


Cancer Care in Pakistan: A Descriptive Case Study

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Abstract

In this descriptive case study, we aimed to understand the experiences of cancer diagnosis, treatment, and palliative care in Pakistan. The case was limited to a hospital for cancer and hospice care in Karachi, Pakistan. Data collection included interviews with patients who had a cancer diagnosis, family members, healthcare providers, and unstructured observations. Two themes of suffering and late diagnosis were developed to describe the experiences of people with cancer. Suffering occurred as a result of poverty, social ideas about cancer, and physical suffering. Late diagnosis happened because of cultural ideas about health, low health literacy, and healthcare challenges, although both themes are interconnected. The findings illuminate three key pathways that will improve cancer diagnosis and palliative care in Pakistan: specifically, the need to (a) educate healthcare providers about cancer and palliative care, (b) eradicate corruption in healthcare, and (c) develop policies for universal access to health.

Keywords

cancer, palliative care, access to healthcare, pain, qualitative, quality of life, suffering, professional education, caregivers, determinants of health, Pakistan

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Introduction

The World Health Organization (2018a) has recognized cancer as a leading cause of death around the world. Early detection, accurate diagnosis, and access to multimodal cancer therapy are essential for cancer management (Shah et al., 2019; WHO, 2021). However, in low-and middle-income countries (LMICs) resource constraints and inaccessibility to universal healthcare (Shah et al., 2019) mean people do not receive early diagnosis and treatment (Brand et al., 2019; Hannon et al., 2016). As a result, by the time people access healthcare they are in an advanced phase of cancer. Furthermore, palliative care is often unavailable (Brennan et al., 2019; WHO, 2018a). While most high-income countries provide palliative care, in LMICs—where 80% of the world's population lives—access to palliative care remains low (Poudel et al., 2019). The WHO (2020b) reported that in 2018, 18.1 million people around the world had cancer and 9.6 million died from the disease. Those

figures will nearly double by 2040, with the greatest increase in LMICs. Thus, an urgent need exists for both evidence-based and regional research in LMICs that focus on access to care, cancer treatment, and palliative care (Hannon et al., 2016).

Background

A late diagnosis of cancer in LMICs is due to a variety of factors (Hannon et al., 2016). Financial constraints coupled with cultural and religious beliefs can cause people to delay seeking healthcare

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when symptoms first arise (Azami-Aghdash et al., 2015). As well, people in LMICs strongly believe in traditional healers' powers to deal with palliative care patients (Campbell & Amin, 2014). In some cases, the reliance on these healers is associated with unrealistic hopes for a cure and a focus on the supernatural (Hannon et al., 2016). When people do access healthcare, the healthcare professionals' lack of training in cancer diagnostics and care can cause further delays in diagnosis and treatment (Goh & Lee, 2018). Additionally, palliative care can be thwarted by LMICs' regulatory authorities' restrictions on opioids, an essential tool in pain management (WHO, 2020a). Further, LMICs lack an inadequate system for law enforcement, which leads to illicit production, consumption, and trafficking of opioids (Pettus, 2013); this, in turn, contributes to inadequate availability of these necessary drugs in healthcare settings.

Government expenditures on healthcare partly account for the financial cost to individuals when they seek healthcare (Sadiq et al., 2019). Studies suggest that at least 5% of gross domestic product (GDP) be spent on health (McIntyre et al., 2017), yet Pakistan spends less. The World Bank reported Pakistan's total expenditure on health in 2018 at about 3.2% of total GDP (World Bank, 2021). Notably, Pakistan's healthcare delivery system includes both private sector healthcare and public healthcare in the form of federal and provincial government systems. Private hospitals are either mission-driven (supported by philanthropists) or for profit (Javed et al., 2019), but only the wealthy can afford for-profit hospitals (Javed et al., 2019). Consequently, to access healthcare, people in Pakistan must often pay out of their own pocket, with personal spending amounting to around 58% of the total health expenditure (Khalid et al., 2021). This creates challenges, of course, given that average salaries range from 20,700 Pakistani Rupee (PKR) to 365,000 PKR per month, with an average of 81,800 PKR (Salary Explorer, 2021). This translates to approximately US\$135 to US\$2378/month, with an average of US\$533/month (based on an exchange rate of US\$1 to 153.45 PKR).

