Barriers to Cancer Care in Northern Tanzania: Patient and Health-System Predictors for Delayed Presentation

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abstract

PURPOSE Cancer is a growing problem in Africa, and delays in receiving timely cancer care often results in poorer outcomes. The purpose of this study was to identify the patient and health-system factors associated with delayed cancer care in adults living in the Northern Zone of Tanzania.

PATIENTS AND METHODS Between July 2018 and July 2019, we surveyed adult patients presenting to an oncology clinic in Northern Tanzania. Delayed presentation was defined as 12 weeks or longer from initial symptoms to presentation for cancer care. Multivariate logistic regression and adjusted relative risk (aRR) were used to identify factors predicting delayed presentation.

RESULTS Among 244 adult patients with cancer who completed the survey, 78% (n = 191) had delayed presentation. Patient-related factors associated with delayed presentation included lower educational attainment ($P = .03$), increased travel time ($P = .05$), lack of cancer knowledge ($P < .05$), and fear of cancer and cancer treatments ($P < .05$) on multivariate analysis. On analysis of aRR, patients without private car and those with health insurance had higher risk of delayed presentation (aRR: 1.27; 95% CI, 1.02 to 1.32 and aRR: 1.15; 95% CI, 1.01 to 1.32). There was a strong association with increased number of visits before presentation at the cancer center and delayed presentation ($P = .0009$).

CONCLUSION Cancer awareness and prevention efforts targeting patients and community-level health care workers are key to reduce delays in cancer care in Northern Tanzania.

INTRODUCTION

Cancer is a growing problem in Africa, where there is an epidemiologic shift from communicable to non-communicable diseases.[1] Currently, there are more than 1 million new cancer cases diagnosed every year in Africa, with breast, cervical, prostate, liver, and non-Hodgkin lymphoma being most common.[2] Over the next 20 years, cancer incidence is expected to double in lower-resourced areas of Africa.[2] In these areas, most patients are presenting with advanced disease, stage III-IV.[3-5] Cancer is becoming more prevalent in African countries, and patients are challenged with obtaining timely diagnosis and treatment.

There are many barriers that may contribute to delayed cancer presentation. These barriers are related to the patient, to the health care system, or both. Patient-related factors may be personal (ie, patient characteristics not amenable to intervention, such as age); sociocultural (ie, cancer awareness or stigma of disease); or economic (ie, cost of care and occupation).[6] Health care system factors may include misdiagnosis, diagnostic delays, and waiting times because of capacity challenges.[7] The weight of the different barriers to delayed cancer presentation varies depending geographical location of a patient.

Barriers to timely cancer presentation and treatment have not been widely studied in Tanzania, a lower- and middle-income country in East Africa with a population of more than 50 million people.[8] An estimated 40,000 new cancer cases are diagnosed each year in Tanzania,[2] and cancer treatment is currently available at three centers in the country. One of these centers, Kilimanjaro Christian Medical Centre's Cancer Care Centre (KCMCCCC) serves the Northern Zone of Tanzania, a catchment area of more than 15 million people.[9] To put this in context, Tanzania's ratio of new cancer cases per clinical oncologist is more than 5,000; however, in the United States, it is 137 new cancer cases per clinical oncologist.[10] In light of this challenge, there is an urgent need to explore ways to reduce the burden of advanced cancer diagnosis.

The primary objectives of the study were to investigate the patient and health-system predictors for delayed

CONTEXT

Key Objective

Many patients present with advanced cancer in Africa. What are the key factors associated with delayed cancer presentation in Northern Tanzania?

Knowledge Generated

Key patient-related factors included lower education or cancer knowledge, increased travel time or transportation method, fear, and having medical insurance. In addition, multiple health care provider visits were strongly associated with delayed presentation.

Relevance

Barriers to cancer care are observed globally, and specific factors vary on geographical area. Understanding these barriers in Northern Tanzania is important to prioritized targeted interventions to reduce delayed cancer presentation.

cancer care in the Northern Zone of Tanzania. These data will be used to identify interventions to reduce delayed cancer presentations.

