



Access to Cancer Care: Navigating the Maze

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INTRODUCTION: ACCESSING CANCER CARE

How is access to care experienced by cancer patients in East Africa? Interviews with 467 patients in Kenya and Tanzania showed many ways in which patients struggle to access care, including diagnostic tests, treatment and follow-up. Other participants including health workers and care givers supported patients' accounts. Here is one example of patients' often lengthy and frustrating experiences (Box 4.1).

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Box 4.1: Accessing Care for Colon Cancer

A Kenyan woman of 68 had first experienced bloating of the abdomen and discomfort in mid-2016. At a public health facility, she was told she had amoeba and typhoid, and bought medication. Her symptoms worsened over several months, with constipation, loose stools, pain and failure to relieve herself fully. She became afraid to eat. Worried, she went to a private facility where they suspected cancer of the rectum but could not do a colonoscopy because the only doctor able to do it was away.

At a later visit, she found that doctor was still away. Now in severe pain she went to a faith-based hospital, but they also could not do a colonoscopy. She then travelled to a private hospital in Nairobi (about 130 kilometres away): here she was admitted immediately and sedated for severe pain. A CT-scan and surgery found a large tumour in the colon.

After surgery and four days in the intensive care unit, she was discharged with a colostomy stoma bag, and referred to a mission hospital (MH) about 50 kilometres from Nairobi. While admitted, after a wait elsewhere for a bed, her stoma became infected, requiring emergency surgery and a two-month stay. She was then told to go to a private hospital, again in Nairobi, where she stayed with relatives and underwent chemotherapy and radiotherapy.

Back at the MH, a CT scan showed no tumour, and she refused a third surgery to remove the tumour site, thinking she would die. She went several times for private clinic check-ups at her own initiative. Then in October 2018, she experienced renewed symptoms; a self-referral for a CT scan at the MH found metastases. Referred back to a Nairobi private hospital, she underwent second line chemotherapy. After an MRI scan at a private clinic, she returned with her MRI results to find that her doctor had relocated to Meru. Unwilling to change at a critical time, she referred herself to the Meru specialist cancer hospital (about 230 km from Nairobi), where she was happy to find her doctor. When interviewed in May 2019, she was about to start her second radiotherapy treatment.

This patient declared a monthly household income of KES 20,000 (USD 196). She could not remember all her treatment costs, but the sums she recalled totalled KES 1,841,000, or USD 18,000. She stated that she had raised around KES 1 million (USD 9800) through fundraising. Some payments had been made by the National Health Insurance Fund (NHIF) and some other private insurance; other payments were out of pocket.

This patient's experience illustrates many familiar dimensions of the access challenges faced by cancer patients. She was initially wrongly

reassured. She found some services (colonoscopy) widely unavailable, especially close to home. She had to wait for a bed, and to follow a doctor for continuity of care, then travelled repeatedly to find care, an expensive process, and worse for those with no relatives or friends close to the small number of major cancer treatment centres to host them. She was sent to private diagnostic centres, and treated at times in the private sector, as are many in Kenya. Charges were very high in relation to income, and she used a mix of funding including out-of-pocket spending, fundraising and insurance to access care. Fear and exhaustion made some proposed treatment unacceptable. While waiting for a bed, she felt despairingly that people “wanted me dead”; at another point she “lost hope”, “there was too much suffering”.

Access to health care is a complex notion (European Patients Forum, 2016; Levesque et al., 2013; Shengelia et al., 2003). Different dimensions interact and reinforce each other, including challenges of accessibility and availability of services, and also their (un)affordability. Tiring, tormenting, impoverishing and sometimes hopeless: as a recently bereaved carer said of the cancer experience: “it is a journey that is majorly made up of losses”. People lose their own and family savings, properties and more, yet in the end, “they lose the very life that they protected so much”.

THE ACCESS MAZE

As we read patients’ narratives of their experiences in seeking care, the image of a ‘maze’ sharpened in our minds. Patients had frequently faced a confusing, ‘unmapped’ route through a maze of facilities and other providers such as pharmacies, laboratories and traditional healers. Some patients had started with self-medication; most had gone directly to a health facility in search of competent advice, timely diagnosis and essential treatment. In both countries, what followed that first facility visit was experienced by many patients as groping through a maze without maps or guides.

In the process patients faced dead ends, such as being sent away with inappropriate medication or false reassurance. They often returned repeatedly to particular facilities as their symptoms worsened, or they self-referred on their own initiative, sometimes multiple times, to different facilities. As they moved around, costs rose and patients had to search for funds, creating cumulative delays. Lack of information, unavailable services, long waits for diagnostic results, lack of clear referral pathways,

the need for individual initiative and determination to find help, all these combined to create an experience of the health system as a ‘maze’.