Pakistan's cultural practices and nursing shortages often require that a family member attend to the personal care needs of their family member while they are a patient in a healthcare facility. Nursing shortages also often lead healthcare institutions to employ unregistered nurses who are not fully trained (Hayat et al., 2019; Sultan, 2019). Moreover, as noted, healthcare in Pakistan is connected to individuals' cultural beliefs (Khan et al., 2012). Thus, it is customary for patients or their family members to approach spiritual healers and consult relatives or neighbors prior to accessing hospitals and treatment centers (Shaikh et al., 2008).

Marked variations in cancer types among distinct ethnic groups in different regions of the country, as well as the absence of a national cancer-based population registry have contributed to the lack of accurate information about the prevalence of cancer in Pakistan (Ashraf & Jamil, 2016; Qureshi et al., 2016). In addition, little is known about the experiences of the people in Pakistan related to cancer diagnosis, treatment, and palliative care, pointing to the need

for research to understand and improve healthcare for these patients and their families (Hannon et al., 2016). Therefore, this study aimed to understand the experiences of cancer diagnosis, treatment, and palliative care for this population.

Methodology

Design

We used a qualitative descriptive case study (Yin, 2018) to investigate the experiences of cancer patients, family members, and healthcare providers at a private hospital and hospice that is mission-driven and supported by philanthropists. The case study approach is an empirical inquiry that investigates a phenomenon within its context when the boundaries between the phenomenon and context may not be clear (Yin, 2018). To enhance the rigor of a study, a descriptive case study focuses and details the field through propositions and questions about the phenomenon (Yin, 2018). Here, a social constructionist epistemology guided our understanding, emphasizing that meaning is socially constructed. Yin (2018) asserts that theoretical propositions help to identify the relevant information to be collected about the case; as such, the social determinants of health were our guiding theoretical propositions, as they contribute to understanding participants' experiences in accessing healthcare. These theoretical propositions are outlined in Table 1, derived from literature and the authors' professional experiences (Baxter & Jack, 2008).

Research Setting and Sample

The selected research setting was a cancer and palliative care philanthropic hospital situated in a large urban center in Pakistan. The cancer hospital is located in Karachi, the capital city of one of three provinces in Pakistan. However, the cancer hospital is open to people from anywhere in Pakistan. Philanthropists fund the hospital to provide inpatient and outpatient services to people who cannot afford to pay for their cancer treatment. The philanthropic hospital's mandate is to focus on prevention, early detection, and curative and palliative care for underprivileged people across Pakistan who have cancer. This hospital was chosen as it fit with the theoretical propositions related to the social determinants of health that influence healthcare access.

Using a purposive sampling methodology, a total of 12 participants were enrolled in this study. Inclusion criteria included patients 18 years and older with deteriorating health, the family members who accompanied them, and professionals who had a minimum of 1 year of experience and participated in the care of the patients. We excluded patients who were children and those who did not have cancer.

Data Collection

Data collection methods were individual interviews with patients, family members, and healthcare providers, along

Table 1. Theoretical Propositions.