PATIENTS AND METHODS

Setting

The KCMCCCC was inaugurated in December 2016. Infrastructure includes an outpatient clinic and chemotherapy infusion center with 12 chairs. Staffing at the end of 2019 included two specialized oncology physicians, seven nurses with oncology training, one palliative care nurse, two pharmacists, one administrator, and one public health officer. Patients are referred to the cancer center with a confirmed diagnosis of cancer; however, they may not have a definitive diagnosis at their initial appointment for the case of hematologic malignancies where confirmatory workup may be completed after initial consult.

Study Population and Design

Between July 1, 2018, and June 30, 2019, adult patients with a new diagnosis of cancer were invited to participate in the study. Patient eligibility criteria included age ≥ 18 years, presenting as a new patient to the cancer center with any cancer diagnosis, and Kiswahili- or English-speaking. Prospective participants were contacted directly by trained study staff when in the waiting room before their first visit with a physician at the cancer center or within 30 days of their first visit. The enrollment target was 250 patients based on G* power analysis of 80% with an alpha of .05. The questionnaire was translated into Kiswahili and then translated back to English and piloted with a focus group for comprehension.

At study initiation, written informed consent was obtained from each participant. Participants completed an interviewer-administered structured questionnaire, approximately 30 minutes in length. The questionnaire was divided into three interview sections with a fourth section to be completed by trained staff with information from the patients' medical record (Data Supplement). The first section included participant demographic, socioeconomic information, and delay interval (self-reported). The second section asked the patient to report a list of health care facilities where care was sought for the presenting symptom(s) before the cancer center. The third section of the survey queried the patient about potential barriers leading to delayed presentation. We adapted 14 questions to the Tanzanian context from a survey instrument by researchers in Haiti with permission[6] and added 10 questions. The final section was completed by study staff. This section included cancer type and stage at presentation as determined by the treating physician.

Outcome

Delayed presentation was the outcome of interest in this study. Delayed presentation was defined as 12 weeks or greater from discovery of initial cancer symptoms to presentation at the cancer center. This definition was chosen to be comparable to available literature.[6]

Statistical Methods and Ethics

We compared characteristics and barriers between delayed presentation and nondelayed presentation groups using chi-squared tests for categorical data, t-test for normally distributed continuous variables, and Kruskal-Wallis rank sum test for non-normally distributed continuous variables. Before multivariate logistic regression, we performed multiple imputation using a fully conditional specification method to create complete data sets. Under the assumption of a joint distribution for all variables with the assumption of missing-at-random, the fully conditional specification method uses a sequential regression method to impute missing values.[11,12] A linear regression model was used for age and travel time to clinic, whereas a generalized logit model was used for education, employment, method of reaching clinic, and any survey response that had missing data. All demographic and access-to-care variables as well as all survey responses were included in imputation models. In total, five imputed data sets were created. The five imputed data sets were combined according to the rules developed by Rubin[13] to account for imputation uncertainty.

We estimated unadjusted relative risks (RRs) and adjusted relative risks (aRRs) for all characteristics and survey responses using generalized estimating equation models with a Poisson distribution with a robust error variance[14] and a log-link function. The adjusted model estimating the risk of each demographic and access-to-care characteristics were adjusted for all other demographic and access-to-care characteristics. The aRR of each survey response was estimated in a separate model for each survey response, adjusted for all demographic and access-to-care characteristics.

Data were captured and cleaned in password-protected IBM SPSS Statistics version 24 (IBM Corp, Armonk, NY). We used the tableone package[15] in R[16] to create the tables examining the distribution of the demographic and access-to-care characteristics, and the survey responses between the exposure groups. All other analyses were performed using SAS v9.4 (SAS Institute, Cary, NC). We conducted a complete case analysis and sensitivity analysis where all participants with complete data were analyzed before multiple imputation were included. Ethical approval was received from Kilimanjaro Christian Medical University College within Tumaini University Makumira.

