



Beyond “Late Presentation”: Explaining Delayed Cancer Diagnosis in East Africa

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INTRODUCTION

[Diagnosis] is like the basis of everything. If I am diagnosed early, I have a chance to survive. (Survivor, Kenya)

In Tanzania and Kenya, as in many other low- and middle-income countries (LMICs), the majority of cancer patients are diagnosed when their cancer is at a late stage, with negative implications for treatment options

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and efficacy, the cost of care, and rates of survival (Lehmann et al., 2020; Makau-Barasa et al., 2018; Mlange et al., 2016; Ngoma et al., 2015). Reducing delays to diagnosis, and increasing the number of patients diagnosed, is a policy priority in both countries (Ministry of Health, 2017; Ministry of Health and Social Services, 2013) and internationally (WHO, 2020). Enabling earlier diagnosis is critical not only for patient outcomes but also for its potential to reduce the cost of care for patients and healthcare providers (Espina et al., 2017, Moodley et al., 2018). However, research regarding factors influencing the timeliness of diagnosis of cancers in LMICs remains limited (Nnaji et al., 2022).

Delayed diagnosis is often framed as a challenge of “late presentation” by patients at health facilities, to be explained by patient behaviour and characteristics, and prompting calls for public education about cancer symptoms and treatment and the importance of prompt facility attendance (Kassaman et al., 2022; Mlange et al., 2016, Mwaka et al., 2021). Indeed, interventions aimed at addressing barriers to timely diagnosis in LMICs tend to emphasise improving patient, community, and to a lesser extent health provider knowledge, rather than addressing structural issues such as the financial costs associated with care (Qu et al., 2020).

It is certainly the case, as explored in Chapter 3, that limited knowledge and understanding of cancer and cancer treatment among patients, caregivers, and their communities contribute to fear and experiences of stigma, influencing whether and how patients seek care. However, this chapter builds on Chapter 4’s demonstration, from the accounts of patients, caregivers, and survivors, of the limitations of “late presentation” in explaining delays to diagnosis. We shift here to a more “professional” health system perspective, drawing largely on interviews with health professionals and policymakers in Kenya and Tanzania. These interviews identified key challenges, including access to screening, weak referral systems, the very limited availability of diagnostic pathology, and the direct and indirect costs of obtaining a cancer diagnosis, to which feasible responses could speed diagnosis. We argue that policy aimed at increasing early diagnosis must go well beyond improving population knowledge to

address wider health system issues such as referral procedures, availability and accessibility of diagnostic tests, and the affordability of care.

DELAYED DIAGNOSIS IN KENYA AND TANZANIA

Late diagnosis of cancer is a significant problem in Kenya and Tanzania. Health workers providing specialised cancer treatment in both countries described the challenges associated with “late presentation” of cancer patients at specialist hospital level and the implications for treatment and outcomes. As one Kenyan policymaker explained:

...people are just presenting... to hospitals and being diagnosed with cancer when it is too late...when you present with cervical cancer, for example, and it is stage 1, you might be lucky, maybe you will only need surgery. But when you present with stage 4, you will need surgery, chemotherapy, radiotherapy, I don't know [immunotherapy]... they will be so many treatments and the outcomes may not be that good.

They estimated that 80% of patients “present late, so that means in stage 3 or 4, when it is already too late”. In Tanzania too, a health worker at the national cancer hospital reported that 80% of patients arrived at that hospital “when their disease is at a late stage. Only 10 or 20 percent come at an early stage when their cancer might be curable”. Much of the treatment provided thus involved palliation. A Kenyan nurse working in oncology claimed they had “never seen a patient who [is] stage 2, as in early stages”, meaning “we just try to control and try to prolong life”, something they found “just devastating”, and that meant “it calls for God's grace” to do their job.

Some health workers did attribute late diagnosis to patients' lack of knowledge of cancer and cancer treatment, and their preference for alternative healing:

You know some people think [their illness is] witchcraft and we have to take them from that thinking... I know in Kenya 95% of people believe in witchcraft... 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 the hospital. (Health worker, Kenya)

The use of alternative healers was described as causing patients to delay reporting to health facilities, meaning that “when they figure out it is not working, they present themselves and by then it is a little bit too late in terms of curative options” (health worker, Kenya). By that time, “they have lost most of their income and the situation has worsened to an advanced stage” (health worker, Tanzania).