Propositions for This Study	Source
<p>Social determinants of health influence access to palliative care</p> <p>Those with high income have access to opioids pain medicines, while those with low income suffer. Cultural challenges may exist in terms of the person's knowledge of his/her diagnosis</p> <p>Individuals may be unwilling to get treatment because they do not want to take away their family's resources (financial as well as time) for themselves if access to healthcare depends on the ability to pay</p> <p>Individuals may first approach traditional healers and use alternative therapy. Then these individuals come to hospitals for treatment. This results in late diagnosis and treatment</p> <p>Cancer pain management is not adequate. Opioids are inaccessible in part because cancer pain is perceived as part of the disease. Also, access to opioids is obstructed by strict regulations and controls. Access to opioids is also dependent on income status; those with high income have access to opioids pain medicines, while those with low income do not have access. Thus, they suffer. Moreover, there is a lack of palliative care emphasis at the national policy level. This influences cancer care and symptom management.</p> <p>Health care providers lack palliative care education</p> <p>This influences on cancer care and symptom management</p> <p>Policy level change is required for improving access to palliative care</p> <p>Reducing barriers and improving access to opioids require policy reform at the governmental level with a set of action plans being formulated and concurrently implemented and aimed at different levels of social, education, and economic policy change as severe suffering exists. The WHO and researchers recommend that a public health strategy is to be implemented to address the issue of palliative care</p>	<p>Professional experience and literature: (Donkor et al., 2018; Hannon et al., 2016)</p> <p>Professional experience and literature: (Hannon et al., 2016; WHO, 2018a)</p> <p>Professional experience and literature: (Hannon et al., 2016; Kurji et al., 2019)</p> <p>Professional experience and literature: (Dempers & Gott, 2017; Hannon et al., 2016)</p>

with unstructured observations. After ethics approval at the University of Alberta (ID: Pro00079346), and obtaining the participants' informed consent, interviews began. The semi-structured interview guide that we first developed in English we had translated to Urdu before the interviews themselves, which were conducted in that language (see supplementary file for copies of interview guides).

The first author conducted all of the interviews and observations in Urdu. All were audio-recorded, with the exception of one interview as one participant consented to be interviewed but not recorded. Interview notes were kept of this interview. After the interviews had been transcribed, participants were given the opportunity to read them, indicate if they were accurate, and add additional details. The first two interviews were first transcribed in Urdu, then translated into English, and then transcribed again into Urdu by two translators experienced in this process. Each participant's audio-recorded interview, along with the associated transcripts in English, were saved on a secure password-protected computer and data repository.

Unstructured observations focused on the physical appearance of the environment and the institution's service capacity for inpatients, daycare, and outpatients. Observations also included how patients and families navigate care processes, how people enter the facility, and who they speak with first. These unstructured observations were gathered over 250 hours, with the first author recording notes about them in a journal. For example, notes included how the posters in the setting highlighted the importance of cancer prevention even though such posters are not commonly used in other healthcare centers. She also journaled about personal thoughts and feelings that arose during data collection. In addition, the first author discussed with the other researchers the personal impact of watching the suffering of people in the philanthropic hospital, as well as how to best navigate the challenging situations that she witnessed. This supported reflexivity and promoted data analysis focused on participants' experiences rather than the researchers'.

Data Analysis

Data analysis occurred simultaneously with data gathering and involved a reflexive analysis of the data. Initially, each transcript was read as a whole to develop an overall impression of the individual experience. To get a thorough understanding, each transcript was read two to three times. The primary researcher then wrote theoretical memos that included describing her unstructured observations and reflecting on her analytical thoughts about the findings. All three researchers reviewed the transcripts and the theoretical memos. Data analysis meetings consisted of an iterative process in which all researchers discussed the data and their analytical thoughts about each of the transcripts and all of the transcripts as a whole, to develop themes and subthemes. Through this process, we identified two main themes, with subthemes, to describe the participants' experiences: late diagnosis and suffering. Late diagnosis was due to cultural

ideas about health, low health literacy, and healthcare challenges. Suffering occurred due to poverty, social ideas about cancer, and physical suffering.

Rigor

Rigor was achieved through trustworthiness: establishing credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Credibility was promoted through prolonged engagement in the research field and triangulation of the data among the researchers.

Description of the research context and assumptions that were central to the research inform the transferability of the research, as do the thick descriptions provided by the participants. Dependability was enhanced by the participants' review of their transcripts. A transparent analytical decision trail and the rigorous discussions among the authors contributed to the dependability and confirmability of the findings. Confirmability was also promoted through reflexivity, which included researchers' critical reflections examining biases, preconceptions, and research relationships. Consolidated criteria for reporting qualitative research (COREQ) guidelines were also followed (Tong et al., 2007).