This ‘access maze’ is an image or metaphor, strongly reflecting patients’ descriptions of their experience in groping through a health system with little control and only sporadic guidance. The image and experiences contrast with the smooth continuum for patients that cancer clinicians would aim for. As one clinician explained:

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. (Health worker, Kenya)

Mapping the Maze

How was the maze experienced by patients? We highlight four aspects: where patients entered the maze; how long it took to move through it; how winding their paths were; and how much help patients received on their winding journey.

The maze had many points of entrance. While a minority of patients, faced with worrying symptoms, stayed home initially, or self-medicated at a pharmacy or drug shop, most (66% in Tanzania, 64% in Kenya) had gone directly to a health facility. Patients had to decide for themselves where to go with their symptoms. There was no systematic population-based cancer screening in either country at the time. Just one patient in Tanzania and seven in Kenya had entered the cancer care maze by being picked up in one-off community screening events such as a screening camp.

A majority of patients had used a public sector portal to the maze. A minority had entered at public sector primary care level: through screening, dispensary or health centre attendance (Table 4.1). In both countries, around one-third had gone directly to their local hospital: a district hospital in Tanzania; a sub-county hospital or other Level 4 hospital in Kenya. A slightly larger share of patients in Kenya than in Tanzania had started at a private facility (Table 4.1). In both countries, just over 20% had taken their symptoms directly to more specialist referral hospitals (Table 4.1). This behaviour is consistent with other evidence that patients often “by-pass” lower-level facilities, aiming to

Table 4.1 Levels of entry into the access maze, Kenya and Tanzania (% of all patients)

<i>Level of entry*</i>	<i>Tanzania</i>	<i>Kenya</i>
Primary: screening, public dispensary/health centre	28	17
First line local hospitals**	30	34
Referral hospitals ***	21	22
Private sector / other FBO facility	21	27
All respondents	100	100

* Participants for whom level of entry is available; 3 Kenyan patients started their journey abroad

** Tanzanian district hospital/ Kenyan public, FBO or NGO hospital level 4

*** Tanzanian national, regional or zonal hospital/ Kenyan public or FBO hospital level 5 & 6

Table 4.2 Cumulative time between milestones (median number of days) Tanzania and Kenya

<i>Between milestones:</i>	<i>Tanzania</i>	<i>Kenya</i>
From first symptoms to approaching a facility	0	0
From first facility visit to diagnosis	194	77
From diagnosis to first treatment	58	28
From first symptoms to first treatment	535	184

spend limited funds in facilities they believe to be best able to respond to their needs (Kanté et al., 2016).

Once in the maze, patients relied on health care staff to pick up symptoms and advise whether they might be at risk. Many had then suffered delays and setbacks. In Tanzania, the median time taken, from first experiencing the symptoms that were later found to indicate cancer, to starting treatment, was a year and a half; in Kenya it was six months (Table 4.2). Worryingly, there was a wide spectrum of delays in both countries: a quarter of patients in Tanzania waited well over two years from first symptoms to starting treatment, while a quarter in Kenya waited over 1.4 years. Since cancer survival rates are negatively influenced by diagnostic and treatment delay, such delays are potentially damaging to patients' outcomes (WHO, 2020).

Most hurdles recorded by the colon cancer patient were faced by others too. We tracked participants through the maze, observing their experiences between several “milestones”: when they first noticed symptoms,

first approached a facility, received a diagnosis and first entered treatment. Most patients had accessed treatment when interviewed; a few had left the maze as survivors. The longest delays within the maze were between first entry and diagnosis (Table 4.2), with little time expended before entry. The delays between diagnosis and treatment were generally shorter in both countries (Table 4.2), but again there was worrying variation.

Once in the maze, patients had moved between facilities, sometimes returning repeatedly to the same facility in search of help (Box 4.1). We call this stressful experience ‘churning’ (Makene et al., 2022): multiple visits that generated cost burden for patients and their families, even as their symptoms worsened. A majority of the moves in both countries were so-called ‘self-referrals’: patients’ failing to find the care they needed, hence, trying another facility. From entry to first treatment, a quarter of patients had visited seven or more facilities in Tanzania, and eight or more in Kenya. Many patients had used their own knowledge, advice from friends and family or just tried other places in their search for help.

Clinicians interviewed in both countries acknowledged that referral systems were failing to provide patients with an effective guide through the maze. One commented:

Referral patterns ... need to be improved in our country ... we need to be able to have a proper referral, not just to send a patient to a higher level of hospital without communicating to the doctors there. (Health worker, Kenya)

As a result, the cancer care access maze included many dead ends, where patients turned away and tried another route, with increasing frustration and pain. Navigation was difficult: each individual pathway through the maze reflected a patient’s fears, information, actions, responses, emotions, thoughts and considerations of family needs, and worries as they interacted with health care providers.