RESULTS

A total of 694 new adult patients were seen by cancer center staff during the study period (July 1, 2018-June 30, 2019). Of these, 245 patients (35%) participated in the informed consent process and were enrolled in the study. We excluded one patient because of missing outcome data, and the data of the remaining 244 patients were analyzed. Of the total N = 244 patients, 78% (n = 191) patients met the criteria for delayed presentation at the cancer center (median duration: 39 weeks, interquartile range: 24-52 weeks) and 22% (n = 53) presented to the cancer center in < 12 weeks (median duration: 4 weeks, interquartile range: 4-9 weeks) (Fig 1).

Patient sociodemographic and access-to-care characteristics are shown in Table 1. The majority of patients were adult female (63%, n = 153) with an average age of 52 years; breast cancer was the most common cancer evaluated at the clinic (25%, n = 61), followed by gastrointestinal cancers (24%, n = 58) and hematologic malignancies (21%, n = 51). Delayed presentation was associated with older age, lower educational attainment, travel time to clinic, and cancer type in univariate comparisons (Table 1). The three most common reasons patients reported for delaying care among those in the delayed group were "I thought the symptoms would go away" (150 of 191, 79%), "The pain/swelling/lump, etc didn't bother me" (139 of 191, 73%), and "I did not know what cancer was" (139 of 191, 73%; Table 2). Other barriers in which there were differences between patients in the delay and nondelay groups were "I was not concerned about my symptoms" (63% v 43%, P = .01), "I was afraid I might have cancer" (64% v 42%, P = .004), "I did not think the

problem could be cured by medicine" (47% v 26%, P = .02), "I was afraid of the treatments, including surgery or chemotherapy" (46% v 25%, P = .008), and "I was worried I might be contagious" (15% v 6%, P = .04).

In the adjusted model examining demographic and access-to-care characteristics (Table 3), patients who reached the center using public transportation or walking were at 27% higher risk of delayed presentation (aRR: 1.27; 95% CI, 1.02 to 1.32) relative to those accessing the center using a car. Additionally, those who paid for their treatment using insurance were at a 15% higher risk of delayed presentation (aRR: 1.15; 95% CI, 1.01 to 1.32) relative to those who paid using any other methods.

Controlling for demographic and access-to-care characteristics, patients who reported being fearful of treatments had a 23% higher risk of delayed presentation (aRR: 1.23; 95% CI, 1.08 to 1.40), patients who reported being afraid of having cancer were at 21% increased risk of delayed presentation (aRR: 1.21; 95% CI, 1.05 to 1.40), and patients who were afraid that having a biopsy would cause the cancer to spread were at a 15% increased risk of delayed presentation (aRR: 1.15; 95% CI, 1.01 to 1.30) relative those who did not report those fears. Additionally, patients who did not think that the problem could be cured by medicine and those were not concerned about their symptoms were both at a 19% increased risk of delayed presentation (aRR: 1.19; 95% CI, 1.05 to 1.34; aRR: 1.19; 95% CI, 1.04 to 1.38) relative to those who did not report these thoughts. These risks are
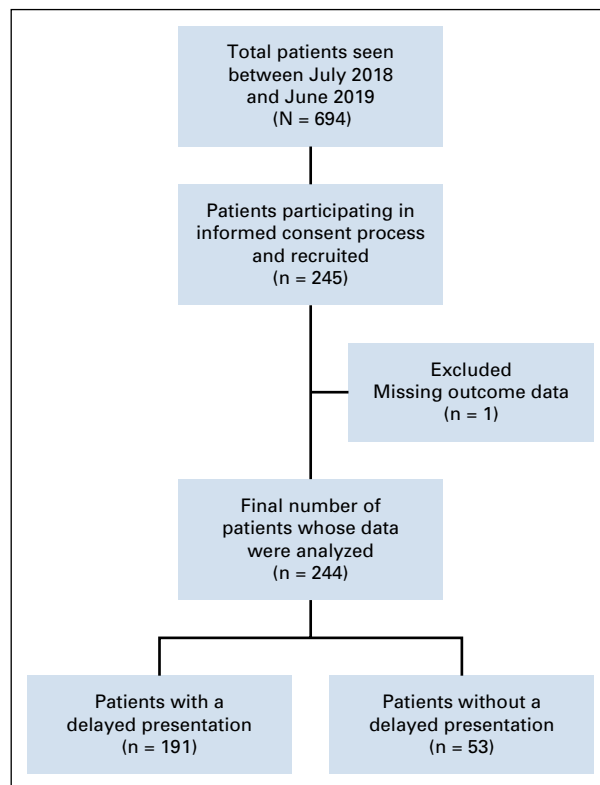

