# The Oncologist®

# Multilevel Factors Affecting Time to Cancer Diagnosis and Care Quality in Botswana

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*Disclosures of potential conflicts of interest may be found at the end of this article.*

## Abstract

**Background.** Cancer incidence is increasing in Africa, and the majority of patients are diagnosed with advanced disease, limiting treatment options and survival. We sought to understand care patterns and factors contributing to delayed diagnosis and treatment initiation among patients with cancer in Botswana.

**Patients and Methods.** We recruited 20 patients who were enrolled in a prospective cancer cohort in Botswana to a qualitative substudy that explored cancer care pathways and factors affecting cancer care access and quality. We conducted an in-depth interview with each participant between October 2014 and January 2015, using a a structured interview guide with questions about initial cancer symptoms, previous consultations, diagnosis, and care pathways. Medical records were used to confirm dates or treatment details when needed.

**Results.** Individual and interpersonal factors such as cancer awareness and social support facilitated care-seeking behaviors. However, patients experienced multiple delays in diagnosis and treatment because of provider and health system barriers. Health system factors, such as misdiagnosis, understaffed facilities, poor referral communication and scheduling, and inadequate laboratory reporting systems, affected access to and quality of cancer care.

**Conclusion.** These findings highlight the need for interventions at the patient, provider, and health system levels to improve cancer care quality and outcomes in Botswana. Results also suggest that widespread cancer education has potential to promote early diagnosis through family and community networks. Identified barriers and facilitators suggest that interventions to improve community education and access to diagnostic technologies could help improve cancer outcomes in this setting. *The Oncologist* 2018;23:1453–1460

**Implications for Practice:** The majority (54%) of patients with cancer in Botswana present with advanced-stage cancer despite universal access to free health care, limiting the options for treatment and decreasing the likelihood of positive treatment outcomes. To reduce time from symptom onset to cancer treatment initiation, causes of delay in cancer care trajectories must be identified. The narratives of the patients interviewed for this study give insight into psychosocial factors, outlooks on disease, lower-level provider delays, and health system barriers that contribute to substantial delays for patients with cancer in Botswana. Identification of problems and barriers is essential for development of effective interventions to mitigate these factors, in order to improve cancer outcomes in this population.

## Introduction

The cancer burden in low- and middle-income countries (LMICs) is increasing. Of the 14.1 million new cases diagnosed worldwide in 2012, over half (8 million) occurred in LMICs, and the cancer burden is expected to increase [1–5]. Mortality is also strikingly high in LMICs because of limited treatment services and a large proportion of cases being diagnosed with advanced disease, highlighting the pressing need for early diagnosis and treatment initiation [4].

Despite access to free public health care, over half of patients with cancer in a nationally representative cohort, the Botswana Prospective Cancer Cohort (BPCC) [6,7], were diagnosed with advanced-stage disease. In fact, the median

time from symptom onset to treatment was 401 days (nearly 14 months) [1,6]. Other research in the region has shown that several complex factors affect access and quality along the cancer care continuum [8–10]. However, the social context of cancer care crosses multiple levels of influence, including individual, interpersonal, provider, health system, and community factors. Understanding the nature and extent of factors contributing to delayed cancer care in Botswana is critical to improve timely diagnosis, treatment quality, and health outcomes [11–13].

The objective of this qualitative study was to explore care-seeking patterns and identify factors contributing to delayed cancer diagnosis and treatment among patients with cancer in Botswana.

## SUBJECTS, MATERIALS, AND METHODS

### Study Setting
Botswana has a tiered health care system with services decentralized to the district level. The network of public health care facilities includes tertiary referral hospitals, district hospitals, primary hospitals, clinics, and local health posts [14]. Although patients may access care at any health facility level, they are encouraged to enter the system at the primary care level, where they would then be referred, if cancer is suspected, to oncology diagnosis and treatment services at a tertiary hospital. Most oncology care is provided at Princess Marina Hospital (PMH) and Nyangabwe Hospital, both public tertiary hospitals, or Gaborone Private Hospital (GPH), a private hospital. PMH and GPH are located in Gaborone, the nation's capital and one of two major metropolitan areas in the country. The catchment area for these hospitals is approximately 1.3 million residents living in southern Botswana, which is over 65% of the nation's population [1]. Radiation is only available at GPH; however, patients relying on public services can access radiotherapy through a government subsidy. In fact, over 90% of radiation administered at GPH is for public sector patients [15].