Did the different points of entry influence experience in the maze? Patients who entered the maze at referral hospital level might be expected to have received more rapid diagnosis. But strikingly in Tanzania that was *not* the case, raising questions about diagnostic capabilities in the regional hospitals (Makene et al., 2022). In Kenya however, those starting at primary level did spend more time in the maze before diagnosis (median 3.3 months) than those starting at hospital level (median 2.4 months).

Yet some patients did find a more rapid route through, avoiding blind alleys. In Kenya, starting at a private facility speeded diagnosis a little. In Tanzania, many of those starting in the private sector found a more rapid path: their median delay between first facility visit and entering treatment was just over 5 months, much faster than 16.5 months for all patients. A Tanzanian breast cancer survivor explained how that could work (Box 4.2).

Box 4.2: A Private Sector Access Pathway for Breast Cancer

A Tanzanian woman cancer survivor, aged about 40, a professional with higher education, felt pain in her left breast. She was unwilling to do anything, but a work colleague informed her employer, who insisted she seek care. She held private health insurance, and went directly to the leading private hospital, also a cancer centre, in Dar es Salaam. Ten days after a mammogram and biopsy she was told she had breast cancer and required surgery. She resisted at first, and sought a second opinion from a specialist private clinic, who counselled her and sent her back for treatment at the initial hospital. The time from first approaching the hospital to starting treatment was just two months. The key facilitating factors were insurance, entering at a cancer centre, rapid turnaround and good advice.

Why was access to cancer care experienced by many as a maze? Two key reasons stand out from patients' stories. First, a malign interaction between availability—whether services exist—and accessibility—whether patients can get to them. And second, the closely linked unaffordability of care, that delayed and diverted patients as they searched for funds.

AVAILABILITY AND ACCESSIBILITY IN THE CANCER CARE MAZE

Unavailable Diagnostic Services Close to Home

For diagnosis to be accurate and fast, essential services need to be close to patients. The Kenyan colon cancer patient (Box 4.1) found the diagnostic services she needed unavailable close to home. Later, having travelled, she found colonoscopy still unavailable. Meanwhile the Tanzanian breast cancer patient (Box 4.2) had unusually benefitted from diagnosis and treatment available in the same private facility in her home

town. An absence of diagnostic capability close to home was a widespread experience among patients interviewed in both countries.

Unavailable services often included lack of recognition and rapid response to early symptoms that could indicate cancer, resulting in false reassurance. Patients had often experienced these failures when going initially to lower-level facilities such as dispensaries and private clinics that might be close to home. They also met delays at hospital level, when health personnel treated patients' symptoms without a detailed search for their underlying cause. It often took persistence and repeated visits before cancer was suspected. Once there was suspicion, local facilities often lacked key diagnostic capabilities, as one breast cancer survivor described:

I was breastfeeding, then my breast started swelling. I went to the dispensary and I was told that it was just milk. I was given painkillers and other medication to use, but they were not working. I went back and was sent to take a mammogram, and then it was found out that there was a mass-like substance, which needed further investigation. I was then sent to do a biopsy, that is when they found out I had cancer. (Cancer survivor, Kenya)

The capabilities patients identified as unavailable included diagnostic equipment, laboratory capabilities and staff with the relevant expertise.

The primary public facilities and local public hospitals, along with some private clinics, were generally the closest facilities to people's homes. Most patients in both countries had started there (Table 4.1). However, the experienced diagnostic limitations—in both staffing and equipment—meant that most patients had to move on as their symptoms worsened. A majority in both countries had been diagnosed at public referral hospitals (61% in Tanzania and 55% in Kenya), while a substantial minority had accessed diagnosis in private facilities, including private laboratories, that offered diagnostic tests and interpretation (22% in Tanzania and 20% in Kenya). Only 3% of patients in Tanzania, but a much larger 23% in Kenya, had been diagnosed in local public or lower level FBO hospitals (mainly district hospitals in Tanzania and sub-county hospitals in Kenya). The winding route to accessing facilities with staffing and equipment available for diagnosis made up much of patients' maze-like experience of searching for care, as Box 4.3 illustrates.

Box 4.3: Accessibility Struggles for Prostate Cancer

A 74-year-old Kenyan farmer and small businessman with a declared household income of USD 20 per month saw a TV advert urging people in his age group to go for cancer screening. Encouraged, he went in February 2018 to a private clinic for a check-up of testicular swelling he was experiencing. The clinic did blood tests, suspected abnormality, and sent him to a referral hospital in Meru town for imaging; the results were sent back to the private clinic for interpretation. There, he was given medication (antibiotics and analgesics) and reassured. His symptoms worsened and two months later he self-referred, on a friend's advice, to a Meru hospital with a cancer centre. After blood tests, he was again reassured. Frustrated by worsening symptoms, he went to another private clinic, receiving more reassurance and medication while his suggestion of surgery was rejected. In worsening pain, he self-referred back to the first referral hospital where a PSA test¹ gave the same result.

