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Scientific Article

A Multi-Institutional Study of Barriers to Cervical Cancer Care in Sub-Saharan Africa

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Purpose: The global rise in cancer incidence has been accompanied by disproportionately high morbidity and mortality rates in low- and middle-income countries. Many patients who are offered potentially curative treatment for cervical cancer in low- and middle-income countries never return to start treatment for reasons that are poorly documented and little understood. We investigated the interplay of sociodemographic, financial, and geographic factors as barriers to care among such patients in Botswana and Zimbabwe.

Methods and Materials: Patients seen in consultation between 2019 and 2021 who were >3 months late for an appointment to initiate definitive treatment were contacted via telephone and invited to complete a survey. Afterward, an intervention connected patients with resources and counseling to return for treatment. Follow-up data were collected 3 months later to ascertain the outcomes of the intervention. Fisher exact tests analyzed the relationship between the putative number and types of barriers and demographics.

Results: We recruited 40 women who initially presented for oncology care but did not return for treatment at [Princess Marina Hospital] in Botswana (n = 20) and [Parirenyatwa General Hospital] in Zimbabwe (n = 20) to complete the survey. Overall, married women experienced more barriers than unmarried women ($P < .001$), and unemployed women were 10 times more likely to report a financial barrier than employed women ($P = .02$). In Zimbabwe, financial barriers and belief-associated barriers (eg, fear of treatment) were reported. In Botswana, many patients noted scheduling obstacles associated with administrative delays and COVID-19. At follow-up, 16 Botswana patients and 4 Zimbabwe patients had returned for treatment.

Conclusions: Financial and belief barriers identified in Zimbabwe showcase the importance of targeting cost and health literacy to reduce apprehensions. In Botswana, administrative challenges could be addressed with patient navigation. Improving our understanding of the specific barriers to cancer care could enable us to help patients who might otherwise default.

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Introduction

The global burden of cancer has increased rapidly over the last few years. It has been accompanied by disproportionately high morbidity and mortality rates in low- and middle-income countries (LMICs).[1] By 2030, 75% of all cancer deaths worldwide will occur in LMICs, while mortality rates will decline or stabilize in many higher-income countries.[2] These disparities appear to reflect differences in access to and utilization of health care. Providing access to effective treatment is a challenge in many LMICs, but where such treatment is available, failure to use it calls for investigation of that failure and then appropriate interventions to overcome the barriers to timely care.

In general, studies of barriers to cancer care identify patients who present late after surmounting whatever barriers they faced to receive the care they need.[3,4] However, many patients are simply lost to follow-up after diagnosis and never return. The barriers these patients face may be different, but they are largely unknown. Previously, a study at the National Radiotherapy Oncology and Nuclear Medicine Centre in Ghana found that more than 50% of patients diagnosed, staged, and prescribed a treatment for cervical cancer never returned for treatment.[5] This finding raised questions about what specific factors constituted barriers to health services for such patients. Investigators hypothesized that factors such as financial constraints, lack of patient education, lack of trust in the medical system, limited radiation facilities, and poor transportation infrastructure might all contribute to the large cancer burden. We therefore undertook to evaluate these factors and to explore an intervention to prevent default in 2 sub-Saharan African countries, Botswana and Zimbabwe, among women who were proposed a curative treatment course but never returned for initiation.

Botswana is a land-locked country with a population of 2.2 million and the fourth highest gross domestic product per capita ($15,015) in Africa, but there is significant wealth inequality. The country has a heavy cancer burden, and cervical cancer is the primary cause of cancer mortality in women, accounting for 18.6% of all cancer fatalities.[6] Government taxes fund 68% of Botswana's health care system, and only 4.2% of the population resorts to out-of-pocket spending.[7]

Zimbabwe has a population of nearly 15 million and a per capita gross domestic product of $2301. It is also land-locked and is a neighbor of Botswana. In Zimbabwe too, cervical cancer is the primary contributor to female cancer mortality, accounting for 19% of the cancer burden in women of all ages and ethnicities.[8] Furthermore, nearly 80% of patients with cervical cancer present with advanced-stage disease and therefore have poor survival.[9] The central government is a major domestic funding source for health care, but funds from nongovernmental organizations and out-of-pocket spending also pay some health care costs. Screening and treatment costs at the [Princess Marina Hospital] in Botswana were fully funded by the government, whereas chemotherapy and radiation treatment at the [Parirenyatwa General Hospital] in Zimbabwe required self-funding by patients.