### Data Collection
We recruited a subsample of 20 newly enrolled male and female adult participants of the BPCC between October 2014 and January 2015 for this qualitative study. Details of the BPCC have been described previously [1,7]. Briefly, all patients with a confirmed diagnosis are approached to enroll in the BPCC immediately after their first oncology visit. We recruited this subsample of BPCC enrollees on all week days when newly diagnosed patients were scheduled. Research assistants approached patients in Setswana as they enrolled in BPCC if conducting an additional interview would not interfere with clinical care. We recruited patients consecutively with the goal of enrolling patients with various types of cancer and age groups (above or below 50 years) for this qualitative study to ensure that a variety of experiences and perspectives was captured. Although we did not select a sample size of 20 a priori, we recruited until saturation.

All in-depth interviews took place in a quiet, private area of the oncology ward. Trained research staff conducted interviews mainly in Setswana with some English depending on participants' preferences. We used a structured interview guide with questions about initial cancer symptoms, previous consultations, diagnosis, and care pathways. Medical records were used to confirm dates, diagnoses, and treatment details when available. A research assistant translated Setswana responses during the interviews, and detailed notes were taken by C.A.B., including verbatim quotations when English was spoken. Immediately after each interview, C.A.B. transcribed patients' responses, quotes, and field notes. The mean interview length was 40 minutes.

### Statistical Analysis
We used ATLAS.ti to organize and analyze all qualitative data (version 1.6.0; ATLAS.ti Scientific Software Development GmbH, Berlin, Germany). Two coauthors (C.A.B. and R.E.K.) read all interview notes and summaries multiple times. We took an iterative approach to coding and data analysis, with both coders initially open coding three interviews individually, focusing on key concepts regarding cancer care access and quality. We developed a coding scheme with definitions and examples, which the primary coder (C.A.B.) used to code all transcripts and notes. Both coders independently reviewed three additional interviews and discussed and defined new codes that emerged; updated codes were applied to previously coded interviews. We intentionally selected the six (30%) interviews based on the diverse patient experiences and diagnoses to generate a wide range of codes and be double coded (by R.E.K.) to ensure coding reliability.

We outlined common care trajectories noting the conditions, actions, interactions, and consequences of different events and behaviors, as described by Strauss and Corbin [16], with a focus on patient and health system delays. We grouped codes according to various levels of influence according to Sorensen et al.'s social contextual model considering how intrapersonal, interpersonal, organizational, community, and societal factors affect cancer-related behaviors [17]. Building on Bickell's framework for breast cancer treatment quality [17–19], we also incorporated provider and health system level factors that affect care. We analyzed code frequencies and co-occurrences across patients to identify thematic patterns affecting health-seeking behaviors, utilization, and delays in care along the cancer care continuum [18,20].

### Ethics
This study was approved by the Health Research Development Committee at the Botswana Ministry of Health and the institutional review board of the Harvard T.H. Chan School of Public Health. Participants provided written informed consent.