FIG 1. Study flowchart.

TABLE 1. Patient Sociodemographic and Access-to-Care Characteristics

Patient Characteristics	Overall N = 244	Delayed Presentation n = 191	Nondelayed Presentation n = 53	P	SMD
Age, years, mean (SD)	52.45 (16.03)	53.87 (15.53)	47.30 (16.89)	.008	0.405
Time, days, median [IQR]	210.00 [90.00-365.00]	270.00 [165.00-365.00]	30.00 [30.00-60.00]	< .001	1.136
Sex, No. (%)				.932	0.038
Male	91 (37.3)	72 (37.7)	19 (35.8)		
Female	153 (62.7)	119 (62.3)	34 (64.2)		
Education, No. (%)				.032	0.603
None	21 (8.6)	21 (11.0)	0 (0.0)		
Primary school	103 (42.2)	84 (44.0)	19 (35.8)		
Secondary	67 (27.5)	48 (25.1)	19 (35.8)		
College or university	51 (20.9)	36 (18.8)	15 (28.3)		
Missing	2 (0.8)	2 (1.0)	0 (0.0)		
Employment status, No. (%)				.074	0.354
Unemployed	96 (39.3)	81 (42.4)	15 (28.3)		
Employed	52 (21.3)	40 (20.9)	12 (22.6)		
Self-employed	95 (38.9)	70 (36.6)	25 (47.2)		
Missing	1 (0.4)	0 (0.0)	1 (1.9)		
Time, minutes, median [IQR]	120.00 [90.00-240.00]	150.00 [90.00-240.00]	120.00 [60.00-180.00]	.048	0.185
Reaching clinic, No. (%)				.086	0.399
Walking	3 (1.2)	3 (1.6)	0 (0.0)		
Car	50 (20.5)	33 (17.3)	17 (32.1)		
Public transportation	184 (75.4)	150 (78.5)	34 (64.2)		
Missing	7 (2.9)	5 (2.6)	2 (3.8)		
Payment type, No. (%)				.603	0.217
Public insurance	112 (45.9)	91 (47.6)	21 (39.6)		
Cash	111 (45.5)	85 (44.5)	26 (49.1)		
Loan	20 (8.2)	14 (7.3)	6 (11.3)		
Selling items	1 (0.4)	1 (0.5)	0 (0.0)		
Cancer type final, No. (%)				.002	0.627
Breast	61 (25.0)	49 (25.7)	12 (22.6)		
GI	58 (23.8)	49 (25.7)	9 (17.0)		
Heme	51 (20.9)	36 (18.8)	15 (28.3)		
Sarcoma	17 (7.0)	14 (7.3)	3 (5.7)		
Gyn	18 (7.4)	8 (4.2)	10 (18.9)		
Other	39 (16.0)	35 (18.3)	4 (7.5)		

NOTE. The data in this table are premultiple imputation and missing data are included in the calculation of percentages.
Abbreviations: Gyn, gynecologic; IQR, interquartile range; SMD, standardized mean difference.

visualized in Figure 2. The unadjusted RRs and aRRs for all survey responses are provided in the Data Supplement. Restriction of our cohort to patients without missing data yielded similar results (Data Supplement).