However, health workers also often acknowledged that patients were not solely responsible for their late diagnosis. As one Kenyan nurse put it, “by the time they land there [in the hospital] they came from somewhere; they have a story in between”. This story involved difficult attempts to navigate the “maze” described in Chapter 4. Indeed, the majority of delays for patients in both Kenya and Tanzania, occurred *after* their first visit to a health facility, so these patients’ delays cannot solely or primarily be attributed to patient attitudes, knowledge or behaviour. This chapter explores the systemic health system factors causing delay, demonstrating that attempts to speed up diagnosis must go beyond efforts to increase patient awareness or discourage the use of alternative healers.

SCREENING AND EARLY DETECTION

For some cancers, screening offers a significant opportunity to increase early detection. Consider cervical cancer, which represents a significant burden in Kenya and Tanzania, and which can be screened for using low-cost methods with potential for early preventative treatment. Both Kenya and Tanzania have adopted cervical screening policies, involving a combination of visual inspection of the cervix with acetic acid (VIA) and/or Lugol’s iodine (VILI), cytology-based screening (e.g. a pap smear), and testing for human-papillomavirus (HPV). However, in neither country is screening provided as a comprehensive population-based, regular service for at-risk populations. Instead, screening is largely provided through ad hoc “outreach” events run by specialised public facilities or non-governmental organisations or is sought or undertaken in response to potential symptoms.

One health worker in Tanzania explained: “only women who suspect they have a problem attend the [cervical screening] clinic...[by which time] it is difficult to help them... Some women come here telling you, ‘I just accompanied my friend’, while at the same time they also need to be screened. So education hasn’t reached many”. These views were echoed by cancer survivors in Kenya, who explained: “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". In addition to education and awareness deficits, research participants in both countries attributed low levels of screening to the absence of a “culture” of attending health facilities in the absence of illness. According to a senior policymaker in Kenya, “[t]he major challenge we have currently in cancer as a society [is] we have never embraced the idea of wellness checks or screening, so ... people are just presenting to hospitals and being diagnosed with cancer when it is too late”. Thus, one health worker in Tanzania concluded “we need to develop a culture of checking our health often”.

Limited *demand* for cervical screening, however, is only part of the challenge. While outreach events in both countries were described as popular, with attendances of approximately 1000 reported at events run by national cancer hospitals, their reach is inevitably limited. One Tanzanian health worker noted, “when we take screening to the community people respond positively. The problem is that it doesn't reach them a lot.” Another health worker confirmed that “all these efforts aren't enough because the programmes reach a very small population” (health worker, Tanzania). In regions outside of major cities, screening is not widely and routinely available in lower tier facilities. Where it is offered, staff shortages and high workloads constrain the ability of staff to provide an effective and consistent service. In Tanzania, staff at one regional hospital, located in a region with very limited other screening provision, noted that the four people trained to perform screening using VIA struggled to do so alongside their other roles. As one nurse explained, “we are not sufficient. Sometimes women go back home without accessing a [screening] service because we might be dealing with other responsibilities”. Indeed, elsewhere, if demand for screening were to increase, it was anticipated it would be difficult to retain existing levels of provision (health worker, Tanzania).

There are also barriers to attending screening programmes where they are available. In Kenya, one survivor articulated the difficulty people faced in spending money on routine and preventative health care when there was no urgent need for treatment, saying:

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”.

Although in Tanzania VIA is available free of charge, the limited geographic coverage meant many people faced travel costs to reach a facility (Chapter 4). Without running events to provide screening closer to people’s homes, health workers realised it could be difficult for people to attend. As one doctor at a facility which only conducted screening at the hospital described, only those who can afford transport are able to attend, meaning “when we are looking for big numbers, we don’t get those numbers, we just get some numbers” (health worker, Kenya).