He then went to a mission hospital (MH) in another town (about 260 km from Meru), where after another PSA test, they finally booked him for surgery. A month later he was told he had cancer. Shocked, he self-referred to a private cancer treatment centre in Nairobi, which sent him straight back to the MH to get the medical report. Back in Nairobi, the hospital required X-rays, CT scan and MRI which he could not afford, so he went home. Later, he went to a private radiology facility for the imaging, but they had no MRI. Sent to a different Meru hospital for the MRI, he found the required staff member was absent. After discussion with his children, he went to a private clinic in Nairobi where the MRI was done. He took the results to the private hospital cancer centre in Nairobi. That hospital referred him to a hospice in Meru. (He commented that he did not understand why.) The hospice sent him back to the Meru public hospital cancer centre, where he paid for yet another CT scan, and was enrolled in oncology treatment in May 2019. The patient commented when interviewed that he was relieved to be now receiving care near his home, which he felt was affordable. Up to that point, before starting treatment, he had spent KES 104,750 (USD 1027). He did not mention any access to insurance.

Travel Challenges

Both the prostate cancer patient (Box 4.3) and the colon cancer patient (Box 4.1) had to travel from home to specialist cancer centres and other

facilities with diagnostic capabilities, located in the major towns or cities away from patients' homes. A cancer survivor shared similar experiences:

...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 survivor, Kenya)

These accessibility challenges were a very common experience. Cancer is a complex disease, and once it is initially diagnosed, more tests are required before treatment can be decided. The prostate cancer patient had faced delays because of inability initially to pay for those further tests, and like many others, he had moved between facilities looking for more affordable tests and, later, treatment options.

A Kenyan health professional in a specialist cancer centre pointed to the range of tests available nationally which patients may not realise they require before and after treatment:

Key diagnostic tests we have are imaging, ranging from PET scan ... to CT scan, MRI, ultrasound and X- rays ... to see the extent of the disease, to be able to stage the patient. We also do laboratory tests of patients which [are] quite available like seeing how the organs work like liver function, kidney function tests. And sometimes just to see that the full haemogram this enables us to make decisions regarding whether they need chemotherapy. (Health worker, Kenya)

In some cases, patients had to travel to another town or city to deliver their biopsy sample to a laboratory. Even when the hospital sent the sample, it could be slow: one caregiver noted that two months later, the patient still did not have the result of a biopsy sent to Nairobi.

All this travel between facilities, and number of payments to facilities, imposed costs on patients. Disparities among patients emerged as patients struggled to raise funds to continue to navigate the cancer care maze. When patients had to travel long distances, they also had to find the means to cater for accommodation and food.

Travel to access diagnostic procedures and treatment emerged as a key reason for delayed diagnosis, sometimes leading patients to abandon their search before diagnosis (see Chapter 5). Health workers in both countries

were aware of patients' responses to these accessibility constraints. One health professional working far from the main cancer centres commented:

Sometimes you might know that this patient will go home with no follow-up and finally they die. Because you identify a problem [abnormal cervical cells] and refer, but they can't afford to go financially... (Health worker, Tanzania)

In Kenya, the same travel constraint was noted as regards treatment:

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, Kenya)

Navigation Constraints Within Facilities

Once patients arrived at higher level facilities expecting available services, accessibility of timely care was still not guaranteed. Access was impeded by familiar navigation challenges that included no clear guides on where to start, long queues and capacity constraints. Navigating very large hospitals not solely dedicated to providing cancer services becomes difficult for patients. It may take a lot of time to get to know where to start, as a patient's caregiver explained:

So, when they talked of [a national referral hospital], we went there and we stayed for like two 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 and to follow the line [queue], as was compulsory. I wanted it to be faster. (Caregiver, Kenya)

The long queues to book appointments were familiar to many:

You come to [a referral hospital], 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] another two weeks" ... while your cancer is growing. (Cancer survivor, Kenya)

Another said:

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. (Patient, Kenya)

The patient is thus smacked with the reality of the health systems' challenges even at high level hospitals, including shortages of staff and equipment. Cancer as a disease is complex, and there are many types of cancer, making care and management varied and difficult. Cancer care requires patients to interact with different departments, facilities and health personnel, who in most cases are not well linked up. Different professionals with different expertise have to be accessed to reach a milestone such as diagnosis. Patients' stories show how the disease demands great resources from them and their families, and the winding path can be disheartening.

As the cancer burden has risen, specialist cancer centres in both countries have multiplied and improved (see Chapter 5). In Kenya, a clinician commented:

We do all types of treatment for cancers here, all kinds of cancers, both liquid and solid cancers, we are managing here. (Health worker, Kenya)

In Tanzania, recent improvements in availability of oncology medicines and also equipment, for example for radiotherapy at the specialist national cancer hospital, were mentioned.

