-wide shortages have] not been a very major challenge, just once we had one product that we really couldn't get or were getting very short expiry at some point but that





usually normalizes after a while...It's seasonal it's never that common.' (Health worker, Meru)

The capacity to provide comprehensive services within one facility noted above in relation to diagnostics was also described in relation to other services. One health worker outlined their efforts to ensure that patients could receive a blood transfusion in the cancer centre as a day patient, rather than being admitted to a general ward:

'A patient can be in the ward and stay for almost one month chasing blood, the patient doesn't get and the patient gets worse and worse. But [in the department] we have actually changed and improved, that now a patient has a low [haemoglobin level and] needs some transfusion, we just do it here... I think the PR I have put, with the lab people and showing them the urgency of the blood and then they have always been very cooperative... Because unlike those days whereby you could admit the patient and then get problems, getting the blood and then the next day you hear your patient is gone just because of waiting for blood.' (Health worker, Mombasa)

Treatment capacity

Constraints on capacity to provide chemotherapy are discussed further below. However, at a public level -5 facility, health workers were able to provide treatment '*almost…every day, from Monday to Friday*' (health worker, Mombasa). This was said to attract patients from as far away as Kenya's Western Region.

Palliative care

Facility 001 had an outpatient clinic for palliative care and dedicated palliative care nurses (Health worker, Nairobi).

In some facilities, staff worked closely with the facility's outpatient hospice to provide care for patients. One health worker explained:

'I can tell you that most of the patients that are admitted in the oncology ward don't actually need to be there. So we are actually working closely with the hospice... to secure space, so that they can provide the continuum of [care] at home...instead of them always coming for admissions for small things.' (Health worker, Meru)

In Meru, outpatient care and homecare visits supported by the county meant hospice staff: ...are able to visit patients in their home and can provide the care there, so that they can save the patient from coming to the hospital and lining up and being uneasy. So they are able to make the patients be at home and be with their families and be able to identify what the patient needs and manage that in a home setting.' (Health worker, Meru)

Staff at lower tier health facilities can also refer patients for hospice care. One worker at a health centre explained:





"...there is the bit of hospice care, we can refer them to Meru hospice care because there they get follow up, and they are taken care of the psychological needs, social and spiritual, all the aspect that that patient will require." (Heath worker, Meru)

As indicated in the quotation above, some participants expressed a strong recognition of psychosocial and 'spiritual' aspects of pain experienced by cancer patients and sought to address this in their work. The importance of counselling was recognised in an oncology unit, for example:

"...most patients in cancer need counselling generally...like every patient has her own issues she is undergoing...from social, financial all the way up to fear of death, because once somebody gets cancer she feels like this is a death sentence, so like now I am working in an inpatient set up, when we admit patients mostly counselling begins ...right from admission, because of course they come...to get chemotherapy. So once we receive those patients we counsel them on the treatment first of all because they have heard chemo, there are side effects, like those coming to go for radio, there are side effects involved so we counsel them pertaining that, to acceptance of the treatment, accepting themselves, it is a continuous process up to maybe when we discharge them to coming back again." (Health worker, Nairobi)

Another discussed 'occupational therapy', which recognises:

"...this patient it is not only that they are sick physically, mentally, spiritually they are also sick, so if you train them how they can be able to cope with such type of...Like now dancing a patient can listen to the music, that is a type of conventional treatment. This patient if possible can go for jogging, they can do some exercises in the house...they can join other people in the groups, like now church groups, men groups, women groups those are also types of occupational therapy...[occupational therapy is about] occupying your mind.' (Health worker, Nairobi)

Government support and political will

Financing from the County administration was credited by participants as having increased availability of cancer drugs. Health workers explained:

'Mainly we rely on the county government, it is facilitated mainly on the buying of drugs, and all of that mostly through KEMSA and MEDS' (Health worker, Meru)

…recently at least the county has really come in, and through the county have been able to purchase a good sum of stock. (Health worker, Meru)

Health workers also welcomed efforts from the County administration to improve availability of facilities for cancer care. As one health worker noted:

"...initially when we started we did not have anything, we just had a room and that room was everything. It was a place where we could mix the drugs, it was the nursing station, and it was the clerk station. But as time went by that is why we had to change and get a better place, now where we are. Through our county government initiative and our wellwishers, they came on board and they gave us something which is better now." (Health worker, Mombasa)





More broadly, staff at all facilities described the sense that there was significant political enthusiasm for improving oncology services at both national and county level:

'There is goodwill in terms of the governor's manifesto. He wants to improve oncology services. There are big plans to do that, we have had several meetings, to get a cancer centre and to get going so there is this goodwill across the board from the county, hospital administration and even the staff.' (Health worker, Meru)

⁶ So for the governor himself he actually took it by the horns you know, everything about this unit he has actually tried. And the county has been very supportive by the way, very supportive to put the drive of this unit.... From his aspect is that he has taken it as a personal task but most of things they are done by the county through him, getting some initiatives here and there, and once in a while he comes around to see how things are done, so you can imagine.' (Health worker, Mombasa)

'I think there is a lot being done, many forums, national, government level, NHIF is an example, I think it is getting a lot of focus and attention...from the government and from us...I can see there is general awareness about cancer that is taking place... [The nation's climate] is better and conducive... I think [political will, policies] is there.' (Health worker, Nairobi)

Other government institutions were also identified as having assisted in providing funding to facilities, including the National Cancer Program, which had donated 5 chemotherapy chairs and some biosafety cabinets to facility 002 as well as a 'starter pack' of drugs (Health worker, Meru).

Partnerships with national and international non-governmental organisations were also important in determining availability of drugs and other items, discussed further below.

Partnerships with NGOs/private sector:

In addition to county financing and support from other government institutions, interviewees identified partnerships with non-governmental organisations (NGOs) and with private corporations as supporting access to commodities and training.

In one of the study counties, it was noted that the main source of support was the county administration (Health workers, Meru), but they also identified a range of partners, including AMPATH⁵, who had donated drugs that were not available at the facility, as well as conducting screening and histological analysis of biopsies for free and supporting staff training and administration of chemotherapy (Health workers, Meru). The facility was also part of an AMREF⁶

⁵ AMPATH is a partnership of Kenyan and North American universities, Moi Teaching and Referral Hospital, and the Kenyan government.

⁶ The African Medical and Research Foundation is an African international non-governmental organisation focused on health.





programme which offered training from oncologists and had meant 'we are able to upscale the clinic and still have more patients coming here' (Health worker, Meru).

Other organisations who had provided training at the three facilities included in the study included the MSI Reproductive Choices on cervical cancer and KEHPCA (Kenya Hospices and Palliative Association) on safe administration of chemotherapy. KEHPCA also supported access to rehabilitative commodities and morphine when it was out of stock (Health worker, Meru).

Staff at facility 002 along with the county were also helping to develop a public private partnership to come up with an oncology centre in the hospital' (Health worker, Meru). At facility 003, the cancer centre was financed by a large business with local headquarters.

Challenges

The survey findings reveal that about 30% of the survey sample identified something they needed that had not been available; some respondents identified multiple missing items. Table 9 lists the type of items missed, with the percentage of each type missed because of lack of money. While some of these challenges arose because the item was unaffordable, as discussed above, other availability challenges also emerged.

Type of item missed	Number of times mentioned	Share (%) of items missed where the access problem was financial
Medication	43	19 (44%)
Tests	66	24 (36%)
Treatment	60	30 (50%
Pain relief	7	4 (57%)
Essential commodities	1	1 (100%)

Table 7: Items missed

<u>Personnel</u>

Oncology staff: Within oncology units, staff shortages were identified by patients, survivors and health workers.

At Facility 002 there were only two people who could administer chemotherapy, meaning that when one was on leave the other was left to handle it alone (IDI 2). Only one pharmacist was available to mix chemotherapy drugs, which could take a long time, causing delays for patients attending for treatment (IDI 2). One interviewee described the difficulties this could cause, explaining:

'We are limited on the number of cases I am handling per week because of the personnel. So if I am alone I run one chemo per week rather than if I had an oncology nurse I would run 5 cases per week.' (Health worker, Meru)





Staff shortages were also considered partially responsible for unavailability of treatment for paediatric cancers, meaning children had to be admitted to facilities elsewhere that were far to reach:

"A paediatric oncologists asked if she could write a protocol for three children to be treated by me just to save the parents and the children the costs and the time and the resources but we are just not comfortable here...They...have to be admitted...which then means mixing the chemo and you know, the mixing is not the problem but it is the administration and it is for a fact that there is no oncology nurse in the ward, and the monitoring of that chemo. That will be the problem....The challenge is because we do not have the expertise. We do not have the capacity you know, we do not have the human resource available.' (Health worker, Meru)

Attempts to meet the demand for chemotherapy could lead to potentially unsafe mixing practices. In one facility, the pharmacy dedicated one day to mixing chemotherapy for patients, but this was insufficient as demand continued throughout the week. Drugs were thus sometimes mixed on the ward, without access to bio-safety cabinets (Health worker). Additional training on safe handling practices for health workers and medical students supporting provision of care was identified as a key need by two health workers.

The challenges with staffing, in addition to limited capacity in terms of equipment and ability to admit inpatients, meant patients could face delays. Survivors in Nairobi recalled delays in being able to book appointments at level six public hospital, as outlined in the following quote:

"...you come to Kenyatta and then you are given a booking and then you are told "come the next two weeks this Tuesday is [fully booked]" and then you come again, you are told again the clinic is fully booked, "we will give you [an appointment in] another two weeks" [while your cancer is growing]." (Cancer Survivors, Nairobi)

A caregiver noted that:

"You have to book in the clinic and in the clinic there are many patients and given that there is only one cardiothoracic surgeon in the facility, it also takes time." (Caregiver, Mombasa)

Waiting times caused particular concern for patients when they had purchased chemotherapy drugs that required refrigeration as explained.