As seen in Figure 3, 37% of patients in the delayed group saw a provider more than five times before coming to the cancer center. There was a strong association with increasing the number of visits before presentation at the cancer center and delayed presentation (P = .0009). Most patients' first visit was reported as in a health care facility (235 of 244, 96.3%), whereas 3.7% (9 of 244) reported seeing an herbalist, faith-based healer, traditional healer, or other initially.

DISCUSSION

This study highlights the large burden of delayed cancer presentation in Northern Tanzania and the specific patient

TABLE 2. Questionnaire Responses Regarding Potential Barriers Leading to Delayed Presentation: *Did Any of the Following Prevent You From Coming to the Clinic Sooner?*

Potential Barrier to Cancer Care	Overall N = 244, No. (%)	Presentation Delayed n = 191, No. (%)	Presentation Nondelayed n = 53, No. (%)	P	SMD
I was afraid of being examined by a doctor or health care provider	24 (9.8)	20 (10.5)	4 (7.5)	.71	0.102
I was afraid if I had a biopsy, it would cause the cancer to spread	84 (34.4)	72 (37.7)	12 (22.6)	.06	0.333
I was afraid of the treatments, including surgery or chemotherapy	101 (41.4)	88 (46.1)	13 (24.5)	.008	0.463
I was afraid I might have cancer	145 (59.4)	123 (64.4)	22 (41.5)	.004	0.471
I did not know where an appropriate medical facility was	76 (31.1)	64 (33.5)	12 (22.6)	.179	0.244
I knew someone who had a bad experience at a hospital before[a]	21 (8.6)	17 (8.9)	4 (7.5)	.715	0.155
I had seen or heard of other people with cancer not be cured[a]	164 (67.2)	134 (70.2)	30 (56.6)	.108	0.335
The clinic was too far away to travel	172 (70.5)	136 (71.2)	36 (67.9)	.77	0.071
I was worried I might be contagious[b]	31 (12.7)	28 (14.7)	3 (5.7)	.039	0.356
I did not know what cancer was	172 (70.5)	139 (72.8)	33 (62.3)	.189	0.226
I did not know I needed to see a doctor	80 (32.8)	67 (35.1)	13 (24.5)	.2	0.232
The doctor was not concerned and did not refer me for further evaluation	59 (24.2)	51 (26.7)	8 (15.1)	.118	0.288
It was too expensive to travel to the clinic	161 (66.0)	128 (67.0)	33 (62.3)	.63	0.1
I did not think the problem could be cured by medicine[a]	104 (42.6)	90 (47.1)	14 (26.4)	.017	0.474
My husband or family did not give me permission to go to the hospital	7 (2.9)	6 (3.1)	1 (1.9)	.985	0.08
I did not want anyone knowing that I had a health problem[c]	75 (30.7)	62 (32.5)	13 (24.5)	.459	0.207
The pain or swelling or lump, etc did not bother me	173 (70.9)	139 (72.8)	34 (64.2)	.293	0.186
I was not concerned about my symptoms	144 (59.0)	121 (63.4)	23 (43.4)	.014	0.408
I thought the symptom would go away	187 (76.6)	150 (78.5)	37 (69.8)	.252	0.2
I thought treatment might be too expensive	161 (66.0)	128 (67.0)	33 (62.3)	.63	0.1
I was too busy at my home or job to go to the doctor	48 (19.7)	39 (20.4)	9 (17.0)	.718	0.088
I was worried the treatments would be too painful	102 (41.8)	82 (42.9)	20 (37.7)	.602	0.106
I tried treatment with a traditional healer or prayer first	82 (33.6)	70 (36.6)	12 (22.6)	.081	0.31
I saw one or more health care provider who treated me for an infection or problem other than cancer first	119 (48.8)	97 (50.8)	22 (41.5)	.298	0.187

Abbreviation: SMD, standardized mean difference.