International and local NGOs play a big role in cervical screening provision in Kenya and Tanzania, including the provision of training to health workers, funding of clinics and equipment, and organisation of outreach events. For some health workers, this model raised concerns about its likely sustainability and ability to cope with greater numbers of patients. In Tanzania, where a different international NGO supported screening in each region in which research was carried out, some funders had indicated that cost-sharing might be required in the future, suggesting providers “need to be independent because in the future they might not be able to supply us with the necessary equipment” (health worker, Tanzania). In Kenya, a health worker described attempts to encourage people to attend screening, and to incur the travel costs associated with doing so, by offering lunch, but “the sponsors ran short of it and they just had to go away”.

A more general difficulty associated with maintaining donor-sponsored initiatives also posed a potential challenge to the sustainability of cervical screening, as described by one Tanzanian health worker:

The problem is that this training is part of vertical programmes... for example, people come to a place for research and diagnose many women etc. and incentives are made available. But when they leave, despite the fact they built capacity, when the programme ends those who are left don’t continue...I have seen this in [my previous posting]. You realise [the work has stopped] after you see the number of people who visit the centre going down. Their argument is that they don’t have money to keep it going...these vertical programmes make our health providers lazy because they think this is the way of doing things that should continue while in reality these are their responsibilities... The problem arises when it comes to sustainability. When they [the sponsored projects] leave is when we see

gaps. You made this guy feel comfortable with the programme, when you ask them to start walking by themselves they start going backwards.

Others highlighted the importance of donors in shaping priorities within the health system, comparing the relative lack of support for cancer to that available for HIV or for maternal and child health, which indeed were largely the primary focus of those international NGOs supporting cervical screening. One pharmacist concluded, “we only prioritize things that will be supported by our partners” (health worker, Tanzania).

WEAK REFERRAL PROCESSES

In order to access diagnostic imaging and laboratory tests, patients who entered the health system at lower tiers generally had to be referred, or to self-refer, to a referral hospital (levels 5 or 6 in Kenya; regional, zonal or national hospital in Tanzania), or to access procedures in the private sector. As described in Chapter 4, referrals were a challenging aspect of the maze. The “churning” (Makene et al., 2022) described there also affected patients prior to diagnosis, contributing to delay. In both countries, national cancer treatment guidelines and cancer control strategies emphasise the importance of effective referral systems, while also acknowledging challenges faced by patients in obtaining timely referrals at present (Ministry of Health, 2017; Ministry of Health and Social Services, 2013). Indeed, Tanzania’s National Cancer Control Strategy notes that the current referral system is “long and leads to late detection of cancer and delays in treatment” (Ministry of Health and Social Services, 2013, p. 8).

Health workers, survivors, and patients recalled examples, and sometimes their own experiences, of mis- or partial diagnosis over extended periods and multiple visits to health facilities, which led to costs and delayed the start of appropriate treatment. One survivor in Kenya who was a member of a support group for those with cancer of the colon, for example, reported that many of their peers had been “treated for typhoid, amoeba, ulcers, h-pylori, for a very long time. Some even for years”. Limited capacity to identify potential cancer symptoms at lower tiers of the health system was part of the problem, as a senior policy maker in Kenya described: “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”. One health worker in Tanzania explained, “the bad thing is that when people [at lower tiers] can’t detect [cancer] early, in most cases they just offer medication and give [patients] prescriptions to use them for three weeks and come back for a check up again”.

A health worker at a facility providing cancer treatment agreed that sometimes “it is our fault” (health worker, Kenya). They recalled a patient who had arrived at the facility with breast cancer so advanced that:

Her breast is...just like a wound until the necrosed flesh is falling off until the chest becomes flat...So 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 came to [national hospital]’...Now this clinician in a dispensary could have suspected... 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, could have taken an initiative, this patient maybe right now could be having a different stage of illness, not the metastasized stage. So...I think...we as the health care providers, we contribute in delaying the diagnosis.

Even when given a referral for suspected cancer, patients face challenges and delay. It was not always possible for patients to move directly from lower tiers to a facility at which they could be treated. One health worker at Tanzania’s national cancer hospital, which does not have its own pathology lab, explained:

You cannot open a file if the documents are not signed to indicate [prior investigations are complete]... If they are not signed it means there is a problem and a patient requires further investigative procedures... If a patient has been referred by a general practitioner, we will have to send them to [another national hospital] if we think what has been done is not sufficient, but if there is adequate information you can admit them.