Although both countries are working toward universal health care coverage, cancer incidence and mortality rates continue to rise.[10] Additionally, the COVID-19 pandemic has had a devastating effect on national health care systems and economies, further highlighting the importance of evaluating and addressing the reasons why patients fail to use available cancer care.

Methods and Materials

Sampling and data collection

This study was a multicenter cross-sectional study in 2 sub-Saharan African countries, Botswana and Zimbabwe, designed jointly with local investigators in [in sub-Saharan Africa, University of Pennsylvania, Philadelphia, PA and Columbia University Irving Medical Center, New York, NY]. Paper and electronic charts were reviewed at [Princess Marina Hospital, Botswana and Parirenyatwa General Hospital, Zimbabwe] to identify patients with cervical cancer seen in consults who failed to return for curative cancer treatment consisting of surgery, radiation therapy, or chemoradiation. From January 2019 to December 2021, patients over the age of 18 years at enrollment were selected if they had missed appointments for treatment >3 months after the last visit. Institutional review board approval was obtained at [Columbia University Irving Medical Center, the University of Pennsylvania, and locally in Botswana and Zimbabwe].

For each subject, demographic and cancer data were recorded from the charts. Data included age at diagnosis; date of diagnosis; date of presentation to cancer center; address; distance from cancer center (calculated); marital status; number of children; occupation (or current employment); insurance coverage; social welfare coverage; cancer pathology; TNM (tumor, node, metastases) stage; planned treatment (surgery, radiation, chemotherapy); cost of proposed therapy (calculated where applicable); HIV status; primary language; and date of last follow-up.

Trained researchers contacted the patients or their next of kin by phone to remind them of their appointment and to invite them to participate in a telephone survey on barriers to cancer care. Next of kin or husbands who completed the survey resided in the same home as the patients and relayed the pertinent information. In this study, barriers to care were defined as any reported factor or obstacle that prevented patients from returning to the clinic for review or curative treatment. After informed consent, a standardized telephone questionnaire was

administered in language appropriate to the interviewee and translated by the local investigator when needed.

After the questions, interviewers offered to connect patients with resources available in their area, whether financial, transportation, social services, or other. Three months after the survey was completed, charts of patients who had completed the questionnaire were reviewed, and the number of patients who returned for cancer treatment was noted as a measure of the success of the intervention. Follow-up interviews with defaulting patients were conducted through March 2022 because of delays from COVID-19.

Statistical analysis

Statistical analysis was conducted using R via the R Studio program (R. RStudio, PBC, Boston, MA). Descriptive statistics, including total frequencies and percentages of responses were collected for each question. Twenty patients were selected for the sample size based on feasibility and expert consensus among members of the research team. Because of this sample size, Fisher exact tests were used to analyze the relationship between number and types of barriers and demographics. The purpose of this analysis was to determine the associations of age, occupation, HIV status, stage, or education with barriers to care. A P value of .05 or less was considered statistically significant.

Results

Sociodemographics

A convenience sample of 40 patients who initially presented for oncology care but did not return for treatment at [Princess Marina Hospital in Botswana] (n = 20) and [Parirenyatwa General Hospital in Zimbabwe] (n = 20) completed the survey. Table 1 lists the demographic characteristics of the cervical cancer patient populations in Zimbabwe and Botswana (n = 40). Patients ranged from 32 to 84 years with a median age of 48 in Botswana (IQR, 40-57 years) and a median age of 52 in Zimbabwe (IQR, 43-61 years). Most patients were unemployed, possibly homemakers (n = 29, 72.5%), with a higher unemployed population in Zimbabwe at 95% (n = 19) compared with 50% in Botswana (n = 10). In Botswana, a majority of patients were unmarried (n = 12, 60%), whereas in Zimbabwe all patients were either married or divorced. Seventy-five percent of Zimbabwe patients attended any secondary school (n = 17), whereas only 30% (n = 6) of those from Botswana attended secondary school. All Botswana patients believed that the cost of treatment would be covered by the government, whereas in Zimbabwe patients expected to pay at least P1000 ($77 United States dollars [USD]).