## RESULTS

### Sample Characteristics
Of the 20 patients with cancer we recruited, most were women (14 patients), over 50 years of age, and unemployed (Table 1). Approximately one third were married, and half had primary-school education or less. We recruited 13 patients from the public hospital and 7 from the private referral facility, although the majority recruited at the private facility were public patients receiving

**Table 1.** Clinical and sociodemographic characteristics of cancer participants interviewed (*n* = 20)

| Clinical and sociodemographic characteristics | Number |
|---|---|
| **Sociodemographic characteristics** | |
| Age | |
| <30 | 2 |
| 30–39 | 5 |
| 40–49 | 2 |
| 50–59 | 6 |
| 60+ | 5 |
| Male | 6 |
| Married | 7 |
| Education | |
| None | 1 |
| Primary | 9 |
| Secondary | 6 |
| Tertiary | 4 |
| Occupation | |
| Unemployed | 9 |
| Employed | 8 |
| Other/student | 3 |
| Rural residence | 17 |
| **Clinical characteristics** | |
| HIV positive | 9 |
| Initial symptom | |
| Bleeding | 3 |
| Lump/mass/lesion | 8 |
| Pain | 4 |
| Shortness of breath | 1 |
| Swelling of leg | 1 |
| Other[a] | 5 |
| Cancer diagnosis | |
| Breast | 6 |
| Cervical | 4 |
| Lymphoma | 4 |
| Head and neck | 2 |
| Other[b] | 4 |
| Time from initial symptom to treatment | |
| <1 year | 9 |
| 1 year | 6 |
| 2 years | 5 |
| Ever used traditional medicine (any reason) | 5 |

[a]Other initial symptoms included itching, anal sore, and fever.
[b]Other cancer diagnoses included esophageal, prostate, Kaposi's sarcoma, and rectal cancer.

radiation using government waivers. Over half of the patients initiated cancer treatment more than 1 year after experiencing their initial symptom. Although nearly half of our sample was HIV positive, none of the patients mentioned antiretroviral therapy access or engagement in HIV care as a facilitator for diagnosis or care.

We identified complex factors contributing to delays in cancer care (Fig. 1). Below we describe themes that emerged from the data grouped by the following levels of influence: patients, providers, health system, and community and society.

## Patient Psychosocial Factors Affect Behaviors

Patients' knowledge and perceptions of symptoms and cancer influenced their initial help-seeking behaviors and time to diagnosis. Six of the 20 participants reported being aware of cancer because of family members, largely because of a family history of cancer. Some of these patients had multiple relatives diagnosed with cancer, including cousins, siblings, parents, and grandparents; most relatives reportedly died from the disease. In two cases, patients with a family history sought information and resources and reported less time from symptom onset to entry into oncology care. However, several with family history still took longer than 1 year to get into treatment, as did those who had an information-seeking reaction to their family history that had improved trajectories. Patients with family histories of cancer also had strong emotional reactions to their own diagnoses, particularly if their relatives had died from cancer. Close proximity to cancer death made patients fearful and worried about their own diagnosis and prognosis. A 29-year-old female patient with lymphoma said, "I was scared because like, I remembered my aunt passed away from cancer. Lots of thoughts came to my mind. I wondered if I was going to survive or not survive, and whether it was curable or not. And what was going to happen then."