Diagnosing cancer often involves multiple types of diagnostic procedure, often not available in the same place, generating delays when patients have to raise funds for travel or to wait for appointments or results (Chapter 4). Health workers in Kenya and Tanzania recognised the burden imposed by the requirement to move for care and identified the value of having tests and treatment available in one place for increasing speed of access to treatment. A health worker in Kenya reflected on the tumour boards they convened at their hospital, at which staff discuss the

patient’s pathway to diagnosis. This helped them to understand the extent to which patients “are taken up and down: go to surgical clinic, they are delayed; they [perform a] biopsy, the results get lost. So you are delaying the patient care”. They noted this was even a problem when patients were required to attend different departments within the same hospital and explained the aspiration for the oncology unit to be a ‘one stop shop’, with the ability to provide screening, symptom assessment, and to perform and analyse biopsies, “because it will prevent so many people coming when they are late”. With the current system, “sometimes when we go for tumour board we discover that some patients have... [had a] biopsy, but after the surgery nobody referred them to oncology for review and for treatment. So we need to pull our socks up on that bit”.

Experiences of long waiting times, broken equipment, or absent staff made it even harder and more expensive to negotiate referrals for many, and increased delays. One health worker in Kenya described challenges that could arise when referring patients with possible cancer to an already busy minor surgery unit in the emergency department for a biopsy: “sometimes emergency is also busy, they are delayed a bit, many activities—it is busy, there are accidents coming in—so sometimes you find a patient went for a biopsy and by the time he is coming with the result [it has been] like 3 months. It takes long actually”.

The weaknesses of the referral system meant patients often had to try to navigate the system themselves, self-referring up and down the tiers in search of a diagnosis and relief from their symptoms. Indeed, as explained in Chapter 4, a majority of moves by patients between facilities were self-referrals, which could involve moves up and down the tiered health system, and between the public and private sectors. Former patients described their own attempts to navigate the health system to obtain a diagnosis, often relying on advice from family and friends. This account, from a survivor in Kenya who had been treated for what they were told was “just a sinus problem” at ten different facilities over a six-month period is illustrative of the extent to which patients sometimes had to struggle to be heard and obtain a diagnosis:

I kept telling [health professionals] ‘no, I have been treated for this twice, it has not gone away.’ They tell me ‘take this antibiotic’ or ‘take this particular medicine – in two weeks it should be okay.’ And even when you are telling the doctor that ‘I have been treated for this thing twice, this is not what it is, it is something else’, he still prescribes the same things. So

even when you challenge them, they assume that you are a lay person, you don't understand these medical things. 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 [away]'. 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'. But it is just that process of going back and forth and even when you challenge, they assume you are not a medical professional, your opinion does not matter: 'I know what I am doing this is a sinus problem'. And that is why it took six months to diagnose (survivor, Kenya).

Thus, contrary to some analysis that suggests a "lack of personal initiative" on the part of patients who are diagnosed late (Mlange et al., 2016, p. 1), one survivor in Kenya, who had undergone tests in three public and private facilities before being advised to see a specialist who diagnosed them with breast cancer, observed, "if I didn't insist, I don't know where I would be, I would be six feet under". Persistence on the part of the patient was important in speeding up diagnosis but was often dependent on the ability to bear the costs associated with moving between facilities, and access to advice about how best to do so.

Moving between facilities, whether due to a formal referral or self-referral, was a major contributor to delay, with patients in Tanzania who moved more times waiting longer to be diagnosed (Makene et al., 2022). In addition to the time spent pursuing inappropriate treatment or waiting for appointments, moving between facilities involved additional costs for patients without insurance or who needed to travel away from their homes to access care. It could therefore be challenging to persuade patients to follow a referral, due to the cost and inconvenience it represented. One health worker in Tanzania described the response of patients to news they were being referred as follows:

...the big issue is that when you ask a patient to go for a referral they become resistant....[for two reasons] one is education and another is distance, because if a patient came from far away and had already spent a lot to come here thinking that they will get everything from here and you then ask them to go for a referral...they resist.. [they give] you excuses, even if

they have money they get argumentative thinking they can be treated from here.