Currently about 80% of medicines are available at the hospital. This situation is not like it was before.² At that time patients prescribed three consecutive rounds of treatment often could not get the drugs on time as the hospital used to run out of stock, forcing patients to look for other alternative drug stores. (Health worker, Tanzania)

Increasingly, these facilities were drawing patients for chemotherapy and radiotherapy treatment from all areas of both countries, exacerbating pressure on available services in the major towns and cities. Like diagnosis, patients had to travel long distances and repeatedly in order to access multiple treatment sessions for cancer management, in facilities based mainly in the major cities:

We are treating people from as far as Western [Kenya] ...From Ukambani [Eastern Kenya], they have been coming here. (Health worker, Kenya)

Access to required blood transfusions had been experienced by many patients as a source of treatment delay, experiences health workers confirmed:

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...then the next day you hear your patient is gone just because of waiting for blood. (Health worker, Kenya)

Transfers and movement of key staff also posed accessibility challenges for patients. Trust is an important value in health care and one of its key aspects is loyalty to particular doctors or facilities (Gopichandran and Chetlapalli, 2013). The colon cancer patient's experience (Box 4.1) of following their doctor's transfer worked out well in the end, but for others, care might stop if personnel changed. Drug stock-outs that truncate treatment continued to be experienced by patients: another angle of unavailability:

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... they knew you are supposed to take it continuously, 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 survivor, Kenya)

Furthermore, even at specialist public health facilities, targeted cancer therapies were generally unavailable:

Yes, we do have the main regimens, I would classify them as first line, and we have like at least 80% or 90% first line regimens. The only challenge we have is targeted therapy, which can still be included in and give very good outcome especially with breast cancer patients... We currently are not able to access most of the regimens. (Health worker, Kenya)

Finally, counselling remains largely unavailable for patients groping through the maze, despite the scale of spiritual and psychosocial pain associated with cancer by patients and their carers (Chapter 3).

Most patients with 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. (Health worker, Kenya)

UNAFFORDABLE CARE

Cancer is *expensive*, in terms of money, resources and time. Payments by patients were a heavy financial burden on the low-income families who made up most of those interviewed. Health professionals saw the need to reduce costs:

... because it is expensive ...the screening, the treatment, the investigation, the diagnosis, everything is expensive to them, and these people are poor. (Health worker, Kenya)

Unsurprisingly, some participants felt that seeking cancer care becomes a narrative by only those who could afford it. Many managed to pay large sums, but the amounts families had raised should *not* therefore be characterised as ‘affordable’. Rather, these families had lost assets, foregone other essential expenditures and lost future opportunities (Chapter 3). In truth, cancer care was *unaffordable* and impoverishing for most patients interviewed, concurring with other recent findings (Kizub et al., 2022). Hence, we cannot know what happened to those excluded for inability to pay: are they the forgotten?

Three aspects of unaffordability are discussed here: how unaffordable payment demands interact with unavailability and inaccessibility to worsen delays within the maze; the effect of the private sector in raising costs for patients even while facilitating access for some; and the regressive and impoverishing impact of payments on family incomes.

Unaffordability and Delays Within the Maze

Why are cancer costs so high? Some elements of cancer care are inherently expensive: chemotherapy uses expensive medication; radiography uses expensive machinery. Scanning and laboratory investigations add to costs: cancers are complex illnesses and good diagnostic testing is key to both diagnosis and effective treatment.

However, the maze experiences add severely to the financial burden on patients *and* the health system. Every time patients moved around, or returned to a facility, in search of care more payments were accumulated. Most were paid out-of-pocket (OOP), especially before diagnosis. Difficulty in finding money caused delays and frustrations, causing more “churning” between facilities hence further financial costs. The next narrative (Box 4.4), from a patient undergoing treatment for metastasized cancer, illustrates how unaffordability, distance, locally unavailable services, and delays in diagnosis and treatment interacted.

Box 4.4: Unaffordability and the Costs of Delay

A female Tanzanian farmer, with primary education and a household income of USD 43 per month, first experienced pelvic pain and fever in 2017. After treatment for malaria had no effect, a dispensary ultrasound found a suspected lump in her uterus. She was referred to a district hospital, who repeated the ultrasound, did blood tests, and diagnosed a urinary tract infection. Antibiotics did not relieve her symptoms. In mid-2018, with pain and heavy bleeding, she returned to the district hospital which repeated the ultrasound, found a lump in her uterus, and referred her to the national referral hospital for surgery, a road trip of at least 200 kilometres. She did not go. Two months later, with more severe symptoms, she went to a regional referral hospital where the lump was found again, and she was again referred to the national hospital as the only place for a surgical biopsy. She could not pay the TZS 150,000 (USD 65) biopsy cost, so she was discharged. At the end of 2018, now very weak, she returned to the district hospital and again was referred to the national hospital for surgery. She did not go. Two months later however she went directly to the national cancer hospital where she was admitted and diagnostic tests repeated, this time without charge.