Table 2 lists the Fisher exact P values for the difference between the number of unemployed and employed women who had barriers and the difference among women of various marital statuses. Unemployed women reported many more barriers than employed patients (Fisher exact P = .004), and unemployed women were 10.32 times more likely than employed women to report a financial barrier (P = .02). In addition, married, unmarried, and divorced/separated women reported different degrees of delays to care (P < .001). However, education level was not associated with the number or type of delays to cancer care.

Clinical features

Table 3 lists clinical factors by country. Overall, 14 patients (35%) had advanced (stage III or IVA) cervical cancer at diagnosis. Nineteen patients (47.5%) were HIV-positive and 20 were HIV-negative (n = 20, 50%). All self-reported HIV-negative patients in Botswana stated results from previously received HIV testing; however, 1 patient who stated she was HIV negative in Zimbabwe had never been tested for the virus. Neither the age of presentation nor HIV status was associated with the number of barriers experienced in Zimbabwe or Botswana.

Follow-up data

Table 4 shows the follow-up appointment data for Zimbabwe and Botswana subsequent to the interview. Of the 20 patients in Botswana, 16 returned for follow-up and started chemotherapy, radiation, or surgical treatment. Of the 20 patients in Zimbabwe, 4 returned for review or treatment initiation.

Barriers to care

Table 5 shows a breakdown of the sociodemographic factors associated with default in Zimbabwe and Botswana. The obstacles were divided into 3 categories: financial, logistics, and beliefs. As expected, patients from Zimbabwe reported significant financial barriers due to limited financial support from the government and high out-of-pocket costs. Additionally, the Fisher exact P value was significant at P<.0001 for the difference in the total number of patients who reported at least 1 financial barrier in Botswana and Zimbabwe. Patients in Zimbabwe also reported obstacles reflecting their doubts regarding the efficacy of treatment, fear of side effects, and lack of trust in

Table 1 Demographic characteristics of patient population by country

Category	Zimbabwe (n = 20)	Botswana (n = 20)	Total (n = 40)
Occupation			
Employed	1 (5.0%)	5 (25.0%)	6 (15.0%)
Unemployed	19 (95.0%)	10 (50.0%)	29 (72.5%)
Unknown	0 (0.0%)	5 (25.0%)	5 (12.5%)
Marital status			
Divorced/separated	10 (50.0%)	3 (15.0%)	13 (32.5%)
Married	10 (50.0%)	5 (25.0%)	15 (37.5%)
Never married	0 (0.0%)	12 (60.0%)	12 (30.0%)
Number of children			
0-3	10 (50.0%)	1 (5.0%)	11 (27.5%)
4-5	5 (25.0%)	1 (5.0%)	6 (15.0%)
>5	5 (25.0%)	0 (0.0%)	5 (12.5%)
Unknown	0 (0.0%)	18 (90.0%)	18 (45.0%)
Social welfare			
No	19 (95.0%)	11 (55.0%)	30 (75.0%)
Yes	1 (5.0%)	0 (0.0%)	1 (2.5%)
Unknown	0 (0.0%)	9 (45.0%)	9 (22.5%)
Education level			
Any primary	3 (15.0%)	4 (20.0%)	7 (17.5%)
Any secondary	17 (85.0%)	6 (30.0%)	23 (57.5%)
Unknown	0 (0.0%)	10 (50.0%)	10 (25.0%)
Insurance coverage			
No	18 (90.0%)	12 (60.0%)	30 (75.0%)
Yes	0 (0.0%)	1 (5.0%)	1 (2.5%)
Unknown	2 (10.0%)	7 (35.0%)	9 (22.5%)
Anticipated treatment*			
Surgery	1 (5.0%)	2 (10.0%)	3 (7.5%)
Chemotherapy	12 (60.0%)	15 (75.0%)	27 (67.5%)
Radiation	17 (85.0%)	17 (85.0%)	34 (85%)
Patient expectation of cost†			
P1000	1 (5.0%)	0 (0.0%)	1 (4.3%)
P2000	9 (45.0%)	0 (0.0%)	9 (39.1%)
P5000	10 (50.0%)	0 (0.0%)	10 (43.5%)
Paid by government	0 (0.0%)	6 (30.0%)	6 (26.1%)
Patient expectation of insurance coverage†			
No	17 (85.0%)	15 (75.0%)	32 (88.9%)
Yes	1 (5.0%)	0 (0.0%)	1 (2.8%)
Unknown	2 (10.0%)	1 (5.0%)	3 (8.3%)
Travel time (h)			
<1	10 (50.0%)	12 (60.0%)	22 (55%)
<3	7 (35.0%)	3 (15.0%)	10 (25%)

