



Facilitators and Barriers to Accessing Cancer Care in Tanzania: *Patients' Perspectives and Recommendations*

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Background

The brief highlights some findings as part of a project on *Innovation for Cancer Care in Africa* (ICCA)¹. The study provides insights on the experiences of 62 Tanzanian cancer patients, the journey from their first symptoms to the point of diagnosis and treatment. The project brings together researchers from Tanzania, Kenya, India and the United Kingdom to address the opportunities and challenges of linking industry and health systems to widen access to cancer care in Tanzania and Kenya.

Key findings and recommendations

Improving access to cancer care is a Tanzanian policy priority (URT, 2017), including access to early stage diagnosis. At present most cancer patients present late, reducing treatment effectiveness (FCCT, 2015). A survey of 62 Tanzanian cancer patients' experiences found:

- An average delay of over two years from first symptoms to diagnosis;
- Widespread failures to identify symptoms and refer patients rapidly leaving patients to move around the system seeking information and diagnosis;
- A heavy burden of out of pocket spending before treatment, especially for low income households, alongside loss of livelihoods from illness.

The survey also found good practice that can inform policy:

- Some diagnosis at district hospitals, and/or rapid referral from district level;
- Free cancer treatment reducing financial burden and supporting access for low income patients;
- Some rapid referral from diagnosis to treatment.

Recommendations, supported by patients, include:

- Better symptoms identification and faster referral for diagnosis up to regional hospital level;
- Treatment and follow-up closer to home;
- Better public information on cancer;
- Financial support for low income patients to reach diagnosis and treatment.

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Findings²

Respondents were interviewed at Ocean Road Cancer Institute (ORCI) (40 patients); at Tumbi and Kitete Regional hospitals (9); and, at Aga Khan hospital (7). Six cancer survivors were also interviewed. A majority of respondent (71%) were women. Cancers reported included cervical, breast, prostate, skin, uterine and others. Most respondents (76% of all, 90% of those interviewed in public hospitals) had primary schooling or below and the age range was wide. Half (51%) declared household income of under TZS 200,000 per month.

Loss of livelihood:

- Before illness, 87% stated they were working or studying; 44% gave their occupation as farming; when interviewed a majority (52%) reported that they were not working.

Extent of delayed diagnosis:

- The average delay between the patients' first presenting at a health facility with symptoms that turned out to indicate cancer, and a cancer diagnosis, was 2.13 years. These delays underlie reported late presentation of cancer patients for treatment.
- The range of delays was wide; however half of those interviewed in public hospitals, and 44% of all respondents had waited over a year for a diagnosis; 25% had waited over two years (Figure 1).