Two months’ later the results showed advanced cervical cancer that had spread. Surgery at the national referral hospital also diagnosed inoperable ovarian cancer. The patient returned to the national cancer hospital for six cycles of chemotherapy. After three cycles she was asked to go back to the national hospital for a biopsy to check the impact, but again she could neither pay TZS 150,000 (USD 65), nor afford to go home and come back, so she continued with the last three cycles at the cancer hospital, where we met her in mid-2019. She calculated OOP spending by then of over TZS 1.1 million (USD 482), more than seven times her

declared monthly household income. She had raised this through considerable financial support from her mosque, some help from other local organisations including local government, and USD 155 from personal funds. We cannot know what her prognosis would have been if she had undergone a biopsy when a dispensary first picked up a suspected lump, two years before we met her.

This upsetting story illustrates several key aspects of the maze as experienced by patients: a hospital failure to follow up on an early suspicion of cancer (showing that it was not always at lowest levels that cancer symptoms were missed); inability to pay for surgical biopsies delaying diagnosis and preventing diagnostic investigations important in fine-tuning chemotherapy; the costs and difficulty of travel also delaying diagnosis; and the sheer burden of accumulating payments causing reliance on religious communities and local forms of solidarity just to reach a diagnosis. Conversely, chemotherapy without charge at the specialist hospital facilitated access to treatment.

Diagnostic failures generated cumulative payments by patients which could quickly become unmanageable. Payment for diagnostic tests was often preceded by a history of other payments: charges for medication, tests and surgery, using up scarce family financial resources as well as delaying treatment. Patients had spent money on multiple consultations and inappropriate or unnecessary treatment. Each visit of this type generated payments and used up precious savings. Even screening in response to public health information—as the prostate cancer patient had undertaken—could be prohibitive:

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 other costs. (Cancer survivor, Kenya)

Diagnostic charges had repeatedly caused delays as patients searched for funds. For example, a Tanzanian patient with a breast lump paid for an ultrasound and X-ray at a faith-based referral hospital. However, the hospital also “wanted to take sample from my breast, but I didn’t have

extra money”. This caused a further five months’ delay until money was found, and earlier tests had to be repeated: her total OOP cost including the later biopsy after the patient found more money was TZS 190,000 (USD 83).

The costs of travel for consultations, tests and treatment could be prohibitive, as the cervical cancer patient’s story (Box 4.4) illustrated. Even when more accessible hospitals could take biopsies, patients in both countries frequently had to travel to take their biopsy samples to a higher-level hospital laboratory for analysis (see Chapter 5). Lack of accessible services close to home, and long distances and costs of travel to a specialist hospital meant that some patients gave up, as a health worker in a geographically remote Tanzanian hospital noted above. A Kenyan health worker concurred:

...those who are 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, Kenya)

Just fear of these costs could derail care. A Tanzanian female patient, and farmer, recounted that she had waited more than six months after diagnosis before travelling to the national cancer hospital, because she did not have the bus fare, and because people had said it was so expensive that she initially decided not to go at all.

That fear was based on experience. The highest charges faced by patients were for surgery and treatment. Chemotherapy medicines are unaffordable for most patients. In the Tanzanian specialist public cancer hospital where free treatment depended on availability of drugs, supply was good in 2019, but patients in earlier years had experienced stock-outs. In Kenya, those who had paid OOP for chemotherapy drugs reported delays and drop-out:

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. (Patient, Kenya)

It reached a point I had no money to continue with chemotherapy treatment. I used to buy the drugs. (Patient, Kenya)

Insurance and Private Care: Facilitation but High Costs

Each of the patients' stories, except the cervical cancer patient (Box 4.4), had included use of the private sector. Resort to private, independent faith-based and NGO facilities had been greater in Kenya than in Tanzania: 27% of Kenyan patients had started there (Table 4.1), and 36% had been diagnosed there. The figures for Tanzania were 21% and 22%, reflecting greater private sector availability in Kenya.

Private facilities in both countries focused on offering diagnostic services. Multiple tests were sometimes proposed, and charges could be prohibitive. A patient recounted a visit for urinary pain to a private doctor, for a second opinion after medication had not resolved his symptoms:

The surgeon asked me to do some tests including ultrasound of the prostate, colonoscopy, blood tests, rectal examination. I went home to look for money. (Patient, Kenya)

The payment for those tests at a private hospital was KES 24,000 (USD 235). Kenyan patients in particular were aware that private facilities imposing these high charges were benefitting from limited testing availability within the public sector:

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 [demands]. (Cancer survivor, Kenya)

The private facilities and laboratories had increased availability of care while exacerbating the serious affordability challenges.