(*continued on next page*)

Table 1 (*Continued*)

Category	Zimbabwe (n = 20)	Botswana (n = 20)	Total (n = 40)
<6	3 (15.0%)	2 (10.0%)	5 (12.5%)
Unknown	0 (0.0%)	3 (15.0%)	3 (7.5%)
Religion			
Christianity	20 (100.0%)	5 (25.0%)	25 (62.5%)
Unknown	0 (0.0%)	15 (75.0%)	15 (37.5%)
Who responded to survey?			
Offspring	6 (30%)	2 (10.0%)	8 (20%)
Husband	1 (5.0%)	0 (0.0%)	1 (2.5%)
Patient	10 (50.0%)	16 (80.0%)	26 (65.0%)
Next of kin	3 (15.0%)	2 (10.0%)	5 (12.5%)

* Patients can select multiple answers.
† $n \neq 40$ because of blank responses.

the health care providers. Figure 1 highlights that in Botswana, the women mainly noted logistical obstacles, such as lack of communication with the hospital, delays due to limited radiation machines, and administrative delays due to the COVID-19 pandemic.

Discussion

In Botswana and Zimbabwe, many patients with cervical cancer experience major delays in receiving treatment or are lost to the health care system completely. In this survey, the barriers for patients who never returned for curative cancer treatment were identified and classified as belief-based, financial, and logistical. The data were presented by country to reveal the relationships of the barriers to the countries' cultural, geographic, and socioeconomic landscapes.

Previous studies in sub-Saharan Africa have looked at patients with disease that was diagnosed at a late stage, but such individuals by definition had surmounted their barriers and either received or were beginning to receive treatment. Studying patients who have failed to surmount their barriers is essential if we are to design effective outreach efforts, influence public policy, and help facilitate patients' return to the hospital. Furthermore, by comparing 2 countries, we could shed light on the country-specific barriers and address them accordingly.

This study showed that demographic factors, such as marital status and employment status, were associated with the total number of barriers experienced. Overall, similar numbers of women were married, never married, or divorced. Patients who were married reported more barriers than those who were never married or were divorced from their partners. Married women may have had a greater number of familial responsibilities, less disposable income because of larger family size, or husbands

Table 2 Fisher exact results for financial barriers to care

Category	Total number of barriers per patient			*P* value
	1-3	4-6	7-9	
Employed	5	0	1	.0428*
Unemployed	8	10	11	
Divorced	2	7	4	.0017*
Married	5	2	8	
Never married	11	1	0	
Botswana	18	2	0	<.0001*
Zimbabwe	0	8	12	

* P <0.05.

Table 3 Clinical features of patient population by country

Category	Zimbabwe (n = 20)	Botswana (n = 20)	Total (n = 40)
Cervical cancer FIGO stage			
Stage I	3 (15.0%)	3 (15.0%)	6 (15.0%)
Stage II	12 (60.0%)	6 (30.0%)	18 (45.0%)
Stage III	5 (25.0%)	8 (40.0%)	13 (32.5%)
Stage IV	0 (0.0%)	1 (5.0%)	1 (2.5%)
Unknown	0 (0.0%)	2 (10.0%)	2 (5.0%)
Age at last visit (y)			
30-50	9 (45.0%)	11 (55.0%)	20 (50.0%)
50-70	9 (45.0%)	8 (40.0%)	17 (42.5%)
70-90	2 (10.0%)	1 (5.0%)	3 (7.5%)
HIV status			
Negative	11 (55.0%)	9 (45.0%)	20 (50.0%)
Positive	8 (40.0%)	11 (55.0%)	19 (47.5%)
Unknown	1 (5.0%)	0 (0.0%)	1 (2.5%)
Test for HIV given HIV (−)	Zimbabwe (n = 11)	Botswana (n = 9)	Total (n = 20)
No	1 (9.1%)	0 (0.0%)	1 (5.0%)
Yes	9 (81.8%)	9 (100%)	18 (90.%)
Unknown	1 (9.1%)	0 (0.0%)	1 (5.0%)