'There are some chemotherapy drugs especially for breast cancer that require refrigeration, when you go to the private wing, your drug will be refrigerated but in the public wing you are forced to stay with your drug. One patient received drugs that were not refrigerated and the skin on the breast started peeling off.' (Cancer Survivors, Nairobi)

In addition to delays experienced in arranging and attending appointments, there was lack of coordination between facilities to support urgent cases, one caregiver recalled their experience of attending the hospital in an emergency. They had arrived in Nairobi in an ambulance with their daughter who had been diagnosed with a brain tumour requiring urgent attention:

"We saw the doctor and he told us to go back home because there was a queue. We came here on a Wednesday and we were told to come the next week on a Tuesday to see the doctor. She was very sick...after five days we came back here and met the





consultant doctor, and when he saw, he said it was very urgent. We were admitted, we went there on a Tuesday and the surgery was done on a Friday." (Caregiver, Nairobi)

The impact of an increase in patient numbers and shortage of staff as reiterated:

"We don't have staff... sometimes we have to turn the patients away because the clinic [is] full...Previously before I was here, they were seeing like 15 patients...and they up scaled it to 40 – 50 patients [per week]...We have one oncologist here in the county, we do not have trained oncology nurses..." (Health worker, Meru)

Inpatients could also be affected by staff shortages. Study participants reflected on their experiences, outlining delays that could also affect inpatients:

"...you find that in public hospitals, they are not necessarily understaffed but they are operating beyond capacity, if for example this particular staff is supposed to take 1000 patients for example facility 001, but it is the only referral hospital that has a radiotherapy machine, so everybody is sent ...from everywhere to facility 001 so you are supposed to be operating with a thousand patients, you have five thousand patients. Children would stay in the bed for over a week just to go for an x ray because there is nobody to take them, there are three nurses dealing with the whole ward, they are overwhelmed, they are talking to parents, they are administering medicines, even just going down to the pharmacy to get medicines, they didn't have someone to do that. So you find everything is delayed. Some of these cancers especially in children will double in one week's time, someone is sitting there, waiting to go for an x-ray to see how to be treated. Or sitting there for one week just because there is nobody to take him to the doctor's appointment because the nurses are overwhelmed...' (Cancer Survivors, Nairobi)

The survey patient pathways data concurs with the finding on shortages of medical staff. The survey also included five patients whose access was delayed by strikes, one of whom went to Tanzania in search of treatment, three had diagnosis delayed, and one had radiography delayed. The shortage of medical staff, and their movements between facilities also affected treatment experience. The following examples recount patients' decisions to stop attending a particular facility due to staff shortages or movements of staff:

"My doctor had gone to India. Sent to their palliative centre. The doctor I found there told me she doesn't operate from there daily... Referred me to (private cancer hospital)... Then after a second chemotherapy round, and when tests and images were ready: was told my doctor had relocated to Meru. I was not willing to change the doctor so I self- referred myself to (public level six), because, I was not willing to change the doctor it was too critical for me at this point in time" (Female patient, age 68, Meru)

"I used to be given appointment[s] but every time I would come, the doctors were busy because they were few and client[s] many and so I decided not to come any more. (Female patient, age 49, Mombasa)

In addition to causing delays for patients, shortages of staff led to significant **workload challenges**, and health workers were aware of the impact on the care they could provide to patients:





'When it comes to giving these patients chemotherapy and all sorts, that work is a lot, because you are the same one giving this chemotherapy, you are the same one taking care—so at time we don't give our best. We feel bad because you want to give your best but you are few. So you just concentrate on the priority things and maybe you fail to attend to the other like social aspect of this patient. Psychological aspect and other factors that could have maybe aided in this patient to come out well.' (Health worker, Nairobi)

Staff outlined the **psychological toll** working in the oncology unit could take, where they witnessed much suffering and lost many patients, which was 'so painful and emotional' (Health worker, Nairobi) . The impact on the wellbeing of health workers was compounded by shortages. As one nurse explained:

"...actually we get burnout in the process because it is just stressing honestly it is not easy.... Number one we are few, then number 2, there is no job satisfaction... you wish to have done more but due to the shortage you can't, then the most affecting thing is when - the nature of the work... the illness itself, taking care of this patient who is undergoing so many challenges." (Health worker, Nairobi)

Outside of specialised oncology units, shortages of skilled staff were also perceived by health workers, caregivers and survivors to compromise availability of care and to result in delays for patients, particularly in receiving a diagnosis. Survivors who participated in FGDs and caregivers discussed examples of misdiagnosis or failure to diagnose, affecting themselves or others. For example, one participant had been treated for severe anaemia for 10 years before a different doctor suggested testing for leukaemia (Cancer survivors, Nairobi); the daughter of one caregiver had been advised to purchase glasses in response to visual impairment and collapses later shown to be caused by a brain tumour (Caregiver, Nairobi); and one member of a support group for those with cancer of the colon reported that many of their peers had been 'treated for typhoid, amoeba, ulcers, h-pylori, for a very long time. Some even for years!' (Cancer survivors, Mombasa).

Some credited their personal persistence or ability to move between facilities and to seek specialist care with enabling them to eventually obtain a diagnosis. One FGD participant had been repeatedly treated for different nasal and sinus issues at ten different hospitals over a sixmonth period:

'It is only when I started talking to friends and family and saying look I have been going to [these] places they have been treating me for this I don't know what is going on because they keep treating and it is not going on. And then I started talking to people and someone said maybe you should see an [Ear, nose and throat (ENT)] specialist, I went to see two or three, same thing, then somebody actually referred me to a specialist, I know this is a very good ENT go and see him, he might be able to sort you out.' (Cancer survivors, Nairobi)

Another participant recalled:

`...in my case the first five tests, even the first three biopsies, they didn't see anything, all of them were negative. If I didn't insist, I don't know where I would be, I would be six feet under... One [biopsy] was a public it was negative, then my doctor who happened to work





in private and also in public, advised me go to a private and also, I went to two [wellknown] private hospitals...but they didn't see anything. But then after then I was insisting to my doctor, okay the good thing was my doctor was undergoing the same problem, he had breast cancer...so he had all the information. So when this test failed he would advise me now do this, he would refer me to this oncologist, until I was diagnosed.' (Cancer survivors, Nairobi)

Health workers acknowledged these challenges. Experience of patients who had eventually been referred to their facility was expressed the following statement:

.at times [patients] don't discover that it is our [health professionals'] fault, because a patient will come with a story, her breast is completely, it is just like a wound until the necrosed flesh is falling off until the chest becomes flat, I have seen such a client... the client will start telling me I went to this clinic and they were dressing me with different solutions the wound was not improving, now after the breast worsened I now came to Kenyatta is when a sample was taken... and it was tested and the doctor told me that it is cancer, already it has metastasized. When we were talking about the caution, the warning signs [of breast cancer] one of them is like an abnormal swelling in your breast. Now this clinician in a dispensary could have suspected I would analyse and say there was low suspicion index in this health care provider at that level because he or she had this information to suspect this patient is having cancer [and] could have taken an initiative [meaning] this patient maybe right now could be having a different stage of illness not the metastasized stage....I think... we as the health care providers we contribute in delaying the diagnosis... some [with gastric cancer] are even treated for peptic ulcers for a long time and one of the signs that you could have suspected, let me just do like something like endoscopy, just to look at the [gastro-intestinal tract] of this patient. You only end up to find that this patient has advanced gastric cancer at the late stages.' (Health worker, Nairobi)

Another interviewee at a health centre had had one week's training on oncology and palliation, but felt they would like further training to enable them to provide cancer care:

'The equipment is not available [to diagnose cancer...[and] also the human resource...[Staff] may be sufficient [in number] but...you see like me I am telling you [I] had my first [cancer-related] training last week, [there] are many of us [in this position]. [All] you know [is that] cancer exists and the knowledge that you got from school. There is no updates... There could be [on the] job training.' (Health worker, Meru)

Capacity and equipment:

Compounding shortages of staff, the limited availability of equipment or capacity to accommodate patients was also identified as a problem that could cause delays for patients.

Screening and diagnostics

Screening in Meru was reported to be conducted through mobile outreach programmes organised by the county, but was not available routinely within lower tiers of the health system (Health worker, Meru).





While as discussed above, staff at facility 002 felt they had 'the basics' (Health worker, Meru) required for diagnosing cancer, the MRI scanner available could not be used for pelvic or abdominal scans, meaning patients may have to be referred (Health worker, Meru). The following patient, for example, recalled their experience of being unable to obtain diagnostic tests:

"I did not get the tests in the county Level 5 hospital. I had to travel to Thika for the tests." (Male age 36 Nairobi)

Patients elsewhere could also experience difficulties in accessing diagnostic imaging. As one health worker explained:

'The diagnosis services are not easily available. The accessibility is a problem because you find that—like the CT scan it is not every facility that has. And the MRI it is not everywhere. ...' (Health worker, Mombasa)

At the time of the interviews, a PET CT scan was reportedly not widely available in Kenya. One health worker explained:

'In Kenyatta it is only the PET scan we cannot do where people usually go to India, for PET scan...Aga Khan they have [a PET CT scanner] but they have not started because it is very expensive.' (Health worker, Nairobi)

In contrast, another interviewee did believe the machine was already in use at Aga Khan and that patients could be referred there to access this using NHIF, however they noted that the cost of newer treatments could be a challenge (Health worker, Nairobi).