Results

Participants included four patients, three family members, and five healthcare providers at the study setting. All of the patients presented at the late stage of their disease. The female patients were 29, 32, and 50 years, and the male was 44 years of age. While a patient is hospitalized one family member must stay present round the clock as an attendant to take care of the psychological and emotional needs of the patient. This attendant assists the patient in activities of daily living, such as bathing, shifting the patient in and out of bed, and feeding them meals provided by the hospital. The family members included a wife and two daughters, all from different families. The healthcare providers included two nurses, one pharmacist, and two doctors. Their working experience ranged from 3 to 9 years. The physicians and the pharmacist all had 5 years of education. One nurse reported having a diploma in nursing, but we are unclear about the educational level of the other nurse who participated in the study.

The participants' details are presented in [Table 2](#)

The two themes of late diagnosis and suffering were developed from the data to explain the experiences of accessing and undergoing cancer diagnosis, care, and palliative care. Late diagnosis occurred due to cultural beliefs about health, low health literacy, and healthcare system challenges. Suffering arises from poverty, social ideas about health, and physical suffering. ([Table 3](#))

Late Diagnosis

Late diagnosis describes how the diagnosis of cancer was not made until the disease was at a late stage and had already metastasized, limiting treatment options. Late diagnoses were

Table 2. Study Participants.

Patients (n = 4)	Family Members (n = 3)	Healthcare Providers (n = 5)
P1 Female	FM1 female (daughter)	HCP1 Registered nurse Male
P2 Female	FM2 female (daughter)	HCP2 Pharmacist Female
P3 Female	FM3 female (wife)	HCP3 Registered nurse Male
P4 Male		HCP4 Physician Male HCP5 Physician Male

due to cultural beliefs about health, seeing a healer first, low health literacy, and healthcare system challenges.

Culture Beliefs About Healthcare

Cultural beliefs that included approaching spiritual healers and consulting relatives about health problems inhibited an early diagnosis and treatment. People go to healers because they believe they will provide divine intervention in spiritual and physical healing; moreover, they were less expensive than accessing the healthcare system. As one healthcare provider noted, “People assume healers are cheaper than private medicine but these healers may charge you something that may seem very small but in reality, it costs more” (HCP5). In the end, the delays in seeking medical attention could lead to a premature death—certainly, a very high cost. Moreover, when in the care of a healer, people were instructed “to follow their regime and not to take any other treatment. This is how a patient’s core time gets wasted and the disease gets to an advanced stage,” said one healthcare provider (HCP1).

An example of cultural beliefs in healers that cause delays in cancer diagnosis is found in the account of one woman who ignored a tumor growing in her breast until it was noticeable to others. When she finally did go to a hospital, surgery was the recommended treatment but she delayed this until she had an ulcerating cancerous wound in her breast. Instead of medical and surgical treatment, the woman had been seeing a spiritual healer. The woman explained that her hesitancy in undergoing surgery were related to fears “that if I go for surgery I will die” (P3) and because the spiritual healer had told her she would be “cured without a surgery and then you should go and tell the doctors... I am alive [and] well” (P3).

In Pakistani culture, the head of the family is the decision-maker and gatekeeper for accessing healthcare. This individual, who could be the husband or the mother-in-law, is so

Table 3. Themes and Subthemes.

Theme	Subtheme
Late diagnosis	Culture ideas about health Low health literacy Healthcare system challenges
Suffering	Living in poverty Social ideas about cancer Physical suffering

powerful in the family context that they make crucial decisions about pursuing mainstream healthcare. This can influence whether people seek attention from spiritual healers or from mainstream healthcare. One healthcare participant (HCP1) reported that often this means by the time a patient reaches an oncologist, the patient’s disease has advanced to stage three or four,

Low Health Literacy

Low health literacy also contributed to fears that a diagnosis of cancer meant death. One woman explained that she had not sought medical attention when the nodules in her breast did not disappear because “no one thinks that cancer could be the problem. There was no concept of cancer as a disease” (P2). Since her own experience with breast cancer, this person advised her sister, when she developed a lump in her breast, to seek medical attention. Fortunately, her sister was able to have the lump removed and did not require further treatment.