[a]Missing two responses each in presentation delayed group.

[b]Missing one response in presentation nondelayed group.

[c]Missing one response in presentation delayed group.

and health-system predictors for obtaining cancer care. The strongest patient predictors were lower educational attainment, travel time, use of public transportation, lack of cancer knowledge, fear of cancer diagnosis and treatment, and surprisingly, having medical insurance. We found there was also a health-system component, with more than a third of patients with delayed presentation reporting multiple health care visits before reaching the cancer center. To the best of our knowledge, this is the first study to evaluate predictors of delayed presentation of patients with cancer in Tanzania.

Delayed patient presentation for cancer treatment is common in low-resourced health systems across the globe.[6,17-20] Studies have reported that the delays for patients with breast cancer in Africa range from 4 months to 17 months; our study falls in the middle of this range at nearly 10 months.[21] Delays in cancer diagnosis may lead to

TABLE 3. Univariable and Multivariable Poisson Regression Results for Risk of Delayed Presentation for Demographic and Access-to-Care Characteristics

Main Results (N = 244)	Unadjusted RR (95% CI)	P	aRR (95% CI)[a,b]	P
Age	1.006 (1.001 to 1.01)	.02	1.004 (0.999 to 1.01)	.09
Sex				
Male	1.02 (0.89 to 1.16)	.8042	0.99 (0.86 to 1.13)	.85
Female	1 (reference)	NA	1 (reference)	NA
Education				
Primary or below	1.19 (1.04 to 1.36)	.0131	1.10 (0.94 to 1.29)	.23
Secondary or above	1 (reference)	NA	1 (reference)	NA
Employment				
Employed	1 (reference)	NA	1 (reference)	NA
Unemployed	1.13 (0.99 to 1.28)	.0645	1.08 (0.94 to 1.24)	.27
Method of reaching clinic				
Car	1 (reference)	NA	1 (reference)	NA
Public transport or walking	1.24 (1.004 to 1.5295)	.045	1.27 (1.02 to 1.57)	.03
Payment type				
Insurance	1.07 (0.94 to 1.22)	.2959	1.15 (1.01 to 1.32)	.04
Other payment	1 (reference)	NA	1 (reference)	NA
Travel time	1.00008 (0.99999 to 1.00016)	.09	1.00009 (1.00 to 1.00019)	.06

Abbreviations: aRR, adjusted relative risk; NA, not available; RR, relative risk.
[a]Adjusted models were run on imputed data.
[b]Adjusted for all covariates in the column.

more advanced disease at presentation and increased mortality. This has been most widely studied in breast cancer; delays over 12 weeks are correlated with worse 5-year survival in breast cancer.[22-24] Thus, reduction of delays is imperative for cancer control.

An unexpected finding was that patients with health insurance had increased risk of having delayed presentations. We assume that having health insurance, and hence less financial constraints in paying for services, might have led to more unnecessary diagnostic steps with lengthy waiting times for appointments and results in other hospitals or health facilities before reaching KCMCCCC. Following the logic of this assumption, it would emphasize the need for further oncologic training among health care workers in the primary health sector for timely referral. However, we cannot assess whether the patients with health insurance were already correctly diagnosed outside KCMCCCC (with staging and histopathology results), which would mitigate or even outbalance the delayed presentation because of faster initiation of therapy.

Patients with lower educational attainment and those without a private car had an increased risk of delayed presentation. However, employment was not associated with delay in our study. This may indicate that the majority of patients presenting for specialized cancer care had access to financial and/or other economic resources. Other studies found that an association between lower levels of education and other measures associated with poverty are correlated with delayed presentation for patients with cancer.[6,17,19,20,25] Our results may suggest that most patients seeking care for cancer had less significant economic challenges, and measures should be taken to increase access to specialized care for all patients such as providing travel vouchers to those in rural communities.