Improving the speed of referral for those with suspected cancer could therefore play a key role in reducing delays. However, the necessity for referral and the difficulties patients face in navigating moves between facilities are closely linked to the availability of diagnostic tests at different levels of the health system, and the cost of care and of travel required to reach it.

PATHOLOGY AND LABORATORY CAPABILITY

A key factor necessitating referral to higher tiers of the health system, and consequently generating delay, is availability of pathology. This challenge was particularly acute in Tanzania, where regional referral hospitals cannot provide pathology. While some regional facilities can extract a biopsy, patients are still required to transport the sample themselves to a zonal or national hospital for analysis. Even at the highest tiers and in the private sector, pathologists are few. A leading private hospital had only one pathologist at the time the research was conducted, meaning that when this individual was on leave, they had to refer cases to a public national hospital (health worker, Tanzania). Although pathology services were available at the Kenyan level 5 facilities included in the study, capacity remains concentrated in Nairobi (Lehmann et al., 2020), and health workers described other challenges that caused delays for patients, meant they had to be referred elsewhere, or led them to use the private sector.

Limited access to pathology in the lower tiers of the public health sector means patients with a visible mass or other visually identifiable symptoms are likely to be referred upwards for further investigation (Schroeder et al., 2018; Stefan et al., 2015). While possible indicators of some cancers can be identified through a physical examination at lower tiers of the health system where pathology and imaging are not available, such as cervical, breast, skin, and advanced oesophageal cancers, others, such as blood cancers, are “very difficult to identify because it needs laboratory diagnosis” (health worker, Tanzania). As one Tanzanian health worker located a long distance away from specialised cancer care explained:

We only provide physical examination services to patients suspected to have cancer. For example, a woman who comes with a history of vaginal bleeding who reached the menopause three years ago and reports pain during sex with her husband; a man who is coughing up blood – we suspect these people have cancer and they are referred to referral hospitals.

In Tanzania, health workers at regional facilities without pathology capability identified expanding pathology as a key way in which their provision of cancer care could be improved. At one facility located over 340 kilometres away from the nearest public hospitals where a biopsy could be performed, the inability to carry out diagnostic tests meant staff were sometimes unable to provide surgical treatment despite its availability at the hospital. A doctor gave the following example regarding prostate cancer:

...you cannot plan to start treatment before you know whether it [prostate swelling] is benign or malignant. There is a very small tool we use called a tru-cut needle. It's something we insert to take a flesh sample to take to the laboratory. But our laboratory isn't equipped to do such a test which is very basic. If we could get such a tool and get a pathology lab... At least in every regional hospital there must be a small pathology unit so that small operations like that can be carried out. We wouldn't need to make a large number of referrals, because sometimes you get a patient with an enlarged prostate. We can remove it, but we aren't allowed to do this before confirming the type. So you have to send people to [zonal hospital over 340 km away] or [national hospital over 800 km away] or [zonal hospital over 400km away] just for a biopsy so that they can bring back the results as a go ahead. But if regional hospitals could be empowered in terms of supplies and equipment, as well as personnel, and have the capacity to do all those basic cytological investigations, I think we would have made a very big step within cancer care... If we have a pathologist in every regional hospital and good laboratory infrastructure we will move forward.

This was particularly pressing because health workers knew of cases when people had abandoned treatment prior to being diagnosed due to the cost imposed by a referral for diagnostic tests, as described in the following section.

Although the facilities outside of Nairobi at which research was conducted in Kenya could perform some pathology, interviewees identified challenges that could delay diagnosis. Delays in receiving biopsy

results due to congestion in surgery were described above, and health workers at one facility also discussed delays that arose due to relying on the general laboratory, rather than one dedicated to cancer. Shortages of reagents and equipment could also delay patient access to procedures. One health worker explained “in the side of diagnosis, we are lacking, because most of the patients you are given a request form and you are told to do the tru-cut [biopsy] or the FNA [fine needle aspiration] and you can wait as long as two weeks, three weeks, and a month, waiting to be booked”. They attributed this to reagents not being available, also noting that sometimes patients were asked to purchase biopsy needles to undergo a procedure, which meant that some patients chose to wait until the facility could provide this.