As another example, a healthcare provider (HCP3) explained that teens were consuming substances known to cause cancer, in part because “they [were un] aware of the consequences. They go for short-term effects, [and] they [become] addicted to these things” (HCP3). Another healthcare provider explained that because “the rate of

patients with different types of cancer is increasing, we should increase the rate of the programs for protection” (HCP1). Focusing on youth for the future of the nation was also emphasized by yet another healthcare provider who said, “Teens, due to their peer pressure, develop habits [that are unhealthy]” (HCP5). These behaviors have long-term health consequences.

Educating the masses was strongly advocated as one of the ways to minimize the prevalence of cancer. In the study setting, posters were displayed in the visitors’ lounge, which provided information about substances that cause oral cancer and about the importance of self-breast examination for early detection of breast cancer. These posters were culturally tailored and used culturally acceptable language.

Healthcare system challenges

Inaccurate diagnosis and scarce resources ultimately led to delays in accessing diagnosis, treatment, and palliative care for many patients. Some of the participants did seek healthcare when they first began to experience health concerns, but an inaccurate diagnosis delayed treatment. For example, a female participant in her mid-40s, who experienced chest pain and an elevated temperature, first treated herself at home with medicines to relieve of pain and fever. When she did not recover, she went to a government healthcare setting where she was diagnosed and treated for tuberculosis.

Her symptoms persisted and so she sought healthcare from several other government healthcare settings in different cities within her district. The physicians consistently diagnosed her with tuberculosis, despite her lack of sputum and response to their treatment. As she explains: “The doctor started treating me for tuberculosis. I was assured that my disease would be cured. I was on tuberculosis treatment for 2 months and after that, I came for the follow-up. My x-rays were done. The doctor told me that again there is fluid accumulation in my lungs” (P1). This time the participant was told that she did not have tuberculosis but some other type of infection. Her anti-tuberculin treatment was discontinued, the chest fluid drained and she was prescribed antibiotics. However, she was not correctly diagnosed, nor did her problem resolve; once again, she developed a pleural effusion. At this time, the woman’s family took her to a private hospital that had a welfare and zakat¹ assistance program. Finally, 4 years later, the woman received diagnostic procedures including a lung biopsy and thoracentesis, which led to a diagnosis of lung cancer with metastasis. The family was informed that palliative care was the only treatment option.

In another case, a female participant at about 19 years old felt some nodules in her left breast (P2). She explained that she had visited a doctor, was assessed, and an ultrasound was performed. The doctor informed her that the nodules were veins in the breast that were congested and that once she married this congestion would be resolved. Every month during menstruation, she continued to notice that the hardness

and pain in the lump continued to increase. Once menses was over, both the pain and hardness subsided. As time went on, she considered the hardness and pain a normal state of affairs and did not worry about it. At about 30 years of age, her infant refused her left breast but fed well from the right breast, leading her to visit her obstetrician, who told her she was “not feeding [her] baby properly” (P2). As an experienced mother of three children by this time, she was not satisfied with this answer. She went to another obstetrician/gynecologist who performed an ultrasound of her breast and told her there were some abnormalities requiring further assessment and investigation. Because it had taken years to get this diagnosis of cancer, the disease was now at stage two. Although there is no way to know for sure about the events 11 years prior to this, the woman herself questioned if the cancer could have been diagnosed when she first went to the doctor years ago.

Scarce resources were described by all of the participants, which is compounded by corruption—all of which severely influenced their access to diagnosis and treatment. Such corruption took the form of bribery to move ahead in the line for consultation, investigation, a bed in the hospital, medical treatment, and procedures. As one participant said, “In Pakistan the required resources are almost not available at all” (P4). People must wait long periods to access healthcare resources. As this person further explained, “Wherever you go you have to wait in the queue... by the time he gets his turn [the patient] is on the verge of dying... we have agents [healthcare staff] who cheat the people who are in need” (P4). One healthcare participant added that there was no one to report the corruption because “our government is also a thief. A person working as a peon [up to] ... the person working as the president, all of them are taking the bribe” (HCP4).