Insurance, conversely, was a key facilitator of access to cancer treatment, as the breast cancer patient's story illustrates. The National Health Insurance Funds of Tanzania and Kenya (NHIF in both) covered public employees, some other employees, and individuals who paid for the cover. In Tanzania, 31% of patients interviewed held NHIF, private insurance or both, far higher than the national population coverage of 9% estimated for NHIF in 2019.³ In Kenya patients arriving at cancer treatment centres without insurance were encouraged to take up NHIF insurance, though it covered only part of cancer care costs:

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, Kenya)

This advice had clearly been facilitative for patients in Kenya. Strikingly, only 20.5% of the patients interviewed in Kenya had *not* had recourse to NHIF funding at some point. However, 88% had paid part or all of their first treatment costs in cash. Treatment exclusion is likely for those who cannot reach hospitals where treatment is free in Tanzania, or fail to gain NHIF membership in Kenya.

Payment Burdens and Impoverishment

Many people have sold a lot of things at home. When you get cancer, you and your family will get poor. (Health worker, Kenya)
Cancer treatments should be at low cost in order to be manageable by low-income people. (Patient, Tanzania)

Patients could not afford these cost-related delays, which reduce survival, nor the impoverishment and financial stress the payments implied. Most were on low incomes, and almost all were interviewed within the public health system (all in Kenya, 80% in Tanzania). Of the public sector cancer patients, 25% in each country declared household incomes of below one dollar a day; half declared less than 3 dollars a day. Payments that impoverish families can never be called “affordable” even if, somehow, people have managed to pay.

Patients’ strategies to find money had brought much collateral family damage (see also Chapter 3). Many payments had been far beyond the limit of what was truly affordable while continuing to support families’ basic needs. Furthermore, these were patients who had succeeded in *finding* the resources to continue through the cancer care maze, despite delays. Their struggles strongly suggest that there will be many people living with cancer in Kenya and Tanzania whom we could not interview

because they had been unable to meet the financial demands and had dropped out of the maze. There exists no database in either country of people living with cancer excluded from diagnosis and treatment because of inability to pay.

Cancer had leached family resources in multiple ways, as patients explained:

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, Kenya)

I needed money to pay for treatment. All I had, pigs and cows, were sold to access treatment at [a private] medical centre. By the time I came to [the cancer centre at a public hospital], I had nothing to sell. (Patient, Kenya)

Many had lost family assets that would otherwise produce income. In Tanzania, one patient sold a plot of land to finance a CT scan (USD 173); the husband of another sold chickens to fund an ultrasound, X-ray and surgery (USD 78); a third sold a cow to fund a biopsy (USD 65); another sold 4 hectares of land worth TZS 1.2 million (USD 522) to fund six chemotherapy cycles costing USD 417 at a time when the national cancer hospital had suffered severe shortages of oncology medication.

Worse still, this impoverishing effect was greatest at the lowest income levels. Table 4.3 compares total reported out-of-pocket spending on consultations, tests and treatment, from first symptoms to our interview, to patients' reported household income levels. It shows that, at the lowest of three income bands, median cumulative OOP spending had reached 72% of patients' declared annual income in Tanzania, and 155% in Kenya. A quarter of patients in Tanzania in the lowest income band furthermore had spent over 1.5 times their annual income; in Kenya the figure was 4.5 times. The burden of OOP spending was sharply lower at higher income levels in both countries.

These participants were at different stages in their cancer journey, so spending had necessarily varied. But the finding of regressive impact of OOP spending is robust.⁴ OOP spending by these cancer patients in both countries was unjustly distributed, falling most heavily on the poorer households. Cancer is unaffordable.

Table 4.3 Household burden of OOP payments: Median cumulative OOP spending from first symptoms to interview date as % of annual income, by income bands

<i>Income bands</i>	<i>N*</i>	<i>Median OOP spending % annual household income</i>
Tanzania: Bands of declared household monthly income (TZS)		
Up to 150,000 [Up to USD 65]	12	72%
160,000–390,000 [USD 70–170]	13	9%
400,000 upwards [USD 175 upwards]	13	9%
All respondents	38	17%
Kenya: Bands of declared household monthly income (KES)		
Less than 5000 [less than USD 49]	116	155%
5000–10,500 [USD 49–107]	138	45%
11,000 upwards [USD 108 upwards]	134	17%
All respondents	354	43%

*Number of patients able to recall 70% or more of payments. Currency conversion equivalence established according to the exchange rate at the time of interview

TACKLING THE MAZE?

Access to cancer care, as patients described, formed a ‘maze’ experience that was often frustrating, frightening, slow, confusing, expensive, exclusionary and debilitating. What would it take to straighten patients’ pathways and dismantle the walls of the ‘maze’ (Fig. 4.1)?