Patients who reported receiving social support also exhibited better help-seeking behaviors. In almost all the nine interviews with patients who received cancer treatment in less than 1 year from symptom onset, informational and emotional support from family members prompted patients to seek care [21,22]. Both men and women reported receiving support from family members, but it was often female family members who strongly urged their loved ones to seek care, even accompanying them to visits. Patients relied on family members throughout their cancer care, but social support was particularly evident early on when symptoms were first noticed. For example, patients frequently turned to family members with concerns about initial cancer symptoms. And in eight interviews, family members encouraged patients to go to the clinic or hospital, emphasizing a sense of urgency to seek care. Whereas some people initially dismissed the symptom or were unsure what it was, talking to family members increased patients' perceptions of severity. This informational support also served as a cue to action, prompting patients to seek care. For example, a patient with rectal cancer noticed an anal/rectal sore but did not tell anyone for 4 years: "It was just my secret, I didn't even discuss at home. Even the doctors I didn't tell." But her sister urged her to get help after learning about the symptom, and the patient finally decided to go to the doctor. Additionally, another patient recalled how her aunt's insistence was critical: "she was the one who told me to go to the hospital so I could get it checked. But I thought it wasn't anything serious, so I thought maybe it would just go away. But she was the one that kept pushing me to go to the hospital." Patients also received emotional and tangible/instrumental support from relatives
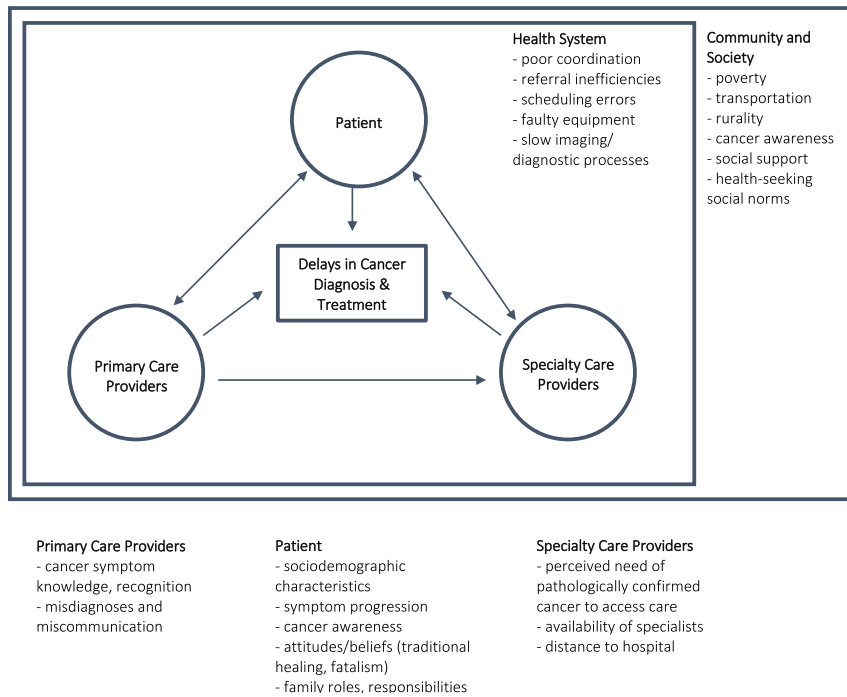
**Figure 1.** Contributors to delay in cancer diagnosis (adapted from [18]). Arrows indicate directionality of interaction; i.e., patients and specialists (oncology care providers) interacted with each other over time, whereas primary care providers generally relayed information to specialists and not vice versa. The boxes show embedded social contexts, with patient-provider interaction occurring within the health system, and all embedded within community contexts and social norms.

[21,22], such as accompanying a patient to their first clinic visit, providing transportation to health facilities, and being present at the appointment when the diagnosis was made.

Although beliefs in traditional medicine were not common in this sample, the few patients who consulted a traditional healer experienced delays in care. Five patients reported using traditional medicine at some point in their lives, and three of these sought help from a traditional healer for their cancer symptoms. Two of these took over 2 years from their symptom onset to start cancer treatment, including a male patient with breast cancer who said that he stopped using traditional medicine (and went to the hospital) because of a dream.

**Outlook on Disease Affects Care-Seeking**
Over half of the participants conveyed a sentiment of hopelessness and fatalism about their diagnosis and prognosis, saying their "life has finished," and that they "just surrendered." For example, one patient explained, "When you are told you have cancer you think it is the end of the world. I even thought of taking a rope and hanging myself." Patients also mentioned thoughts about giving up on their care and being unmotivated to pursue treatment. For example, one patient believed his chemotherapy was killing him, so he stopped treatment, and reportedly felt better only after he stopped chemotherapy. Another patient shared that her whole family experienced great stress after the doctor casually told her daughter that she was going to die. Among female patients exclusively, being worried about household and family responsibilities and being unable to take care of them was commonly mentioned. These attitudes may be from insufficient counseling and

education to combat concerns about diagnosis, treatment, and prognosis, which only two patients reported receiving after being diagnosed. One of them stressed the need for better education about cancer treatment and positive outcomes, suggesting that increased knowledge about curable cancer might decrease suicidal ideation after a diagnosis: "Cancer has got hope. People should know there is hope."