Exceptions: some rapid diagnosis

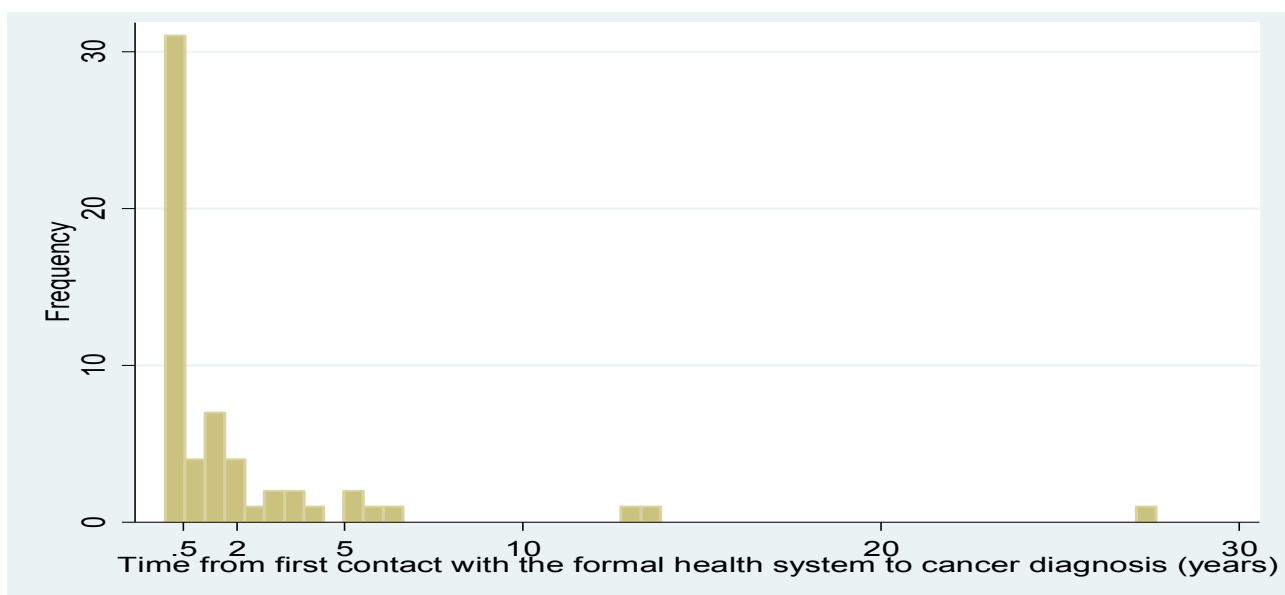
- A quarter of patients reached a diagnosis within three months, and 44% within six months (Figure 1).
- Diagnosis was most rapid for those who had gone first to a private facility: 50% were diagnosed within 0.37 years (about 19 weeks).
- However nearly half (46%) of patients who first presented at a dispensary or district hospital were diagnosed within six months, and 25% within 3 months, including four patients diagnosed directly at district level.

Patients' search for diagnosis: test and referral problems

- Many patients had suffered frustration and discouragement, moving between facilities and in and out of the health system in search of care; many painful stories were shared (Box 1).
- While 20 patients narrated self-medication or delay before visiting a facility, most delay before diagnosis was after the first facility visit.
- Only six respondents had been diagnosed at the first facility visited; on average respondents visited 3.9 facilities before diagnosis (maximum was 12), some visited several times.

² <http://esrf.or.tz/dpaper.php>

Figure 1: Years from first contact with formal health system to first cancer diagnosis



- Most of this movement between facilities was patient-driven or advised by family or friends; only 15% of moves in search of diagnosis were formal referrals.
- Many experienced long waits for tests and for test results, and the need to repeat tests, especially biopsies.

Box 1: delayed journeys

One patient initially presented with stomach pain and vaginal discharge. Her journey was partially shared as follows. She started in mid-2017 at a district hospital in Pwani Region where she was admitted; a test showed a urinary tract infection and she stated she “received medicine and an injection”. With worsening symptoms, she went to a dispensary where she was given injections, and later to a traditional healer where she “received traditional medicine”. Five months later, with more severe symptoms:

“I went to a private hospital, where they took a sample of tissue for a biopsy test and I received medicine and was asked to come back after one month.”

After this diagnosis, it was a further 15 months, including admission to a referral hospital in Dar es Salaam, as she was severely ill, before she went to Muhimbili Hospital where she was referred for cancer treatment at Ocean Road.

A care giver for another respondent described a visit to a Catholic Mission Hospital with abdominal pain and bleeding, she recounted that at repeat visits an ultrasound test was done with no conclusive results. The patient had continued to complain of severe pains, but the doctor said he did not know why, so she went back home without any medication. She travelled to Ocean Road seven months later and was prescribed radiation treatment.

Out-of-pocket payments as barrier and burden

- Respondents recorded out-of-pocket (OOP) spending on average of TZS 411,831 on consultations, tests and treatments including surgical investigations before diagnosis, plus an average TZS 48,425 on transport.