Abbreviation: FIGO = Federation of Gynecology and Obstetrics.

dominating decision-making for the household. This idea is consistent with findings of a 2019 study showing that women's participation in health care decision-making in sub-Saharan Africa is one of the lowest in the world, and that in many households husbands make unilateral decisions.[11] It is also possible that rejection of cervical cancer treatment could be because of limited knowledge regarding the condition. A study of Ghanaian men revealed that the most common belief about cervical cancer was that it is caused by "too much sex." However, some men indicated that if they were more educated about the diagnosis, they would encourage their wives to be screened and treated.[12] Qualitative research looking into the household beliefs of married women and men in Botswana and Zimbabwe could provide more insight regarding this issue.

In addition to marital status, employment status also significantly affected the number of barriers reported. Most study participants were unemployed; they may have been homemakers with primary responsibility for the care of their families. Patients who were employed were much less likely than others to report financial barriers. Although the government covers treatment costs in Botswana and largely in Zimbabwe, cancer treatment still entails out-of-pocket costs with regard to transportation, lodging, and medications for treatment and side effects.[13]

Age, HIV status, and education level were not associated with barriers. Approximately half the patients were HIV-positive, but a previous study in Botswana showed that HIV status did not cause delays in receiving

Table 4 Zimbabwe and Botswana follow-up appointment data

Category	Zimbabwe (n = 20)	Botswana (n = 20)	Total (n = 40)
Returned to health facility only for review	2 (10.0%)	1 (5.0%)	3 (7.50%)
Returned and received chemotherapy, radiation, or surgery	2 (10.0%)	15 (75.0%)	17 (42.5%)
Did not return	16 (80.0%)	4 (20.0%)	20 (50.0%)

Table 5 Sociodemographic factors associated with barriers to care by country

Category	Zimbabwe (n = 20)	Botswana (n = 20)	Total (n = 40)
Financial burden			
Treatment cost	15 (75.0%)	1 (5.0%)	16 (40.0%)
Transportation cost	4 (20.0%)	1 (5.0%)	5 (12.5%)
No health insurance	16 (80.0%)	1 (5.0%)	17 (42.5%)
Logistics			
Delays due to COVID-19	9 (45.0%)	2 (10.0%)	11 (27.5%)
Waiting for hospital call	1 (0.0%)	15 (75.0%)	16 (40.0%)
Hospital delays	4 (20.0%)	1 (5.0%)	5 (12.5%)
Need to care for family member	8 (40.0%)	0 (0.0%)	8 (20.0%)
Beliefs			
Afraid of side effects	3 (15.0%)	3 (15.0%)	6 (15.0%)
Believe treatment ineffective	2 (10.0%)	0 (0.0%)	2 (5.0%)
Prefer alternative treatment/provider	14 (70.0%)	1 (5.0%)	15 (37.5%)
Do not understand treatment	2 (10.0%)	0 (0.0%)	2 (5.0%)
Don't trust doctors can cure cancer	1 (5.0%)	0 (0.0%)	1 (2.5%)