Many of the patients we interviewed cited multiple delays in care but rarely expressed an understanding that early cancer detection is a key predictor of a good cancer outcome. They described their delays but did not usually perceive them as delays, instead believing that once they started seeking care of some kind, they were doing what they could. However, several patients took it upon themselves to push for earlier visit dates, retrieve biopsy results from the lab themselves, or show up for specialized services without a referral. These patients were proactive not only for diagnostic workup and treatment services, but also in seeking their initial care: they received treatment in less than 1 year from symptom onset. Of note is that among these proactive patients, women were more proactive in pushing for timely care.

Another commonality among patients who received cancer treatment in less than a year from symptom onset was a heightened cancer awareness from the radio. Four patients reported hearing a radio advertisement about signs of cancer—either cervical or breast cancer symptoms—and the radio advertisement was an important factor in their seeking care.

**Delayed Care at Lower-Level Facilities**
Some health care providers at local clinics did not recognize cancer symptoms and misdiagnosed participants as having

**Table 2.** Examples of delays across levels of health facilities

| Facility type | Occurrences | Number of participants | Example case |
|---|---|---|---|
| Clinic | 16 | 8 | Female participant presented to local clinic with pelvic discharge and bleeding. She was treated for 6 months for an STI although symptoms worsened, after which she sought care at a local hospital without a referral. |
| Primary hospital | 10 | 5 | Female participant had breast biopsy and was told to return to the local hospital 4 months later for results. Every month for 8 months she returned and was told the results were not ready. Eleven months after the biopsy was performed, her biopsy results were found, and she was scheduled for further testing to assess cancer stage and suitability for treatment. |
| Specialty department/ward (within referral hospital) | 18 | 9 | A male participant received biopsy results indicating maxillary SCC and brought them the same day to the ENT specialty ward at the referral hospital. The specialist was not available, and the participant was told to return in 2 weeks. |
| Oncology ward | 7 | 5 | The oncology ward at a referral hospital could not find the pathology report for a participant with cervical cancer, so the participant had to get a copy from the National Health Lab herself and bring them back before she could receive treatment, delaying her several days. |

Abbreviations: ENT, ear, nose, and throat; SCC, squamous cell carcinoma; STI, sexually transmitted infection.

other common health problems, such as sexually transmitted diseases or tuberculosis. According to patient self-report and medical records, 15 patients experienced incorrect treatments and/or misdiagnoses. When misdiagnoses were reported during an interview, patient stories were corroborated with medical records whenever possible. During these delays, which were most severe at the clinic level, symptoms progressed. Incorrect diagnoses and/or treatment also meant that patients made multiple visits to local clinics, where they were only given pain medication and sent home. For example, one participant later diagnosed with prostate cancer was given pain tablets from a clinic for 2 years for his complaints of extreme trouble passing urine. In the five cases in which it took the patient 2 years or longer to receive cancer care after initial symptom onset, incorrect treatment was often received at clinics or lower level hospitals, most frequently from nurses (who provide the vast majority of outpatient care in Botswana).

**Poor Coordination for Diagnostic Evaluation**
Although patients described many delays at local clinics and health posts, delays occurred across all levels of care, such as being referred for additional follow-up or specialized care in a hospital (Table 2).

Patients frequently described problems with referrals to higher-level facilities, mainly regarding lack of communication and poor coordination. They went back and forth between two to four facilities because they were not told which documents to bring to referral appointments, facilities could not find test results, and imaging and laboratory services had limited availability. It was also unclear when and where specialists were working, so patients were shuffled between facilities without receiving any care while symptoms progressed. Patients generally had to arrange their own care coordination; they described traveling to facilities in other towns for biopsy procedures and laboratory work, personally

retrieving results from the National Health Laboratory, and then delivering results to the specialists. In these cases, it generally took over a year from symptom onset for the patients to begin receiving cancer treatment.