<u>Radiotherapy services</u>: Within the public sector, radiotherapy was only provided at facility 001 at the time the research was carried out. This meant significant demand was placed on services. Patients attended to receive treatment as early as 6.30am and some staff began work at 6am because 'the patients are many and now [staff] volunteer to come early so that they can be able to handle the number of the patients here' (Health worker, Nairobi). Despite this, patients could face long waits. One FGD participant recalled their experience as follows:

….there were even people from Western and even Rift. [There were people from] everywhere and we used to wait even until 9pm because there were no machines.' (Cancer Survivors, Meru)

This could cause delays and additional expense for people who had to travel to Nairobi. One caregiver explained:

"...we went [to Kenyatta] and we stayed for like two months. Just looking for ways of entering the place. Since Kenyatta normally has so many people, we were told that we will be called. We followed the line, and we were told we will be called. That is compulsory. I wanted it to be faster [and for] my mum to feel well so that we can go back home. So we went to Texas [a private hospital]." (Care giver, Meru)

Some patients may abandon treatment when required to wait, as described by one health worker at a health centre:

'Some [patients who have been referred] have gone to Kenyatta for more than 4 days and still, they have not gotten a chance to be attended to, because there is a long queue...





[So they come back and we have to manage them] with what we have...It is not common but we have some cases.' (Health worker, Nairobi)

After receiving radiotherapy, patients may have to continue to travel to Nairobi to receive followon treatment. One FGD participant described having to travel to a private hospital in Nairobi every three months for an injection that was not available in Meru where they lived (Cancer survivors, Meru).

Although chemotherapy is available at facilities other than the level six public facility, there was also high demand there for these services as people were referred from all over the country. One health worker suggested that upgrading additional hospitals around the country would help to ease 'congestion' in the hospital and enable patients to access care more quickly (Health worker, Nairobi). Availability of chemotherapy was also impacted by availability of drugs, discussed further below.

In some facilities staff discomfort with preparing and administering chemotherapy, also reportedly created challenges in providing inpatient chemotherapy, where treatment was only being provided on an outpatient basis (Health worker, Meru). Further, treatment for patients with leukaemia could not be provided due to the need for blood products or for paediatric cancers. These patients were referred to Nairobi (Health worker, Meru).

Inpatient capacity could also be limited due to shortages of beds as explained during one of the Focus group discussions:

"You know government hospitals it was difficult to get a bed and 3,4 5 months and they have known you have it, and so my family decided I be taken to a private wing, to a private doctor, because in Kenyatta, I could not find a bed..." (Cancer Survivors, Meru)

As discussed above inpatient chemotherapy was not feasible in some facilities and wards were generally very crowded. Regarding the oncology department one health worker felt:

'We do not have enough space. As you have seen we only have two rooms ...where we can see patients and they are like 3, 4, and when we get support from partners, they are more and you see them in the corridors.' (Health worker, Meru)

Space was also a concern in Mombasa where one health worker noted:

"If there is an improvement that I need [it is] space, maybe expansion of the place, anything but I need space...we are now dealing with 25 patients, some patients actually putting them on chairs to give them chemos and these chemos are cyto-toxic drugs. They are very bad drugs, they cause nausea, they cause vomiting now being on chairs and then you start vomiting, you can imagine.' (Health worker, Mombasa)

Patients may find it challenging not to be admitted as described in the following quote:

'...cancer treatment, especially chemo, it is very harsh in terms of the side effects. If you come to a place like Kenyatta or any other public hospital they tell you beds are full, they can't treat you as an inpatient. You are given something and sent home to look after yourself. That is the language they use you see. So we suffer a lot.' (Cancer Survivors, Nairobi)





<u>Surgery:</u> Patients could face long waits for surgery. At one of the study counties, there was only one operating theatre and the surgeons faced very high demand for services, thus patients might wait for two months before having an operation (Health worker, Meru).

Pathology: Some pathology services were available at all facilities included in the study, which meant important diagnostic procedures could be carried out, as discussed above. However, patients could face delays in receiving test results due to shortages of skilled pathologists and limited laboratory infrastructure. For example, one interviewee emphasised the need for a dedicated pathology lab, as the general hospital laboratory took up to two weeks to analyse samples from fine needle aspiration (Health worker, Meru). Samples requiring histological analysis were sent away to a private hospital in Nairobi, which could cause delays and increased costs for the patient (Health workers, Meru).

Within the public sector, some specialized analysis is not available, meaning patients requiring diagnostic tests including trephine biopsies and lymph node biopsies would need to undergo the procedure at a private facility or take a sample for external analysis (Health worker, Nairobi).

<u>Drugs</u>

Financial and other constraints could mean some drugs were not available within public facilities as noted by one health worker :

'Drugs is a problem, in terms of the pharmacy, we are only able to access basic drugs and also other drugs are very costly we cannot meet the budget.' (Health worker, Meru)

In particular, targeted reagents, biologics, targeted therapies and immunotherapy were considered lacking (Health workers, Meru).

The cost of the treatment to patients was also a constraint on the drugs that could be made available, in addition to facilities' budgets. One health worker explained using a hypothetical example of a prostate cancer patient:

"...if a patient is used to first line which is lucatimole and glycelorin that would cost the patient like KSH24,000 which is covered under NHIF, whereas if we were to do second line, one tablet ... which is mainly used for metastatic prostate, or recurrent or the one that is not responding to first line it would be very expensive, it would cost almost KSH 180,000 or there about...NHIF will only cover up to a certain amount after which the patient will now have to buy for themselves, the other thing is the facility will not be able to buy such molecules because we don't have the capital." (Health worker, Meru)

Whether drugs were available could thus influence which treatment regimens were prescribed: ...you already know if breast cancer patient comes in this particular stage, this is the first line regimen you will start, so [the oncologist] will definitely prescribe but she will have to consult, is it available, because she is also in understanding that if it's not available most...patients will not benefit because they will [have to] go buy the drugs, so she will only prescribe with such consultations and with such things in mind.' (Health worker, Meru)





Some interviewees identified challenges in procuring cancer drugs. At facility 002, oncology had only recently become a department with its own budget allocation and due to 'logistical challenges' it had not yet been possible to place an order for drugs with this budget (Health worker, Meru). Until this point, oncology drugs were purchased through the general pharmacy budget described by one health worker as having entailed 'begging from other departments' (Health worker, Meru). The role of the County administration and other governmental and non-governmental partners in supporting availability of drugs and other commodities was outlined above. Nevertheless, limited resources made the procurement process challenging. One health worker explained:

'I wish we can one day become ...like the HIV programme, where they just have a wish list, you don't even know the price of the drug you just know this drug will help my patient and this is the recommended first line drug for the patient and what you just need to do is to write an order to [the National Aids and STI Control Programme and] by tomorrow you will have the drug, for me ...[I have to] remove some of the products as much as am liable to the patient because of cost implications because I never have enough to buy what I would need...' (Health worker)

The procurement process itself could also be lengthy and lead to stock outs while awaiting new supplies. One health worker explained:

"... the process is long [as] you have to raise quotations that takes a few days for them to come back because suppliers as I told you are in Nairobi, and the process has to be manual so we have to send the order quotation, it has to come back to make the order then now send the LPO again so that in actual sense the deed time takes a month or more and within that time the stocks might run out." (Health worker).

Pharmacists might also be required to purchase just one or two products from a range of smaller retailers and distributors with limited product ranges, in addition to dealing with larger companies and the state agency, KEMSA, which became 'very tedious' (Health worker, Meru).

In terms of medication for pain management, methadone and oxycodone were reportedly unavailable in Kenya. Other forms of pain relief, such as ketamine patches and slow-release morphine, were also typically unavailable due to being expensive (Policy Maker, Nairobi).

At lower tiers of the health system, patients may face challenges in accessing appropriate pain medication. One health worker at a health centre explained:

'You know at our level [health Centre] I would speak of the drug supply. Now you see here we have paracetamol - that's the only analgesic that we have and for sure for cancer patients...paracetamol cannot control the pain. So I think there is also the need to bring the morphine to be contained at our levels. Rather than sending our patients all the way to [the county headquarters].' (Health worker, Meru)

As discussed under 'Affordability' above, <u>stock-outs</u> meant patients were sometimes required to purchase medicines privately. One FGD participant described this as a very common occurrence:





'Most of the times we do not have drugs. Most of the times and not just half time, most of the times they are not there. They just prescribe and you...purchase' (Cancer survivors, Meru)

Stock outs were particularly distressing for patients when they were in the middle of treatment. As one survivor explained:

"...you had started a treatment...and you are told you have to go for 18 sessions but after 10 sessions you are told that the drug is not available... and they started they knew you are supposed to take it continuous and then you are told to come back the next month, when you do the drug is not available...and you don't know the consequences [of not finishing the treatment]." (Cancer survivors, Nairobi)

Shortages of drugs can also cause delays for patients. As one patient explained:

"There were a lot of delays in initiation of treatment…because not all drugs were available. We had to move up and down looking for them… (Female age 56 Nairobi)

<u>Shortages of reagents</u> were also considered to pose a problem, reportedly causing delays of two weeks to a month in analysis of biopsies at facility 002 (Health worker, Meru).

Focus group participants also recalled experiences when reagents had been missing:

'...like PSA I have come from there and it is not there. And you are told that the chemical is not there. Now if you cannot find PSA in a big hospital like this, where will you go? And that is a determining factor for a sick person in cancer.' (Cancer survivors, Meru)

<u>Medical devices</u> were also sometimes reported to be unavailable, meaning patients were required to purchase items such as true-cut needles themselves in order for a biopsy to be performed (Health worker, Meru).