When certain tests were not available in public facilities, patients had to use the private sector, which could have significant cost implications, or were sometimes required to travel or faced a delay while samples were sent away to Nairobi. As one health worker at a facility which offered some pathology, but not histology, noted, “human resources is a problem, infrastructure is a problem, equipment is a problem. If we could get a better MRI machine and other things in processing like histology in the lab [that would be an improvement], because that runs around the cost of the patient”. Indeed, in Kenya, 27% of first visits to a health facility made by patients who participated in the research, all of whom were being treated in a *public* hospital at the time they were interviewed, were to a private sector facility (Chapter 4). Private clinics and laboratories played an important role in providing diagnostic tests for many, even as they continued to seek care in the public sector. Indeed, almost a fifth (18%) of all health facility visits reported by patients in Kenya since they developed cancer symptoms were to private facilities. This may be due to the wider availability of diagnostic tests in the private sector, which provides the majority of medical laboratory services in Nairobi, as well as perceptions of greater quality, convenience, and anticipation of a faster result for those who are able to afford such services (Bahati et al., 2021).

COST OF DIAGNOSIS

Delays associated with navigating referrals and the limited availability of diagnostic tests at lower tiers of the system were exacerbated by the costs associated with diagnostic procedures and moves between facilities. Patients and their families often delayed while they sought funds.

Although this research could not capture the experiences of those who abandoned the formal health system prior to being diagnosed, the number of undiagnosed cancer sufferers is significant (Gesink et al., 2020; Olson et al., 2020; Severance et al., 2022; URT, 2017). Interviews with health workers and survivors suggest that costs incurred prior to diagnosis and anticipated further costs are an important factor in causing patients to exit the formal healthcare system before diagnosis, or to delay seeking further care (see also Ariga & Mujinja, 2017). Facilitators of access discussed in Chapter 4, and particularly the National Health Insurance Fund (NHIF) in Kenya and the provision of free treatment for cancer patients in Tanzania, did not benefit patients to the same extent prior to diagnosis.

In Kenya, the NHIF covers most diagnostic tests, such as CT scans, MRIs, and some biopsies. However, health workers described encouraging patients to join the scheme *after* a cancer diagnosis. One caregiver described the limited protective potential of NHIF for new joiners prior to diagnosis, noting:

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.

Some procedures, which were not available in public facilities, could not be paid for using NHIF, such as lymph node biopsies, which must be taken to the private sector for analysis, meaning “for the biopsy, they [are] deep in their pockets, the relatives” (health worker, Kenya).

In Tanzania although free treatment is available in the public sector for patients who have been diagnosed with cancer, many incur significant costs prior to diagnosis. One health worker explained:

Cancer patients receive free medical treatment from dispensary level up to referral level, including palliative care. However, anybody who hasn't been diagnosed with cancer would find it almost impossible to get free treatment, even if they have all the symptoms of cancer.

As another health worker in a different region summed up: “treatment is free, but people pay”.

Challenges linked to poor referral systems and low capacity to diagnose outside of specialised cancer treatment centres, described above, meant some patients incurred costs from attending multiple consultations and receiving inappropriate or unnecessary treatment before cancer was suspected see also (Kohi et al., 2019). A survivor in Kenya described his story of treatment prior to diagnosis with prostate cancer:

In 2009, I could not go for a short call. Our family doctor advised me to take him a sample. It was very painful to pee. So he took it for examination. He did not tell me anything – he told me that it was normal for people my age.... He injected me and half an hour later I could now urinate normally. Then after a while... after intercourse with my wife I felt pain. I went back to the same doctor and he did not tell me anything. He told me to go to Doctors Plaza to do physiotherapy, but every day I had to pay 1000 Shillings (8 USD) and I am a retired person. He then told me to go to [public referral hospital]. So the physiotherapy continued here for three good years – 2009, 2010, 2011 – and then [cancer] was discovered early 2012. I spent a lot. The doctor told me to go and do an MRI. I did not know what it meant. I went to [private hospital] and it was costing 46,000 [386 USD] ...biopsy was done and it was discovered that I had stage 4 prostate cancer. PSA [prostate-specific antigen] was 100.... I don't know if my doctor knew that I had cancer, maybe he wanted to mint money off me before he made the right diagnosis.