Common barriers delaying diagnosis included accessing biopsy services and obtaining pathology results. For example, one participant made four separate trips before a successful biopsy procedure was completed. The first time she came on the wrong day, the second time she was told the equipment needed for the procedure was not working, and the third time the doctor conducting the biopsy was not present. Other patients were subjected to repeated biopsy procedures because the results from initial samples were lost. Patients commonly faced additional problems regarding biopsy appointments, faulty equipment, availability of health care providers, and slow turnaround for pathology and imaging results.

Delays within various departments of referral hospitals proved difficult, restricting patients from reaching and accessing care in the oncology ward. For example, one patient made routine visits to the orthopedic department of a referral hospital for 7 months before a biopsy was done and she was referred to oncology. Once a diagnosis was confirmed (usually in oncology care), fewer delays occurred.

**Structural Health System and Logistical Barriers**
Over half of the participants described being turned away, sent home, or rescheduled without seeing a provider after traveling to a facility, and for some participants, this happened multiple times. The reasons for being turned away varied across facilities, but these events occurred most frequently within departments at referral hospitals before patients reached the oncology ward. Although a few participants were confused about appointment dates, the most common reasons included unavailable doctors, high patient

volume, long queues due to arriving later in the day after long journeys, and delayed biopsy results. Patients expressed frustration about the inefficiencies, transportation time and expenses, and lost opportunity costs. A 64-year-old male patient with esophageal cancer said, "If they just give you the appointments, you just follow them […] You know I was worried the way they just kept giving me the days. You know I spent a lot of money. I just wanted one appointment so, you know, they could help me once."

Although patients were frustrated about lost time and money spent on ineffectual or cancelled appointments, none of the 20 patients expressed anger or an understanding that not immediately seeking care or the subsequent delays may have eliminated their chance of cure.

## DISCUSSION

In this qualitative study describing common cancer care trajectories from symptom onset to treatment initiation in Botswana, we found that limited knowledge of cancer and lack of urgency to secure a diagnosis contributed to many delays. Logistical hurdles for accessing specialty care and procedures in distant facilities with uncertain schedules and provider availability compounded these delays. The patient stories described a health system with a focus on empiric treatment of sexually transmitted infections (STIs) and other noncancer conditions that was slow to re-evaluate initial diagnosis and consider cancer. Patients with a family member who had cancer or who had heard cancer awareness messaging on the radio advocated for themselves and experienced shorter time to cancer treatment. Social support from family members was also an important facilitator.

We found important links between psychosocial factors (e.g., cancer awareness, fears, beliefs) and help-seeking behaviors, both of which affected delays in care. Social networks, especially family members, were a key source of emotional, informational, and tangible/instrumental social support in our study. Similarly, studies among breast cancer patients in Egypt and Malawi found that informational and emotional support and social networks more generally were important influences on patients' health-seeking decisions and behaviors [8,23]. Symptom disclosure was often linked with timely health-seeking in a metaethnographic synthesis of breast cancer delay studies [24], which is similar to our finding that social support facilitated faster cancer care patterns. Therefore, information, education, and communication strategies should target the general population to increase awareness broadly and leverage communication and relationships through social networks. Messages should address symptom recognition, emphasizing the importance of seeking care at facilities promptly after noticing symptoms.

In our study, patients' outlook on disease affected their health-seeking decisions. Studies in other settings found similar findings regarding outlook on disease affecting cancer care-seeking and issues with symptom recognition. An international qualitative synthesis on help-seeking experiences and delays in cancer presentation described how patients' fear of consultation was a common experience across seven countries [25]. Emotional reactions after discovering symptoms was common among studies of breast

cancer treatment delays [24], and experiences of pain and isolation among patients with cervical cancer in Zambia led some to suicide ideation [26].