In addition, we found that other sociocultural patient-related factors had an impact on obtaining cancer care. Specifically, patients in the delayed group were more likely to report fear and lack of cancer knowledge or awareness as factors preventing earlier presentation. Lack of cancer knowledge has been shown to be associated with oncologic delays in other studies in Rwanda and Haiti.[6,20] Broad public health education and cancer screening campaigns, especially in cervical cancer, have resulted in significant reductions in cancer mortality in developed countries.[26,27]

Finally, our study highlights the role of the health system in obtaining timely cancer care. A third of our patients saw at least five health care providers before presenting at the cancer center, and the delayed presentation group saw more health care providers compared with the nondelayed group. These visits included traditional medicine as well as dispensary and hospital visits. These results represent an emerging scenario for our patient population, in which the course of care involves multiple providers who may or may not suspect cancer, which ultimately contributes to delay, especially in patients with health insurance. Specifically, this indicates a diagnostic delay, which could include

FIG 2. Forest plot of adjusted RRs for all variables in the main analysis and significant survey responses. *y*-axis labels: above the line: demographic and access characteristics; below the line: survey responses. RR, relative risk.
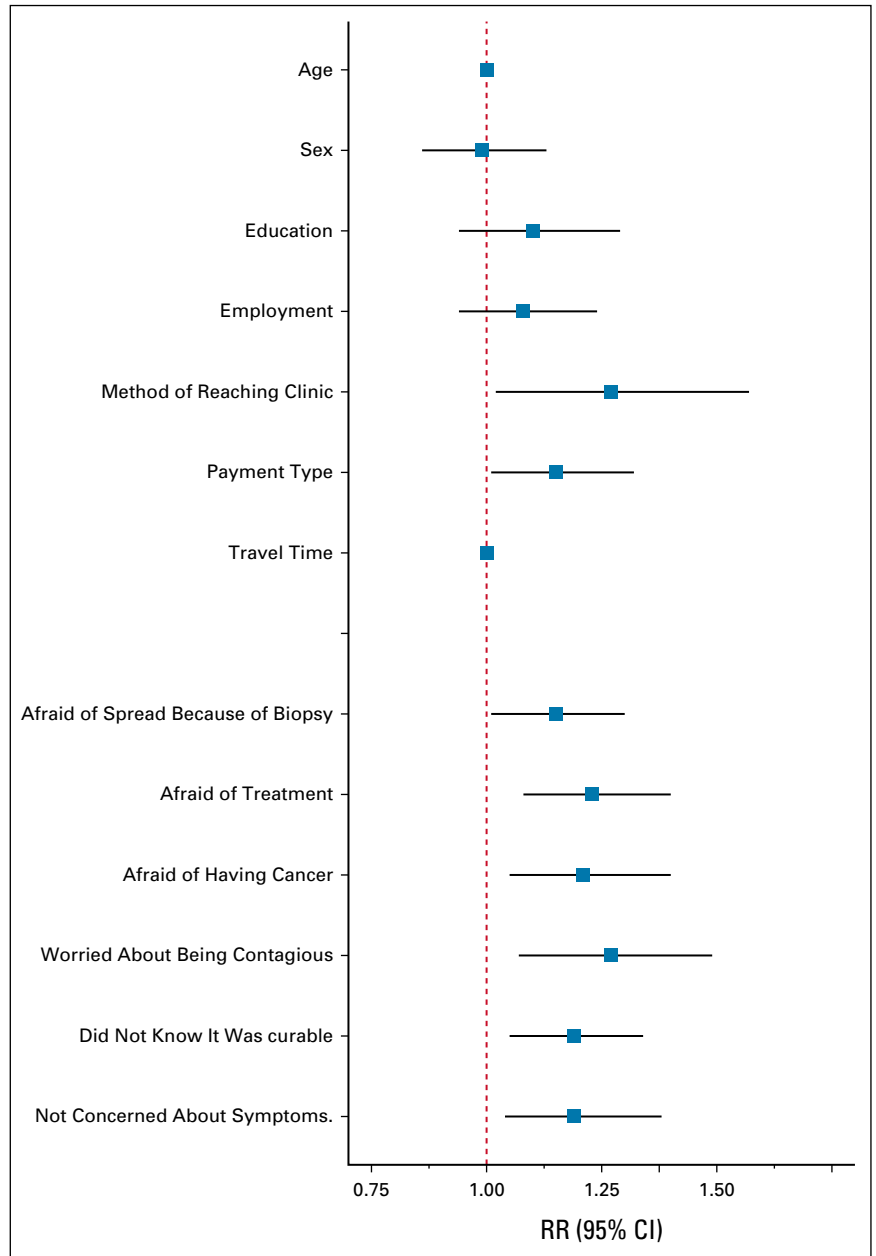
misdiagnosis, inappropriate diagnostic workup, improper treatment, or lack of referral, any of which could play a role in postponing cancer diagnosis and treatment. Previous
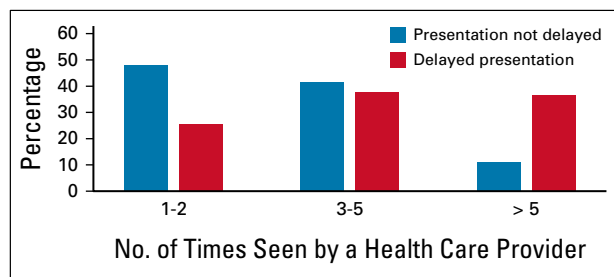