- This OOP spending imposed a severe financial burden on low income households especially (Table 1).
- Just 14 (29%) of patients interviewed at public hospitals had insurance; higher income groups were more likely to be insured (Table 1) and also to have insurance with wide coverage; having insurance shortened delay before diagnosis.
- Payments both before and after diagnosis included consultations, medication, tests, transfusions, surgery and transport and lodgings; patients recorded many delays caused by a search for funds, both before and after diagnosis (Box 2)

Table 1: Household burden of OOP payments from first contact with the health system to diagnosis, not including transport (payments as a multiple of annual household income)

Income bands	Mean burden by income band			N	% with insurance
	Not insured	Insured	All patients		
Up to 49,999 TZS/month	1.17		1.17	2*	0
50,000 to 99,999 TZS/month	0.60	0.16	0.48	11	25
100,000 to 199,999 TZS/month	0.12	0.42	0.20	8	20
200,000 to 299,999 TZS/month	0.32	0.01	0.16	6	44
300,000 to 399,999 TZS/month	0.08	0.01	0.05	11	45
400,000 TZS/month and above	0.14	0.08	0.09	16	73
All participants	0.34	0.09	0.22	54	41

* One very low-income household declared zero current income so the burden cannot be calculated.

Box 2: Funding Constraints

Respondents' numerous accounts of delays for lack of funds included:

A farmer went to a district hospital in Lindi with a stomach swelling, was told he required an operation to remove it, since he had signs of cancer in his colon. However, he did not have the money, so he left. He had surgery several months later at another hospital but, despite the early diagnosis, it was only after recurrence that he was referred for cancer treatment.

A patient with a breast swelling had an ultrasound and X-ray done at Kilimanjaro Christian Medical Centre (KCMC); she stated they "wanted to take sample from my breast, but I did not have extra money", hence, no biopsy was done. The patient returned five months later with worse swelling and pain; the tests were redone plus the biopsy; this cost the patient TZS 190,000 in total, and a five month delay before diagnosis.

A patient waited four months for her test results at Mbeya zonal hospital before being diagnosed with cervical cancer and referred to Muhimbili national hospital. She stated "I went back home to raise funds so that I could travel" and went to Dar es Salaam a month later.

Factors facilitating treatment access

- Two patients had been picked up in one-off screening events after their cancers had not been diagnosed in health facilities.
- Free treatment was key to access for the predominantly low income patients interviewed at ORCI, and hugely appreciated by respondents.
- Respondents with private, NHIF and/or NSSF insurance had on average shorter pathways from first presenting symptoms to diagnosis and treatment.

Reference:

Foundation for Cancer Care in Tanzania (2015) Meeting the Challenge of Cancer Care in Northern Tanzania. United Republic of Tanzania (2017) The National Health Policy 2017, Ministry Of Health, Community Development, Gender, Elderly and Children.

Recommendations for facilitating access to cancer care

- The health system can learn from and build on the successes that do exist in early identification of symptoms, diagnosis at district level, and early referral; much can be done through skills improvement, though diagnostic equipment and pathology capacity are also in need of expansion.
- Greater readiness to refer for tests on suspicion of cancer is required throughout the health system, including at regional hospitals, with referral directly from district to national and zonal cancer centres for potentially severe cases.
- Screening is a key method to pick up cancers, as even this small set of patients indicates, so expanded screening is facilitating.
- Respondents were eloquent about the need for much more public information on cancer including (lack of) transmissibility and typical symptoms.
- Given the barrier represented by travel and lodging costs, respondents also argued for importance of expanding treatment geographically within the country.
- Given the barrier represented by costs of tests and surgery before chemotherapy or radiography treatment, grants or other support for low income patients, and inclusion of more of these payments within local insurance schemes, can facilitate access to diagnosis and treatment.
- Innovations that lower the costs of diagnosis within the health system will facilitate and speed up access.
- Sustaining and expanding free cancer treatment, and ensuring the public is aware that it is free of charge, is key to expanding access further for low income patients.