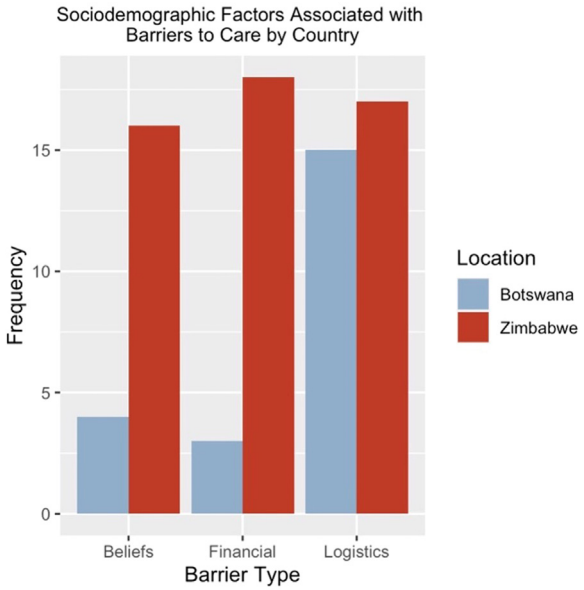

Figure 1 Sociodemographic factors associated with barriers to care by country. This figure showcases the sociodemographic factors identified by patient populations in Botswana and Zimbabwe. The data were classified into 3 overarching groups: beliefs, financial, and logistics.

treatment.[3] Patients' knowledge was not a barrier to receiving care; regardless of primary or secondary education, the number of barriers remained relatively consistent.

Reported obstacles to care were reflective of the medical system where the women accessed care and with socioeconomic and cultural factors. In Zimbabwe, a majority of patients experienced financial struggles with regard to treatment costs, transportation costs, or other associated expenses, probably because the health care funding system in the country is not universal and largely relies on private spending. Patients in Zimbabwe expected the total treatment cost to be around $77 USD; however, chemotherapy and brachytherapy costs can range up to $350 USD per cycle. The high financial burden in Zimbabwe was previously noted in a finding that 13% of the nation's lowest-income households incurred catastrophic health expenditures in 2015.[14] Furthermore, patients in Zimbabwe also reported apprehensions regarding treatment efficacy or side effects, and 14 of the 20 women cited a preference for traditional healers. Although this preference could be attributed to stigmatization and cultural taboos, using traditional healers may be less expensive than going to the hospital. Interestingly, in Zimbabwe, although there were only a few radiation therapy devices, machine breakdown did not serve as a major hindrance. In Botswana, patients mostly encountered logistical challenges, including delays arising from limited radiation machines, medical systems under stress because of COVID-19, and miscommunication between patients and providers. After the initial visit, patients are instructed to wait for follow-up calls from the hospital to schedule future appointments. Limited personnel and resources played a role in many individuals not being contacted to begin treatment. Ultimately, targeting cost of treatment and recruiting cancer navigators to address apprehensions should be a major focus of outreach efforts in Zimbabwe. In Botswana, it is imperative to address logistical delays

and system-based challenges by further developing infrastructure and focusing on timely follow-up calls.

This study also found a benefit from its intervention component, which referred patients to resources available locally and provided patients with opportunities to have follow-up appointments to discuss treatment, side effects, or payment plans. In Botswana, 16 of the original 20 patients returned for review or treatment. Of the 4 patients who never returned, 2 died before the follow-up appointment, and 1 is currently coordinating her next visit. However, in Zimbabwe, only 4 of the 20 patients returned; the others cited continuing financial struggles and a preference for visiting traditional healers as their main reasons. The success of the intervention in Botswana can be attributed to many of the reported barriers being logistical (eg, never receiving a call-back from the hospital) and able to be addressed in a shorter period. Facilitating patient return in Zimbabwe will require more targeted efforts toward low cost-resource sharing to reduce expenditure and the use of health care navigators to overcome patient apprehensions. However, this process may be subject to complications from increasing financial burdens that arise from appointing more personnel.

This study has several limitations. Sample size was small because of difficulties in recruitment and other unique challenges posed by the COVID-19 pandemic. Although 5 institutions were initially recruited for this study, Ghana, Kenya, and South Africa were unable to participate because of the devastating effects of the COVID-19 pandemic on research capacity. Closed health care facilities and limited staff overwhelmed hospitals in Botswana as well, contributing to the high number of logistical barriers reported. In addition, social desirability bias may have influenced patients' responses to survey questions. Finally, the degree of cancer navigation offered by health care providers may have varied by region and hospital. Future studies should focus on identifying systematic factors independently of the pandemic and further examining the feasibility of incorporating patient navigation into primary cancer care.

Conclusion

The barriers to cancer care were multifactorial and related to local cultural, financial, and geographic characteristics. Understanding these barriers may enable us to reintegrate defaulting patients into the health care system. The findings of this study can be used in piloting cancer navigation programs across sub-Saharan Africa and the rest of the world.

Disclosures

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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