Many participants in our study did not understand that timely entry into cancer care is critical to improve outcomes and thus lacked a sense of urgency about their care; this been found in other qualitative studies of cancer care. Perceived severity of symptoms has been shown to motivate women with breast symptoms to seek help [24] and can also interfere with care-seeking patterns [8,27]. Issues around symptom recognition and interpretation were found by other studies as well [25,28].

Patients in our sample described delays at clinics and primary hospitals, which occurred largely because providers did not recognize the presenting symptoms as being suspicious for cancer. It was common for patients to be misdiagnosed initially and treated according to endorsed syndromic algorithms for common infections without recognizing unusual clinical scenarios (e.g., postmenopausal women with repeated STIs or mastitis) or failure to respond to therapy. These findings add to a body of evidence that suggests lack of knowledge among providers can cause delays in cancer care. Studies in South Africa, Malawi, and other LMICs have similarly found that low cancer knowledge among primary care providers led to misdiagnosed cancer cases [27,29–31]. Our findings suggest that educational opportunities and improved training on cancer signs and symptoms could improve timely diagnostic workups and referrals.

In our study, general lack of information, communication, and coordination across the health system led to repeated visits for the referred follow-up evaluations. Strengthening referral systems and communication across facilities to improve coordination may promote more timely entry into specialized care. For example, health system strengthening interventions, focused on health worker training workshops, health system tools and protocols, and a community awareness program [32,33], improved cervical cancer screening services in South Africa and may be relevant to Botswana's context. Additionally, understanding and addressing when, where, and why patients are turned away from health facilities will be paramount to ensuring that patients are successfully linked to follow-up care. Future research to gain insight from the health system perspective could identify where additional staff and resources are needed and would have the greatest impact.

This study has limitations, including that we were unable to record the interviews and instead relied on field notes and interviewer summaries. Real-time translated responses were captured for the remaining interviews and confirmed with interviewer summaries. Additionally, this subgroup of participants from the BPCC allowed a detailed review of clinical records and patient notes to supplement interviews. The BPCC also enrolls participants as they begin oncology care, minimizing recall from recent referrals but also limiting the analysis to examine perceptions of care leading up to initial cancer treatment. Another limitation is the fact that this cohort only included patients who enter care, whereas 45% of people with cancer never receive any care, and these people may experience different barriers

[34]. Additionally, we did not interview providers, so inference on their knowledge came from the patient narratives we collected. We interviewed until saturation of data was achieved; however, with only 20 participants in this substudy, it is possible that some potential care trajectories were not included. Despite the limitations, this study was the first to explore care patterns across among a diverse group of patients with cancer in Botswana.

## Conclusion

These findings highlight factors at multiple levels of influence that affected cancer care delivery and ultimately cancer treatment delays for patients in Botswana. We identified opportunities along the cancer care continuum to improve access and quality through interventions directed at patients, their social networks, health care providers, and the health system. Future work should monitor and investigate health care work force, infrastructure, and quality improvement initiatives to address patients being turned away from facilities. Promoting cancer education at the provider and community levels may improve time from symptom onset to treatment initiation, which is critical for improved cancer outcomes in Botswana.

## Author Contributions

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**For Further Reading:**
Karla Unger-Saldaña, Daniel Ventosa-Santaulària, Alfonso Miranda et al. Barriers and Explanatory Mechanisms of Delays in the Patient and Diagnosis Intervals of Care for Breast Cancer in Mexico. *The Oncologist* 2018;23:440–453.

**Implications for Practice:**
This study's findings suggest that policy in low- and middle-income countries (LMICs) should be directed toward reducing delays in diagnosis, before the implementation of mammography screening programs. The results suggest several factors susceptible to early diagnosis interventions. To reduce patient delays, the usually proposed intervention of awareness promotion could better work in LMIC contexts if the message goes beyond the advertising of screening mammography to encourage the recognition of potential cancer symptoms and sharing of symptoms with significant others. To reduce diagnosis delay, efforts should focus on strengthening the quality of public primary care services and improving referral routes to cancer care centers.