Medical oxygen was also sometimes in short supply. One FGD participant said:

'I have seen a patient suffocating to death, like gasping to death because there is no oxygen, the cylinder is there but there is no oxygen, so [the] nurse looks on as the patient dies' (Cancer survivors, Nairobi)

Blood products, which are often required by cancer patients due to anaemia, could also sometimes be difficult to access. Patients may have to find family or friends willing to donate, which could be challenging:

'...there was a time when I was very anaemic, I needed like five pints of blood, so you don't have the blood, where are you going to get it. You have maybe [potential donors], you call them and they don't talk to you, tomorrow they still don't pick up your call.' (Cancer survivors, Nairobi)





PPE and related equipment

Protective equipment is required for the preparation of chemotherapy. However, some of the available protective gowns were described as 'not the ideal':

We get them from KEMSA and MEDS mainly but they are not the ideal, if you go to Canada or US it's not the one you will find for chemo mixing, we usually use surgical gowns, disposable surgical gowns but there are better based gowns, same [for] gloves.' (Health worker, Meru)

Biosafety cabinets were also not always available when required. At one of the study facility the cabinets were used by pharmacists to mix chemotherapy for inpatients on one day of the week, but high demand meant drugs were sometimes mixed in the ward without the cabinet, which was considered dangerous:

`...without the cabinets, mixing chemo is like you are throwing chemo in the air, people will inhale, and you will be exposed.' (Health worker, Nairobi)

At facility 002, a biosafety cabinet had been donated to the oncology unit, but this was not in use at the time of the research because windows had been removed to enable safer mixing prior to receipt of the cabinet, meaning that incoming air and dust necessitated too frequent replacement of the cabinet's filter. One interviewee explained:

'...so we have been pleading for the management for change to an [air conditioner] in that room so that...we can utilize the biosafety cabinets, but eeh that is still in progress. Things happen very slowly at the county level so we are still waiting.' (Health worker, Meru)

Staff continued to mix drugs using an extractor fan that had been installed in the chimney. Even if AC was installed and the biosafety cabinet could be used, it was anticipated that some drugs would still be mixed outside of the cabinet, because:

'...we are getting more and more patients for chemo, so we need to mix more and more chemos and the biosafety cabinet is such that only one person can mix. And [if] we are to be efficient, we need more than one person [mixing].' (Health worker, Meru)

Post-treatment care

Those who had been treated for cancer identified a range of products required to improve quality of life during or after treatment that were either not available or difficult to obtain.

Breast prostheses for those who have had a mastectomy were discussed in FGD 1. Several participants expressed that they would like to have access to prostheses, but were not aware how they might obtain them. One participant explained:

"... I wanted to talk about these things we wear when you have breast cancer, prosthesis. It is a challenge to us because it is not even locally available and it is very expensive and those people who assist us are those who have relatives overseas.... There were too many people who needed it... (Cancer survivors, Meru)

Compression sleeves also emerged as a difficult to obtain item:





'These ones for the hand this one it is called what? It is in form of plastic and hand slip for someone like me who has a swollen hand [following treatment]...and now I would request that the government to assist us just like P7 has said, she did not know and she is not aware where to get the dressing and even me I cannot know where to get them even if I have stayed for a long time but then if the government wants to import they can.' (Cancer survivors, Meru)

Insertion of stents to ease difficulty swallowing for those with throat cancer was available only in a few facilities and was reportedly expensive (Policy Maker, Nairobi)

Challenges with the affordability of colostomy bags were discussed above. Sometimes they were also unavailable. One participant noted challenges associated with importing the products:

'First of all, I don't understand why we had to import colostomy bags. I have always thought if I knew how they are made I would start a factory myself. We import them, they become expensive, they delay in coming, you know patients have to use nylon bags, we don't even have nylon bags in this country anymore, so you can imagine what they are doing. So we really need to encourage industry to focus on supplying the people in their own country at a reasonable cost.' (Policy Maker, Nairobi)

Acceptability

The research explored the extent to which care available to patients was provided in a way they deemed acceptable. Patients' assessments of acceptability were informed by factors including social and cultural norms, fear of particular forms of treatment, and the extent to which they could access support and information from other patients.

A small proportion (19 of 405) of the patient survey indicated there were aspects of treatment they had found to be unacceptable. Surgery was mentioned by 8 patients, who had delayed or refused procedures due to fear or because they did not accept the necessity for the operation. Three had struggled with the debilitating effects of chemotherapy and two had refused radiotherapy due to fear. Two further patients had found blood transfusion unacceptable and one had refused a biopsy.

Despite having refused aspects of treatment, the patients included in the survey were all still receiving treatment for cancer. Focus group discussions with survivors of cancer and interviews with health workers and caregivers offered further insight into the reasons why patients considered some aspects of care unacceptable, and into decisions made by some to abandon treatment in the formal healthcare system entirely

<u>Fear:</u>

Limited understanding of what treatment entailed and fear that treatment could itself contribute to death was described as limiting the acceptability of cancer care for some patients.





One survivor explained their experience of supporting somebody who had been diagnosed with cancer in 2015:

'…but he was scared of starting the treatment, up to now, we are like bembelezaring [coaxing] that person to start the treatment. (Cancer survivor, Nairobi)

Some reluctance to start treatment was caused by fear of what treatment would entail:

`...you find that chemo is associated with death itself...you find that with the misconceptions...the public view is [seek] another alternative, don't do chemo. It is poisonous...' (Cancer survivor , Nairobi)

Another participant added:

'The message in my home village, it was that if you have cancer, you are being treated in a coffin...I was wondering how you could be treated in a coffin, and when you enter you don't leave, so that was my biggest challenge. And believe me, I got myself stigma for six years, I just kept the symptoms to myself, I tried everything, how can you go to be treated in a coffin?' (Cancer survivor, Nairobi)

They attributed this perception about treatment to the box-like shape of the CT scan or MRI.

Friends, family and other influential people could thus be important in shaping patients' understandings of acceptability. One patient included in the survey, for example, had been advised by their pastor not to undergo treatment after a fellow member of the congregation had died following chemotherapy and radiotherapy (Female patient, age 35, Nairobi).

Fear of screening procedures exacerbated by limited awareness of what screening entailed were reported to deter some from undergoing procedures. One participant in a focus group discussion described seeing an elderly woman flee a cervical cancer screening event after being told to climb on the bed, having not realized what the procedure would entail. She continued:

"...when you tell people to go for screening, tell them that it is going to be uncomfortable, that you will be told to remove your panty. [If people are not told] when you reach there and you are told to remove, some people will refuse the screening...people should be told so that they prepare themselves but most of the times they are not prepared." (Cancer survivors, Nairobi)

Another participant explained that she had personally left a cervical screening before the procedure when she realised a metal instrument would be inserted, which they found 'really scary' (Cancer survivors, Nairobi).

Anticipating high costs of treatment also made some afraid of seeking care:

"...people are fearing very much, because we have seen many people doing harambees [fundraising efforts] and they are seeing many people dying and even those who are dying, people say that it is incurable. Some of the people are going to India and a lot of money is needed, because people who go to Aga Khan Hospital and other hospital. So people when they are got, they see that they don't have money, from harambees and ... they won't get millions if it's needed. You know they become hopeless and they prefer not coming for tests." (Health worker, Meru)





Stigma

Those who had been treated for cancer, caregivers and health workers identified perceived stigma regarding cancer and receiving and providing cancer care. A health worker considered stigma to be important in contributing to late presentation of cancer patients:

"Most [patients] come at a very late stage...you know that there is that stigma. Stigma is the word here, you see once you get a cancer, you know somebody can lock themselves in, not wanting to be seen by others. It will just be said that you have been bewitched, so they go to the local guys, the herbalists and everybody, they take their time there by the time they come to the hospital they are almost at the end stage...cancer has stigma. Okay with HIV we see at least they say they have found treatment that is why people say they are okay with it. But you know they are spreading the gospel that cancer there is no treatment, so somebody knows that now I am just going to die.' (Health worker, Mombasa)

Stigma could be very distressing for patients. One former patient said:

'...sometimes cancer patient doesn't die of the disease, they die of the lack of information, the stigma, the trauma that they are taken through that is what is killing patients, most of the times.' (Cancer survivor, Nairobi)

Some patients did not receive family and community support due to beliefs about cancer. One health worker explained:

'In terms of culture, sometimes it can be...a problem because sometimes patients can say they have been bewitched and have been abandoned because [their families] think it is a curse upon their homes...they have been chased away from their homes without their children left to fend of themselves because of a cultural deterrence thing...' (Health worker, Meru)

Negative beliefs about cancer, including the perception that patients would die, could make it difficult for patients to access financial support to obtain treatment. Feelings of isolation could also be challenging:

'The spouse [of somebody diagnosed with cancer], some leave immediately, some go [and] come back after chemo to see how your reaction is. Also the chemo some [patients lose their] hair...So when people come to see you from chemo and they find you are kipara ngoto [bald], they say this is AIDS definitely so you are isolated...When [people come to see how you are] they find you it is now after one day you are from there, you are kicking, I cannot go back there, so you are isolated also. So that relationship inaaffect sana [is really affected].' (Cancer survivors, Nairobi)

More generally, some participants discussed stigma as related to the possibility of death. For example:

'It could be that in the past almost there was no hope, so you would find [a person with cancer] was in a lot of pain and so they died and we are in a society where death is not discussed. Like I mean how do we discuss death. So I think in where we are discussing possibilities of poor outcomes, a lot of death, then because of all of that it brings stigma.