Information, Maps and Guides

Patients’ experiences of the maze were often lonely. Many repeatedly ‘self-referred’, a phrase that does not do justice to an unguided search for help, relying on advice from family, friends and neighbours. So one big gap for patients was *information*. Many interviewees asked for more information about cancer symptoms, diagnosis and prognosis, care and treatment. There was a widespread lack of information on screening, on key symptoms and on what to do if symptoms were experienced. Public information campaigns would help, explaining symptoms and also providing reassurance that cancer diagnoses are not an inevitable ‘death sentence’.

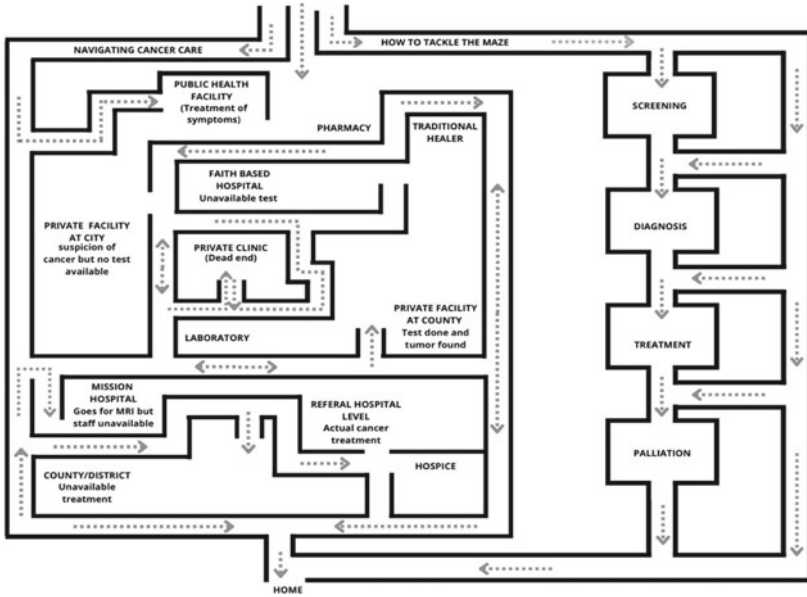


Fig. 4.1 Tackling the maze

Even when a patient was formally referred, suspicion of cancer was often not followed up at a higher-level. Many health facilities’ staff lacked information and index of suspicion about symptoms that could indicate cancer, repeatedly treating patients for other illnesses even as the symptoms recurred. Appropriate referral with relevant data for the receiving facility is essential, as is better support for patients navigating to cancer care services within facilities.

Financial Support and Lower Costs

Maps and guides are no help if a patient cannot afford to turn the next corner in the maze. ‘Affordability’ is a demanding ambition in the context of cancer care. Affordable care requires charging that does not leave families impoverished, nor force patients to delay or drop out of care. Charges remain prohibitive for lower income patients. The more people can be brought into adequate insurance, covering all cancer treatment costs, the less impoverishing the access maze will become. Insurance in turn must be

affordable. Extending social insurance, and subsidising premia for those of lower incomes, would reduce cost barriers. So would subsidy or waiver for diagnostic tests once cancer is suspected. Finally, lowering diagnostic and treatment costs from the supply side facilitates these efforts (see also Chapters 7–9).

Accessible Capacity for Cancer Care

Much public sector cancer care capacity in the maze was inaccessible for many patients from their homes and families. Improvements in diagnostic capability in health facilities accessible at district or sub-County level would reduce travel costs, speed up diagnosis and treatment initiation, and help to reduce OOP spending through less reliance on expensive private services. The more that diagnostic, treatment and palliation facilities can be spread outwards from the larger cities in both countries, the more the inequitable disparities in accessibility can be reduced.

Political and Government Support

Political will to support cancer care initiatives at the counties was reported in both countries, with counties in Kenya, where health planning is devolved, taking the matter seriously. Financing from the County administration in Kenya, and from the national government in Tanzania, was credited by participants with having increased availability of cancer drugs and specialist equipment. Current efforts in both countries to improve availability and affordability can be built upon, including strengthening insurance and fee waivers.

Chapter 5 picks up from these points, and makes a deeper dive, from the point of view of health system professionals and policy makers, into one of the most serious aspects of the access ‘maze’: the delays before diagnosis.

NOTES

1. A prostate-specific antigen (PSA) test is a blood test that can help to identify early stage early-stage cancer.
2. That is, before the current government administration at the time of interview.

3. <https://www.nhif.or.tz/pages/profile#gsc.tab=0> consulted 22/07/21.
4. The OOP spending is also regressive for other categories, such as spending from entry into the maze to diagnosis, and it is regressive across the spending distributions.

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