FIG 3. Number of provider visits before referral to cancer center.

research by Rick et al[28] found that there was a low level of baseline cancer knowledge in community-level health care providers in the Northern zone of Tanzania with nearly 70% reporting no previous clinical education on oncology topics. Long diagnostic delays from the first health care provider to the specialist have also been reported in recent studies from Nigeria, Botswana, and Rwanda.[7,20,29] This indicates a need to educate community-level health care providers on cancer diagnosis as cancer incidence is growing.

Our study has inherent limitations. First, as a prospective study using an interview-guided questionnaire, participants were asked to provide details about their care history, which may introduce recall bias. Second, only a third of all new adult patients who were seen during the study period were

consented and interviewed for the study. We do not know how inclusion of the whole cohort may have affected our results. Similarly, 20% of the data were incomplete and could not be analyzed, affecting our results. However, we used high-powered statistical analysis and controlled for variables to minimize confounding variables with our data as much as possible. In addition, the definition of cancer delays $\geq$ 3 months has been widely used in research; however, the association between this interval and poor outcomes is from higher-resourced settings in patients with breast cancer. Furthermore, it is possible that the most economically disadvantaged are less able to access specialized cancer care and are not represented in the data. Finally, our study was limited to the Northern Zone of Tanzania and cannot necessarily be generalized to other regions of the country because of the fact that Tanzania has a diverse ethnic population and specific ethnics groups may reside in different regions. Nevertheless, this study contributes to the growing literature regarding delayed cancer presentation in sub-Saharan Africa.

In summary, our study highlights specific patient- and health care–related barriers in Tanzania that delay cancer care. Targeted interventions such as patient- and community-level provider education, prevention or screening outreach activities in Northern Tanzania across all economic levels, and expediting referrals of suspected patients with cancer from primary level to tertiary level should be prioritized to reduce these delays. Some of these efforts have now commenced through a program called Prevention and Awareness Campaign (PrevACamp), and future studies will be performed to evaluate the impact of these interventions on delayed presentation and outcomes. Through these efforts, we can strive to shorten delays in patient presentation, minimize delays in diagnosis, and ultimately offer cancer treatment as early as possible, which is critical as the burden of cancer grows.

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