No one wants suffering no one wants death and especially when you have all your effort and you know, I think that is what has brought a lot of stigma.' (Health worker. Meru)

Within health personnel, some fear of providing treatment, and particularly chemotherapy was identified:

'There is a lot of stigma, when it comes to the preparation and administration of chemotherapy. And those who have not trained in that field or those who study earlier, who may not have been exposed to oncology, have the fear or always think that if you are even in the same room as chemotherapy, that you know, you will inhale all the fumes and you know afterwards it is going to happen.' (Health worker, Meru)

One health worker stated that fear of dealing with the drugs contributed to some facilities deciding not to start providing chemotherapy:

"...there are hospitals which are not willing to start chemotherapy... It is because of the rumours they usually hear, about the side effects of the chemotherapy. Maybe they have fear, fear of the unknown but if they can come and see what we usually do the fear will go.' (Health worker, Nairobi)

More generally, attitudes among health workers towards providing cancer care could make it difficult to attract staff to oncology units:

'...in fact people hate that ward, to be honest, when somebody gets to hear of moving to [the ward where] chemo is handled, they fear. In fact some ask why do you have a passion for cancer patients...So there is that like attitude from other people and I don't know whether it is attitude or fear of working like with cancer patients, so people who are there, nobody applies to come to that unit and [staff] are rarely moved.' (Health worker, Nairobi)

One health worker at facility 002 attributed the fact paediatric cancers were not treated at the facility partially to stigma:

'It is because of the stigma among staff remember we are still getting them comfortable with the adults. And for the children, the children it is tough...The staff like you know, they just say they are not comfortable.' (Health worker, Meru)

Cultural influences

Participants explained that cultural norms made it difficult for some to disclose symptoms of cancer. One community health volunteer, for example, noted that older people in particular were sometimes reluctant to talk about symptoms, explaining:

`...these old people, when they get bleeding, those at the vagina, you know they fear telling the children... They hide a lot. And even old men about prostate cancer, they hide a lot... because of the culture. They don't want their children to mention about those areas' (Health worker, Meru)





Alternative treatment

Health professionals and survivors noted that some patients prefer to pursue alternative treatment options they felt were more acceptable. One participant in FGD3, for example, expressed their concern about people they had been in treatment with who had:

'...disappeared to thin air...you find there are drugs available for free, but someone still doesn't come [for treatment], they just go and disappear...we caught up with one who said that he had been prayed for, so how do you help?' (Cancer Survivor, Nairobi)

Beliefs about non-biomedical causes of cancer could lead people to delay seeking treatment within the formal healthcare system or to decide not to do so at all. One health worker outlined the potential impact on treatment options:

'[Some decide] because [they believe cancer is caused by] a curse then we shall use a traditional and spiritual ways to deal with it and then you find that the patients do not present themselves early and when they figure out it is not working, they present themselves here and by then it is a little bit too late in terms of curative options.' (Health worker, Meru)

Another explained:

"...There is also religious barrier, you see there are some religions they just believe, sickness is just from God so it is only God who can take it away" (Health worker, Mombasa)

It was noted that sometimes a preference for alternative treatment could cause patients to abandon formal medical care, explaining:

'you know some people think [their illness is] witchcraft and we have to take them from that thinking...because they can abandon the treatment of that patient and be taking people to those...I know in Kenya 95% of people believe in witchcraft and whatever... I have seen some dying of cancer when they are saying it is witchcraft...there are others in the interior. Those people remain on traditional things. They just use their...what we call traditional medicine and they don't go to hospital.' (Health worker, Meru)

Sometimes people opted to combine biomedical treatment with other forms of care as described by one health worker:

"...a number of them, many but I can't talk about all of them but there are those who most of them by the time they now come to accept the conventional treatment, and now that is funny because there are those who initially once they notice they have cancer, they will go try some herbs. When they find the effects, they are not improving is when they come [to the hospital]. And there are some who are doing it concurrent...There is one I spotted one day in bottle like this one with some green liquid, so she was hiding like behind the curtain drinking the concoction very fast so no one sees them, so interesting I went there and asked her, how are you? Are you taking some soda, then she said no, this is just some strong tea I told -- Ni majani tu, these are just tea leaves that have been brought by my son. So how will the tea leaves help you, of course I knew they had mixed some things...' (Health worker, Nairobi)





Facilitators

Privacy and comfortable and clean setting

Regarding invasive screening procedures, such as the digital rectal exam used in identifying possible prostate cancer, challenges could be mitigated by ensuring privacy for patients and a sense of agency. One health worker explained:

"...many patients are not against [the digital rectal exam] ... because remember they have brought themselves...to be screened...I think the problem comes in terms of the privacy of it being done. When it is screening you might find it is a tent or a room with curtains and there is no privacy, you might find that they will walk away.... but they are accepting. I wouldn't say they are not accepting." (Health worker, Meru)

The appearance of a facility and the general impression a patient obtained could also enhance acceptability:

"......we came here and I found a very good hospital, very nice, clean and cheap. So this is how I started the treatment here..." (Cancer survivors, Mombasa)

Access to support and information from family, friends and other patients

While negative beliefs about the causes of cancer or cancer treatment among friends and family could deter patients from accepting treatment, as discussed above, sometimes family and friends played a key role in helping patients to accept treatment. One survey participant, for example, explained that their children had persuaded them to undergo radiotherapy

Survivors also emphasized the importance of patient and survivor-led support groups that could assist in raising awareness, explaining what treatment entailed to newly diagnosed patients, offering advice on coping strategies, and providing forms of counselling. At facility 002, for example, one focus group participant described having set up a mutual support group of 12 people, which had lapsed due to lack of funds. They appealed for financial support from the government, so that '[the group] can be going to the villages to teach people and to give them encouragement' (Cancer survivors, Meru). Another participant reiterated the need for financial support for survivors, who might play a role in reducing fear and stigma surrounding a cancer diagnosis. They recalled their experience of speaking as a survivor at an AMREF-organised event, explaining, 'people in the rural [areas] do not know what cancer is. Some do not know if a person with cancer can heal. Some do not know that a person with cancer can stand up and speak up to say that they have been sick. So that awareness is what we want to be taken to the rural area' (Cancer survivors, Meru). These ideas were echoed by participants in Nairobi. One survivor explained their own role in supporting patients who did not understand their diagnosis or what treatment would entail:

'...once somebody is diagnosed by the doctor, a lot of times they use very technical terms leaving people very confused. So a lot of children will support their parents then come to us and say what is this chemotherapy thing, what is this radiotherapy what is going to happen to my son? What is going to happen here? and there because they actually don't understand and... there are so many myths and misconceptions concerning the treatment...I know there is now a navigation centre but...people still come back to us





because they are not comfortable with those people. They come and say okay we have been working with you for a long time, what is this thing, can you help me. I am not a doctor I can't tell them but from the little experience I have, I am able to break down what the doctor has said into understandable terms then they understand at least this is what is going to happen.' (Cancer Survivors, Nairobi)

This person described themselves as a 'cancer advocate' (Cancer survivors, Nairobi) who was frequently called when somebody received a diagnosis as people said 'you have been here; you have been in this journey for long please talk to this person' (Cancer survivors, Nairobi). They argued that 'counselling should be done by peer educators like us'. This participant, who was also HIV positive, suggested cancer diagnosis should be accompanied with access to counselling, as was the case for HIV, and that patients' voices should be central to this, noting:

'For HIV we say nothing for us without us. If it is a patient going through a similar condition that another patient has gone through, call this other person to take them through their journey. Even that will give them confidence and hope that oh, that person survived, then if I do ABCD I could also survive.' (Cancer survivors, Nairobi)

They suggested a 'referral system' within the hospital, whereby a patient could be referred to relevant support groups within the hospital. Networks such as KENCO, which include many support groups, also offer the opportunity to identify relevant support services for people facing different challenges (Cancer survivors, Nairobi).

Health workers and survivors described ways in which working with existing locally important institutions also facilitated efforts to educate people about cancer and cancer care, as noted above. One cancer survivor and two health professionals (Health workers, Meru and Nairobi) described having spoken in churches and another referred to asking sub-chiefs to call barazas in order to share health messages:

'These are also our entry points in the community, there are even the churches and the normal gatherings that the community has. We like using them in sharing the messages that concern them.' (Policy maker, Meru)

Greater visibility of cancer in public sphere

One health worker credited increased visibility of cancer in political debate and in public life with helping to reduce stigma surrounding a diagnosis:

'I can say there a good political goodwill...because even the politicians get it even though sadly they do not get well, but they do come out and say they have cancer, which has been important in terms of removing stigma as well as [ever so often] we hear them do petitions...saying cancer should be declared a national disaster, which is good because they recognize that there is a problem on the ground and they recognize that there are not enough services being provided in the country...' (Health worker, Meru)





Accessibility

Accessibility in this section refers to reachability of cancer care services due to geographic distance and prolonged time. Geographical access is determined by how easily the client can physically reach the provider's location. In other cases services were available however not reachable due to the long ques hence prolonged waiting time was also seen to influence delay in cancer care.

Geographic access in terms of Distance:

Patients living in rural areas are disproportionately more likely to struggle to access their clinician than a patient living in an urban or suburban area. This is because even as patients are referred for treatment, there are usually transport logistical issues that they may need to deal with as expressed in the following quotes.

"Because the problem for them is the long distance to go to Nairobi ...from as far as Marsabit coming in for treatment" (Health worker, Meru)

"Distance we all know that is a big challenge in this country, you don't expect a patient from Mandera to be able to get care at the right time, you don't expect even patients who are let's say in any – Baringo to come and be able to get this care, a patient from Meru coming to Nairobi for this care" (Health worker, Nairobi)

"...as we talk about the distance, for instance I have gone to the dispensary and I have done some tests. Later I am referred to the sub-county hospital, and I am told that the tests that I require cannot be done in that facility, so that is a challenge" (Cancer survivors, Mombasa).