As illustrated by the account above, when cancer is suspected, diagnostic tests can be expensive, and patients often required multiple types of test or for these to be repeated on multiple occasions. In Tanzania, patients had spent a median of 150,000 TZS (65 USD) on diagnostic imaging. Reported costs for imaging varied considerably in Kenya, but patients' median reported charge for CT scans for example was 8000 KES (66 USD). Meeting these costs could be very challenging for patients, as described in Chapter 4, where a Kenyan survivor argued that cancer testing had become “a business” there. Indeed, as another survivor reflected, it could feel like “diagnosis is a money minting affair” (survivor, Kenya).

Both patients and clinicians sometimes had to make decisions about care based on the financial circumstances of the patient. A survivor in Kenya described their experience of attending a public referral hospital with symptoms of pain and being told by the doctor that they suspected cancer:

So I asked where to start. He told me if I had 20,000 [168 USD] you can be tested further. I asked if he wanted cash and I told him I could not afford. I went back home, I stayed for 3 days, and my friends called me and advised me to go to [another public hospital]. I went [there] and stayed there for 9 days as they did their own investigations. They [performed a biopsy], and it was cheaper than [the original hospital]. After the operation I was given the mass to take to labs and then they told me that it was cancer and they referred me [back to the referral hospital], because they said that they did not have a cancer hospital.

Thus the patient self-referred, following advice from friends, to seek care that was affordable, delaying their eventual diagnosis and the start of treatment. Although this patient was able to access the tests they needed, sometimes this was not possible. One Kenyan health worker at a facility outside of Nairobi explained, “even if we have done their biopsies, they are sometimes needed to go to Nairobi for histology and [to] do staging investigations because...they cannot afford the CT scans or...we are not able to do tumour markers. So many of the times you will find the socio-economic status of the patient actually limit[s] us, because sometimes we cannot make a clinical decision or a way forward for this patient”.

This meant that patients had spent large amounts on health care, such as consultation fees, medication and diagnostic tests, prior to being diagnosed, representing a significant burden for many households. In both Kenya and Tanzania, the burden of costs relative to household income was much worse for the poorest patients prior to diagnosis, as well as over the course of treatment (Chapter 4). In Tanzania over a quarter of participants in the lowest income band had faced costs prior to diagnosis that exceeded their annual household income (Makene et al., 2022). In Kenya, a quarter of those with the lowest declared incomes had spent at least double their annual income before they were diagnosed.

In addition to the direct costs of care, patients also incurred travel costs when referred or self-referring between facilities, as well as costs of accommodation and subsistence away from home. As noted above, many patients moved multiple times between facilities in search of a diagnosis, which increased the costs they faced. These challenges are compounded when there is high demand for procedures, such as biopsy extraction, meaning that patients may be asked to return to the hospital on multiple dates, which can be prohibitively expensive for patients residing at significant distances from the facility. These costs were not insignificant for many. Reported travel costs are likely to be underestimated, due to the

assistance many received from family or friends with accommodation and subsistence and difficulty in recalling every day-to-day cost incurred. However, the reported median travel costs of 36 USD in Tanzania and 21 USD in Kenya represented a high proportion of annual income for some participants. Indeed, in Kenya, a quarter of those in the lowest income band had spent almost 30% of their declared annual income on transport.

These challenges were particularly acute for those who lived at a considerable distance from referral hospitals. In Tanzania, staff at a regional hospital located approximately 350km from the nearest public hospital with a CT scan and MRI and with the capacity to perform a biopsy, and over 800 km from the specialist national cancer facility, were very aware of the difficulties meeting travel costs could generate for patients. Indeed, they reported that this could cause patients to abandon seeking care entirely, prior to being diagnosed, even when cancer was suspected. A health worker quoted in Chapter 4 explained that after cervical screening found signs of cancer, some patients did not follow up on recommended tests because of unaffordability, and so went home and would die. They continued

If we could manage to take a biopsy here we could send it ourselves and get the results sent here, but when you ask them to go to [zonal hospital over 340 km away] or [national hospital over 800 km away] you know they will not go and you just write the referral.