Patients travel far to seek treatment as affirmed by health workers

"... we are treating people from 'as far as western...From Ukambani, they have been coming here.' (Health worker, Mombasa)

"...but now you see when you send a patient, the patient is not able to follow up for radiotherapy sessions all the way to Nairobi, so it is our wish that these services are at the point where the patient may be in Meru, are well taken care of rather than going all the way to Nairobi" (Health Worker, Meru)

Link between geographical accessibility and affordability

"...it is a challenge to get treatment here, I come from Lunga Lunga to access chemo. You use a lot of money such that you don't have any money to use at home. You are told to go for radiotherapy in Nairobi; you don't know anyone and you can't be admitted. It is costly and you don't know where you are going to and without support it is challenging". (Cancer survivors, MS)

"It is challenging because I don't have money. He has to be brought here and our home is far, Nyeri, and we don't have money to bring him here. We have to borrow from various people to get some money to bring him to Kenyatta" (Caregiver, Nairobi).





Those that come to hospital are those that can afford

"And you see most people where they are sometimes transport, coming to hospital is also an issue...those who are actually coming are the ones who can actually afford to have that fare to come to the hospital. There are others who want to come but they don't have the fare.' (Health worker, Mombasa)

Prolonged booking times

"And then the surgeries, you have to book the clinic so it takes a long time before you start chemotherapy, so the diagnosis takes time". (Caregiver, Mombasa)

"It happened that he shall be admitted and have the meat removed (Biopsy). When they removed the meat, it was sent to Nairobi. It took two months still without the results" (caregiver Meru).

"So when they talked of Kenyatta, we went there and we stayed for like two months. Just looking ways of entering the place. Since Kenyatta normally has so many people, we were told that we will be called. We followed the line, and we were told we will be called. That is compulsory. I wanted it to be faster" (Caregiver, Meru).

And so the treatment seeking process becomes a challenge as following treatment away from one's normal environment becomes a deterrence. There are those that will not continue with the process of treatment, there are those that will go on with the treatment but face challenges such as places of accommodation, prolonged stay at Nairobi, delays in seeking treatment because they lack the resources, and so on.

"They need to be in Nairobi for seven weeks. ...put up in Nairobi where sometimes they do not have anybody in Nairobi to stay with ...so you find that they just don't go (Health worker, Meru)

"So when mum was on the process of treatment, she became sick and we were in somebody's home. We had no place to sleep (Caregiver, Meru)).

You are told to go for radiotherapy in Nairobi, you don't know anyone and you can't be admitted (Cancer survivors, Mombasa)

Adequate/ Appropriate:

Adequacy refers to quality of care, adequate and continued supply of available services. Care should be constantly adapted to the needs of patients. To this end, ongoing dialogue between individual patients and their healthcare team is essential. Appropriate informed consent procedures need to be in place to ensure patients are informed and involved in decisions regarding their care. It requires patient involvement at individual level through shared decision making and adequate mechanisms to capture patients' feedback and at collective level in health





policy decision making. Standard of care or good clinical practices are available for some diseases and can be a good indicator of adequacy. Services available must be relevant to the different parts of a population in terms of their health needs and material and cultural settings if the population is to gain access to satisfactory health outcomes. In other words, available health care resources should meet the needs of different population groups.

Quality of care:

"It depends on professionalism and skills, like when you go to 'a (private hospital) it is a lot of money but the services are okay. When you go elsewhere, they will not give you good service, and therefore you prefer another institution for instance a (private hospital). Instead of coming to a (public hospital) very cheap but a lot of negligence exists (Cancer survivors, Mombasa)

"You see dealing with cancer patients you as a care provider first of all you have to have the heart of dealing with that particular patient. You see the patient sees you as the next god, every time the patient comes the patient sees you as the next god, so you as the next god you are kind of, not empathic with the patient everything changes. Because that patient can call you almost ten times, and you kind of have to respond almost all the ten times and that is what my staff do. You don't – not like other places, you call me and I ask if you are the only patient around here, we don't do that. I think that has helped us as staff plus that bond between us and the patients. In fact, you know if we put them in that sendoff at least we send them off peacefully and nicely, not in a harsh way.' (Health worker, Mombasa)

Health workers and Patients communication

Adequate/Appropriate as an element of access does involve that patients are informed and involved in their health care. In this study, communication emerged from all the data sets to be a major concern.

A health worker expressed her concern thus;

"If you do not tell the patient, may be the diagnosis. You want them to be told at the next level, you yourself don't want to say it is cancer, they will be told at the next level, and they will see you as a liar "(Meru Health Worker).

Data from cancer survivors informed about problems with failure of doctors to communicate clearly – e.g. not explaining what a colostomy was before somebody has the procedure, lack of understanding of requirement to return multiple times for rounds of chemotherapy. Patients expressed being given the wrong diagnosis as first and even when inform of the cancer diagnosis it was sometimes presented so casually that it made patients not believe it as expressed in the following quotes.

"The doctors told me it was hormonal problem and yet it was cervical cancer." Female patient, age 36, Meru





"...from January to February, that's when the disease became severe. It was treated as we thought it was cold. He was injected on one month as we thought it was cold, until the disease became so severe. I came to tell him that this is not cold, we shall go to General (Hospital) (Caregiver, Meru).

2. "The way doctors told me that I had cancer was so casual, until I did not believe it initially. I had to move from one doctor to another just to seek their second opinion regarding the same." (Male patient, age 48 Nairobi)

[The patient] "...still doesn't know the real diagnosis." (Male patient, age 19 Nairobi)

Several patients indeed believed that full information had been withheld from them. For example:

"I was misdiagnosed because I had the doctors whispering amongst each other that I was wrongfully done spinal surgery. Instead I should have been initiated on radiotherapy and cancer management." (51 years Male patient, Nairobi) *"I was lied [to] that I don't have cancer, it made my disease grow."* (Female patient, age 50 Nairobi)

This was also experienced during treatment as expressed

"The drugs were missing. The doctors also were mean with information. They do not want to reveal more regarding the treatment and what you need to do." (Female patient, age 36 Nairobi)

A policy maker pointed out how the system itself could contribute to late diagnosis. Along with that, she expressed sadness regarding patients getting treated before proper investigations have been completed. These sentiments are illustrated with the following quotes:

"Sometimes it is the health system, it is true it contributes a lot to the late diagnosis in terms of number one, health workers especially at the primary care level may not really have a high index of suspicion. So the patient may be treated for the wrong condition even many times before they are found to have cancer" (Policy maker).

In addition to communication concerns, experiences of waiting could also generate perceptions of not being treated well as expressed in the following statements:

"... how people are handled at (Public, level 6) it really disturbs me, when you go to general, sometimes there is a doctor and the queue moves fast other times you find people are [just] sitting [waiting], sometimes your file is missing, like there is a patient who required blood, she [did not get home until] one o'clock in the night." (Cancer Survivors, Nairobi)

"Being sent away multiple times or told to wait for long periods for procedures when worried about symptoms or experiencing discomfort could feel like 'harsh treatment" (Cancer Survivors, Nairobi).





Regarding pain management for patients, availability of morphine and treatment of side effects of treatment, one other policy maker had this to say:

"This year we have run into stock outs and we have had to step in to buy morphine to support the patients, the reason why we have stock outs is because of the government bureaucracy. They have to do a tender, it takes months to accept, it takes months to approve it, it takes months for the drugs to be imported, so this whole process delays the availability, so we have had stock outs because of the government bureaucracy and the government procedures, that is why". (Policy maker)

"....side effects are very important and should be treated because if a patient cannot—most patients stop chemotherapy because they can't tolerate the side effects, and they will not come for the next one because all they remember is how they were wrenching and vomiting. So we need to anticipate those side effects and have those medicines available as we are treating the patients". (Policy Maker)

CANCER CARE RECOMMENDATIONS:

The following section presents recommendations for cancer care as expressed by the study participants.

From the factors identified and the framework used to identify the various gaps in cancer care, urgent work and strategies are needed to align cancer efforts towards ensuring a significant impact on the prevention, early diagnosis, treatment and the general quality of life for people living with and managing cancer.

Prioritization

• **Resource allocation for Cancer prevention and down-staging**- Developing targeted economic incentives to promote early diagnosis, screening, education awareness on the value of early detection and education on lifestyle changes are key long term cost effective strategies for cancer control.

"Well it is a challenge, as I said that right from the national level even before devolution prevention has generally been getting a low bill and funds. This is because of the general perception that health is there to treat and the services are there to treat, and not to caution these people from contracting diseases so basically even when we allocate our resources and measure the impact or measure the utility of these funds, systems are biased to give on curative, not on preventive. (Health worker, Meru)

"That is an interesting question but what I can say is when you think of cancer control, it has to be a continuum of care so you have to address all of it from prevention, to screening, to early diagnosis, to treatment, palliative care, survivorship, all the way. Because there is no way you will say you are just





concentrating on treatment, then what will happen to those people who need to be screened, if I say I am only concentrating on screening, you see there has to be linkage even as I screen, there has to be linkage to diagnosis and those who will be diagnosed of cancer they must be linked to treatment, so in short all this, the continuum of care must be prioritized. So we are actually prioritizing interventions all the way from screening to diagnosis to treatment, palliative care and survivorship, all through so that we don't have a patient stuck, they are not able to access (Policy maker, Nairobi)

 Resource allocation for patients-Considering the limited financial access to cancer services, there is a need to alleviate financial pressure and reduce patient's out of pocket costs by increasing public financing to cater for the expenses incurred throughout the cancer management spectrum. Initiatives such as UHC programs will be central in filling this financial gap for cancer patients and additionally address the delay issues.

"..one of the things that we are seeing is the universal health care, we don't know whether it will be possible to cover cancer patients 100%, so if the costs are going to be covered by somebody, then maybe it will offload that burden to families, relatives because now we are seeing actually many patients for them to be able to get this care because we have to remember that cancer is a chronic disease and it is an ongoing care that patients get for months if not years, so the cost burden is huge, sometimes even for people who are working once you get diagnosed with this disease, you end up losing your job, not being able to be functional, if you are in not so "good employer you end up getting terminated, not getting half salary and at the end not getting salary despite having an expensive if I may call it disease. So getting cushioned from be it like we are saying NHIF or somebody it will help patients to be able to get good care and like I said oncology care patients, you cannot get half treatment and get the outcome" (Health worker, Nairobi)

"...and currently I have seen NHIF what they are trying to do is to see packages of treatment, which makes a lot of sense like instead of covering somebody per cycle or per fraction of treatment, they should come up with a package whereby they are saying if a patient has breast cancer this is the much that is required and we should be covering a 100% of it so I think that is the thing that we should be going in that direction, not to be able to give patients like two cycles of chemotherapy or four cycles and yet they need 6 cycles and then patients are now stranded after the four cycles, now where are they going to get money for the other cycles." (Health worker, Nairobi)

Local involvement in manufacturing for cancer care .

-Every effort should be made towards developing and strengthening already existing links and capacities of different local stakeholders in learning, innovating, manufacturing and developing diverse solutions across the oncological landscape. These may range from pharmaceutical production to innovation around commodities and even technological innovation for simple patient self-management.





"what I can add is we would be very keen to learn from industry, because we know that in countries like India, what worked for them was local production of cancer medicines and commodities, so it is really of much interest to us as a program, to know from industry what we can do to enable Kenya to produce some of these medicines locally. Because again we know there are generics that work and they have worked in other countries, so it is a discussion we would wish to continue. (Policy maker, Nairobi)

"Yeah, they are imported mostly, the colostomy bags, the stents that somebody has got throat cancer and can't swallow, you can actually save their life, at least improve their quality of life for some time but putting a stent, they are expensive, they are only done in a few places. The commodities for cancer, the rest should also be in fact they should be locally manufactured if you ask me at a very low cost. (Policy maker, Nairobi)

Facilitate Availability of drugs

-One of the necessities for delivering affordable cancer by the government is to make all the necessary drugs available to patients and putting in place clear treatment pathways which specify appropriate drugs for each stage of therapies. This in turn will ensure patients awareness of regimens prescribed and the opportunity to make informed treatment choices as well as treatment adherence.

"Yeah, I feel like and if government policies of these countries come together and make a decision as a block and I think this is already in place and I attended one of the meetings with American cancer society and in link with—there are many presentations and ongoing information, and this is something I think even the ministry knows about, and if they are able to negotiate as a block, they can be able to bring these drugs at a lower cost and have only one entry point for drugs in this country such that there are no parallel importers and different people being given that right to bring drugs in this country" (Health worker, Nairobi)

"... What I can request is if the government can facilitate in terms of drugs in the hospital" (Cancer survivors, Meru)

1. **Building capacity for cancer treatment** which should include building healthcare professional capacity, strengthening the Kenyan cancer referral systems as well as creating and linking cancer patient databases for more efficient continuity of care starting from Primary health Care service provision. Unfortunately, oncological human resource capacity is significantly lacking hence the need to address this gap.

"Then another thing at least more people should be trained on the personnel to take care of these patients. Because it is not only about giving that cytotoxic drug, it is more the – because you may find you may talk to a client who is very – just talking the psychological aspect or taking care of the symptoms, and the patient will just be happy. Even before you give the chemotherapy so the skills to tackle these patients and understand those drugs so that in case of a reaction you can





know what to do and where to intervene. Even when the nurses are more empowered I think it will work good for the patient, because something can be prescribed that you according to your knowledge this patient was not due for chemo, maybe the HB is low and whoever who is prescribing is not aware of that, so I think more training, more empowerment, I don't know if I am saying what should be done or what should be changed" (Health worker. Nairobi)

"... then another thing we are proposing to do and rather what we are already doing, is that we are working closely with various stakeholders to capacity build primary health care workers. You know again when you think of cancer in Kenya, many people just think oncologist which is not the right thing, actually the cancer care happens even to some extent at the lower primary level facilities, there is something they can do, before they finally refer the patient to oncologists, so they need to be empowered in terms of what can they do for this patient even as they refer them to the oncologist. And also the oncologist doesn't work in isolation, they work together with the other staff, for example radiologists, pathologists, you need to work with your surgeons, you can't work alone. We call it a multidisciplinary team.(Policy maker, Nairobi)

"...there is referral patterns which need to be improved in our country in the sense that we need to be able to have a proper referral not just to send a patient and say go to a higher level of hospital without communicating to the doctors there, we should be open and we should have phone calls in all these hospitals to enable doctors or nurses when they are referring patients to a particular facility or department they should be able to talk to them, we should talk to each other, doctors should be able to talk to each other so there is no point, a patient was seen in a dispensary let us say somewhere in whichever part of the country and the nurse just, or the doctor there, or the clinical officer writes a small not to the patient and tells the patient, take this somewhere, the patients are not expected to know the seriousness of the things they are being told, and sometimes they don't know what to do" (Health worker. Nairobi)

2. Formation and financing of support groups - Access to psycho-social services is part and parcel of offering optimal cancer care aimed at empowering, informing and guiding patients and their caregivers through treatment. Therefore, the government should create provision for services as part of the standard of care within reach for cancer patients.

"For us it is just to form groups and after putting those groups, the government to assist us financially so that they can be going to the villages to teach people and to give them encouragement...." (Cancer survivors, Meru)

3. Enhance cancer education throughout the cancer care continuum - Enhance communication and population engagement through developing appropriate tools to : support prevention strategies, address health literacy amongst patients and their care-





givers, improve adherence by patients and enhance patient-centered management by health care providers.

"... education because you find women who come like in the reproductive clinic they are taught about how to prevent like cervical cancer for example, breast cancer. Because you know our hospital is specialized, so for the reproductive health you will find them being taught about minimizing many sexual partners, doing continuous pap smears,...take those tests – although that is part of screening but they are taught about how to prevent and minimize exposure so that they might not get cancer." (Health worker, Nairobi)

"On those packets they go around selling, they can put preventive messages, you know now like cigarette smoking – what about if you put on the unga that these amounts of calories per day is enough so don't go beyond that you know such things. They can also help in educating children in school, or if you look at the media, it is an industry also, instead of putting those silly things of dirty dancing, and those silly Nigeria movies, they can put those things that are educative to the children. And even instead of cartoon – they put a cartoon that is telling a child don't drink soda, not a cartoon that is going soda, soda and the kid wants to drink soda. And so there are many ways that we can all work together if we have the same goal, that is a healthy nation we can work together towards that" (Policy maker, Nairobi)

4. Cancer services to learn from HIV financing-

One of the many ways in which HIV care has improved over the years, is by making it a public health priority. Similar steps can be taken towards tackling cancer in that if cancer care is made a public health priority, concerted efforts can be made towards developing a similar model to address cancer in low and middle income countries

"To make it affordable because it's expensivethe screening, the treatment, the investigation the diagnosis, everything is expensive to them and this people are poor..... Should be affordable or free, cancer should be made free like HIV ...HIV treatment is free and people come freely but when it comes to cancer they struggle because everything is expensive ((Health worker, Meru))

5. **Financing and integrating palliative care into the health system** considering palliative care is crucial in providing support for both patients and their caregivers. It gives patients an option for pain and symptom management and higher quality of life while still pursuing curative measures. This in turn leads to enhanced survival rates

"So the gaps for us, the palliative care, we think that they need to put a budget to palliative care, fully integrated, for example pay for the medicines, for example if they are going to pay for medicines in UHC, they should include palliative care medicine, they include things like home visits for patients that are very sick but are not in hospital. Because what one of the things that palliative care does is, it decongests the hospitals, patients come because they have symptoms that are disturbing them, once the symptoms can be assessed and treated the patient can





actually stay at home and continue getting their treatment at home. So the ministry needs to look at how they can invest into supporting hospitals or hospices to do things like home visits. They need to also support patients in their outpatient facilities because they don't pay for outpatient facilities, and some of these patients are so poor most of them by the time they are coming they have sold everything, just trying to get treatment, so they need the NHIF package to cover even the outpatient facilities, home visits and the inpatient facilities. So they need to not just say okay we are integrating palliative care but also invest in it, invest in human resource, invest in infrastructure, invest in everything and not just in palliative care but for cancer as a whole. Because we are still, I think the NHIF covers about 75 per cent of the treatment, the rest of that treatment people sometimes don't have the money to be able to pay the 25% they need to pay." (Policy maker, Nairobi)

6. Prioritize awareness and education for both patients and healthcare providers to ensure adequate cancer prevention, early detection, diagnosis, treatment and overall cancer management across the entire pathway.t

"...So you find—information needs to cut across to the medical profession and as well as the public. So on diagnosis it is a broad area and it is like ni chanzo cha kila kitu, nikidiagnosiwa mapema niko na chance ya kusurvive. (Cancer Survivors, Nairobi)

"What I know it is a matter of education, giving them health talk about that. After that they can accept, but how many people take risk of that information, there are so many to the grassroots. (Health Worker, Meru)

"So I am surprised I think it is a matter of maybe educating the health care workers more to give these patients adequate antiemetic prescription and maybe to address the issue of rehydration. Again it is a matter of the health care worker and what we have done as a program is within the protocol, you see when we talk of a cancer treatment protocol it is addressing all the way from what are the signs of symptoms what will be the diagnostics to do from the priority, so that we don't make the patient so many unnecessary tests, once they are done how will you stage the patient, after staging what are the treatment methods recommended after the treatment methods there is a section for supportive care , it is very clear in the protocols and then palliative care and survivorship. So it is comprehensive and maybe as we continue capacity building we hope to see less and less cases of this we are hearing" (Policy Maker, Nairobi)

7. **Promotion of innovations**-With demand for healthcare rising and health budgets stagnating, one of the ways patient management and outcomes can be improved is by finding new ways to do things better such as championing for innovation in cancer care.