Travelling even over relatively short distances is unmanageable for some, particularly when combined with the costs of accommodation and subsistence. As one doctor at a hospital in a region neighbouring Dar es Salaam explained, lack of access to histology and cytology services at a regional level, “can lead to a patient not going to the hospital because of financial problems, because once they think about going to [a national hospital] for tests they become scared and you find they delay, but if tests could be done from here, at least people from [this region] could come here because they know they can just come here and get treatment, rather than thinking about going to [a national hospital] where they expect expenses to be high” (health worker, Tanzania).

Costs contributed to delays for many patients, who had to seek financial support from friends and family prior to undertaking recommended procedures, or to sell assets. In Tanzania, one patient who was subsequently diagnosed with breast cancer, for example, had spent over a year

seeking a diagnosis and relief of her symptoms before being referred for a biopsy (her third), which she could not afford. After another five months and following advice from a neighbour who was married to a doctor, she was able to return and pay for the biopsy and further examinations and was diagnosed with cancer. This patient calculated they had spent 160 USD on care at public and faith-based facilities, in addition to a further 176 USD on alternative healing, which she had sought out only after four months of inconclusive investigations in the formal sector, prior to being diagnosed, in addition to at least 42 USD on transport to access care. With a monthly household income of only 26 USD, this represented a huge financial burden, before she became eligible for free treatment.

In Kenya, even those with NHIF coverage could find it challenging to afford diagnostic tests, as insurance did not always cover the entire cost. One survivor recalled: “sometimes there are tests that you go for, for instance MRI, when you go to a private facility...They tell you it is [298 USD] and NHIF pays for you [128 USD] so [the rest] has to come out of your pocket. Getting that money is a challenge, and that is why there is a delay...” (survivor, Kenya). Even when tests are available in the public sector at a reasonable distance from the patient, it is sometimes necessary to delay in order to seek funds. One health worker who had described the availability of diagnostic procedures at County level for breast cancer nevertheless highlighted affordability challenges, which meant that “you can get a patient who has come to the hospital with a breast lump; you send them for a mammogram; they come with the results after a month, later” (health worker, Kenya).

A Kenyan survivor gave an example that echoes many of the experiences shared by patients, carers, health workers and survivors:

...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. They refer you to another facility, for instance [public referral hospital], [private hospital], [elite private hospital] depending on your ability [to pay]. So when you get to the facility, you are told the cost of the tests and often they are expensive. So you are forced to go back home and wait until you have more money.

The psycho-social challenges associated with obtaining that money, or being unable to do so, were discussed in Chapter 3.

CONCLUSION

This chapter has reviewed key factors contributing to delayed diagnosis of cancer in Kenya and Tanzania. We argue that rather than framing the challenge as one of *late presentation*, which places responsibility for delay on the patient, research and policy analysis should instead consider the central problem as one of *late diagnosis*, which is caused by multiple interrelated factors, including characteristics of the health system. Thus, although increasing public awareness of cancer, and its symptoms and treatment, may play a role in reducing delays to diagnosis, the health system-related problems explored here must also be addressed. The challenges identified in this chapter echo the relationship between experiences of cancer and cancer care and wider socio-economic inequalities discussed in Chapters 3 and 4. The WHO (2020) identifies the three primary issues hindering early diagnosis in LMICs as the inability of primary care providers to identify symptoms, challenges with referral systems, and limited availability of pathology and diagnostic imaging (WHO, 2020, pp. 78–79). This list overlaps with our interviewees’ identification of key aspects of the system requiring intervention. However it should be expanded to include more routine screening, more affordable diagnostic tests, especially in the public sector, greater availability of diagnostic testing at lower levels of the health system, and reducing the need for “self-referral”, in order to have a meaningful impact.

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