"Yes we should promote a number of innovation across the continuum of care, for example innovation that will help us improve screening, currently there is talk of automated via, where we use artificial intelligence, instead of having colposcopy, you know by colposcops and training health care workers to view the cervix, there





is something that is being developed that uses artificial intelligence, (it is all) being developed here in Kenya by some international partners to be able to just use artificial intelligence to view services and give accurate reports of what – instead of doing the via, the way we do it we just use artificial intelligence. So such innovations in screening are welcome, innovation that will help us to better do our clinical breast examinations, are also welcome. Innovations that will assist to streamline cancer diagnosis or streamline referral are very much welcome. So basically we are open to all sorts of innovation as long as they don't breach the patients' rights "Policy maker

DISCUSSION

Applying a convergent parallel mixed methods design to explore factors that influence access to cancer care was indeed was deemed necessary to unveil elements that may not have been captured well if one methodological approach was applied. We believe that applying this design allowed us to give a more in-depth picture on the dimensions of access in the context of cancer care which in itself is quite complex and would have been missed if one method was applied. Moreover, methodological, data source, researcher and environmental triangulations were applied to strengthen the findings of this research.

The concepts of access drawn from the literature, and used to structure findings from our study participants, focus on access to care within the health system: the range of responses in this research addressed affordability, approachability, availability, acceptability, accessibility and adequacy of cancer care. Underlying these aspects of access to care were other access hurdles also identified by our respondents in the responses presented above: access to the social networks that can raise funds, structured by income and occupation; access to emotional and spiritual support; and access to trusted information,

When these aspects of access to cancer care are facilitated, for example by insurance to support affordability; improved staffing and medication increasing service availability; good information improving acceptability; and lower level diagnostic capability reducing travelling and raising accessibility, then access to all aspects of cancer care is improved. The speed of access to diagnosis and treatment; the access to a course of treatment, for example, to the full chemotherapy cycles required; or continuing access to effective palliative care as needed; all these can be improved by facilitating these various aspects of access.

When challenges to access remain, such as high costs of diagnostic tests and chemotherapy undermining affordability; poor staffing requiring repeated visits by patients to avail themselves of services; poor information exacerbating fear and reducing acceptability; and the need for repeated visits to distant hospitals reducing accessibility, then access to cancer care is undermined. Diagnosis may be delayed – or in the worst case, never obtained; chemotherapy may be delayed of abandoned too soon, radiotherapy out of reach, or hesitancy may undermine acceptability of treatment; and effective palliation may be un obtained.

Furthermore, the very detailed responses outlined in this paper demonstrated to how strongly many of these aspects of access interact and are mutually reinforcing.





Interactions between aspects of access



Figure 3: Interactions between the Access dimensions

Consider for example the responses on experiences of Affordability. Many responses focused on how expensive so many aspects of cancer care are for patients and also for facilities managing limited budgets. Facilitating factors included insurance and fundraising for patients, and also philanthropic and county targeted funding for cancer care in facilities. Access to treatment was particularly noted as facilitated by insurance, while drugs and staffing availability was supported by facility funding. The challenges encountered by patients because of expense ran right across the services required from consultations and laboratory tests, to the costs of pain medication, but costs of chemotherapy were repeatedly noted, with patients reporting running out of money to buy drugs and pay for treatment, and a number reporting access delays and incomplete treatment. Affordability and Availability thus interacted strongly, in the evidence from respondents (see also Table 5), with affordability reinforcing better accessibility or reinforcing barriers to access for example when services or drugs aren't available in the public sector e.g. due to stock outs people have to spend money on them or go to a private facility. Lack of availability also increases costs when people have to go to multiple facilities in search of a diagnosis due to lack of availability of expertise/pathology/diagnostic imaging

Similar interactions were noted between Accessibility and Affordability as presented in figure 3. The distance to Nairobi, and the fact that many respondents had no family there, reduced the chances of access to care that is available mainly in Nairobi, while raising expense for those who accessed this care through travelling substantial distances. Conversely, effective outreach and embedding diagnostic screening in local services could both improve affordability and greatly increase accessibility.





Acceptability in turn was recorded as having strong links to Availability. Better staffed facilities, with higher skill levels, could improve patients' information, while over-worked staff might be forced to skimp on explanation and be unable to help patients overcome fear. Acceptability and Accessibility could also interact. Local outreach could work with local mutual support networks, while conversely the requirement to travel a considerable distance for treatment could reinforce fear and unwillingness to undergo demanding treatment. In addition to possibly greater compatibility with beliefs about causes of illness and effective ways of addressing it, it is important to note that people's decisions to pursue alternative treatment options may also be shaped by the financial constraints they are under or other dimensions of access considered here, such as geographical accessibility of care.

CONCLUSION

Affordability emerges as a major concern dimension of access for cancer care services. Reliance on out of pocket, as a way to finance cancer care services can cause households catastrophic financial loss. Access dimensions interact and cannot be addressed separately. When challenges to any of the access dimensions remain, then access to cancer care may be undermined but when facilitated then access can be improved. Hence, a holistic health system approach to access is more desirable while emphasis should be made at enhancing diagnostic capabilities at lower levels of care.







REFERENCES:

- Shengelia B, Murray CJL, and Adams OB: Beyond access and utilization: defining and measuring health system coverage. In Health Systems Performance Assessment. Debates, methods and empiricism. Edited by Murray CJL, Evans DB. Geneva: World Health Organization; 2003:221–234.
- 2. Levesque JK, Harris MF, and Russell G. (2013). Patient-centered access to health care: Conceptualizing access at the interface of health systems and populations. *International Journal for Equity in Health* **12**:18
- 3. Wyszewiansk L,and McLaughlin CG. (2002). Access to Care: Remembering Old Lessons: Health Services Research 37(6): 1441–1443
- 4. European Patients Forum, (2016). Defining and Measuring Access to Healthcare: the Patients' Perspective *Position Statement*
- 5. (Roche, 2018). Access to healthcare: global -challenge. Retrieved from Roche: https://www.roche.com/sustainability/access-to-healthcare/global-challenge.htm
- 6. Gulliford, M., Figueroa-Munoz, J., Morgan, M., Hughes, D., Gibson, B., Beech, R., et al. (2002). What does 'access to health care' mean? *J Health Serv Res Policy*.
- 7. Peter, D., Garg, A., Bloom, G., Walker, D., Brieger, W., & Rahman, M. (2008). Poverty and access to health care in developing countries. *Annal Of New York Academy*.
- 8. Jacobs, B., Ir, P., Digdeli, M., Annear, P., & Damme, W. (2011). Addressing access barriers to health services: an analytical framework for selecting appropriate interventions in low-income Asian countries. *Health Policy and Planning*.
- 9. Woodward, A., Howard, N., & Wolfers, I. (2014). Health and access to care for undocumented migrants living in the European Union: a scoping review. *Health Policy and Planning*
- Hyuna Sung, Jacques Ferlay, ME, Rebecca L. Siegel, Mathieu Laversanne, Isabelle Soerjomataram, Ahmedin Jemal DMV, Freddie Bray. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries: First published: 04 February 2021<u>https://doi.org/10.3322/caac.21660</u>
- 11. Costas_Muniz, R., Sen, R., J, L., Aragones, A., Ramirez, J., & Gany, F. (2013). Cancer stage knowledge and desire for information: mismatch in Latino cancer patients? *journal of the American Association for Cancer Education*.
- 12. Ministry of Health, Kenya. National Cancer Control Strategy 2017 2022 Nairobi, June 2017
- 13. Chidyaonga_Maseko, F., Chirwa, M., & Muula, A. (2015). Underutilization of cervical cancer prevention services in low and middle income countries: A review of contributing factors. *Pan African Medical Journal.*
- 14. Rosser, J., Njoroge, B., & Huchko, M. (2015). Changing knowledge, attitudes, and behaviors regarding cervical cancer screening: The effects of an educational intervention in rural Kenya. *Patient education and counseling*, 884-9.
- 15. Oystacher, T., Blasco, D., He, E., Huang, D., Shear, R., McColdrick, D., et al. (2018). Understanding stigma as a barrier to accessing cancer treatment in South Africa: implications for public health campaigns. *The Pan African Medical Journal*
- 16. Akuoko, A., Armah, E., Sarpong, T., Quansah, D., Amankwaa, I., & Boateng, D. (2017). Barriers to early presentation and diagnosis of breast cancer among African women living in sub-Saharan Africa. *Plas One*.





- 17. Jones, C., Jack, R., Davies, E., Forbes, J., Lucasg, & Ream, E. (2014). A systematic review of barriers to early presentation and diagnosis with breast cancer among black women. *BMJ Open*.
- 18. Maranga, I., Hampson, L., Oliver, A., Gamal, A., Gichangi, P., Opiyo, A., et al. (2013). Analysis of factors contributing to the low survival of cervical cancer patients undergoing radiotherapy in Kenya. *PLoS One*.
- 19. May, F., Yu, C., & Kaunitz, J. (2018). High quality of cancer care in the Department of Veterans Affairs (VA). *American journal of cancer research*.
- 20. Kakushadze, Z., Raghubanshi, R., & Yu, W. (2017). Estimating Cost Savings from Early Cancer Diagnosis. *Data.*
- 21. Ozawa, S., & Pongpirul, K. (2014). 10 best resources on mixed methods research in health systems. *Health Policy Plan*