A physician asserted that advocating for cancer control through policy-level change must include reducing accessibility to substances such as betel nuts and ghutka (a sweetened mixture of chewing tobacco, betel nut, and palm nut), which are known to cause cancer. If these substances are easily accessible, their consumption will remain high, with the inevitable consequences. In the participant’s words, “Ghutka is so commonly available; [it’s] cheap and [people have] no awareness about it [as a cancer-causing substance]. Letting people start these types of habits [is problematic].” (HCP 005).

Suffering

Suffering often occurred due to a late diagnosis. Yet for many, suffering was part of daily life arising from poverty, social ideas about cancer, and the physical suffering associated with having cancer.

Living in Poverty

Participants with a low socioeconomic status were concerned with their families’ day-to-day survival. A young adult female

participant explained that it was hard to know what was wrong with her mother because her mother did not discuss her health with the family. She kept her illness a secret because she was unwilling to use any of the scarce family resources to seek medical attention (FM2). A healthcare provider explained that such financial constraints influenced access to healthcare. “I have seen the poor patients of the public hospital [and] the rich patients of private hospitals. Finances do affect people’s access to treatment” (HCP5). Thus, day-to-day suffering affected diagnosis and treatment.

Patients and their family members also suffered financially when they had to pay to travel to a healthcare setting for medical investigations and treatment. A participant who was the family member of a woman with cervical cancer explained that “managing transportation was the most challenging...The cost of transportation was more than what I earn in a month working full time” (FM2). The financial suffering was so dire that some people would come to healthcare centers riding on top of vehicles to save costs. One healthcare provider pointed out that “they [patients] do not have any means of transportation. They come in buses. They come in on top of cars” (HCP2).

A patient with breast cancer shared her financial suffering by explaining that for her breast surgery, she was required to pay “PKR 500,000–600,000 rupees” (P2), equal to about US\$3138 to 3766. Another patient (P4) said he was required to pay PKR 800,000 (about US\$5021) for his oral cancer surgery. For both patients, the cost of surgery was staggering in relation to their financial means, prohibiting their ability to pay for their surgery. The inability to pay for the necessary surgery created distress and even more suffering.

Social ideas About Cancer

In Pakistan, when a cancer diagnosis is made, cultural and religious networks also contribute to the suffering of the patient and their entire family. Even mention of such a diagnosis causes patients and family members distress as it elicits fear of pain, suffering, and death. Patients and families often learn of the cancer diagnosis when they are together. However, if they hear the diagnosis separately, patients may hide it from their family members due to the “trauma that occurs with the word cancer” (HCP1). Alternatively, the family members might learn the diagnosis apart from the patient and then may conceal it from the patient. This is because “it is very painful for the patients and their family members to hear the word ‘cancer’ as a diagnosis... They are fearful that cancer is not curable, sickness is prolonged and painful, the person’s condition will deteriorate and the person will die shortly” according to one healthcare provider (HCP1). It seems that some patients and family believe that if they do not talk about a cancer diagnosis, the patient may live longer. As well, healthcare providers sometimes received threats from patients and/or their families because they refused to believe that nothing

more could be done to save their family member’s life. As one person said, “Sometimes we are threatened, we are abused, and we get harassed.... Though we want to help but we cannot; there is nothing that we can do because the cancer has spread.” (HCP5)

A healthcare provider (HCP2) described the social suffering of a female patient diagnosed with breast cancer who came to the clinic accompanied by her husband. The word “cancer” provoked such anxiety and fear that the husband became angry and violent. He immediately broke off his relationship with the wife and divorced her, stating that cancer was her “problem, handle it yourself...he said to her” (HCP2). The woman was in shock, completely lost, and had an “emotional breakdown for what she was going to face” (HCP2). She needed time and courage to share this information with her family members and friends in their social circle and to arrange for how to deal with the change in her circumstances. The administration at the philanthropic hospital admitted the woman to provide her accommodation until she could make other arrangements.

Physical Suffering

Physical suffering could occur due to cancer pain, other physical ailments, or the actual care needed as part of their treatment. A salient example of physical suffering occurred when the first author observed a dressing change for a patient with oral cancer. The researcher noted that the patient was lying in bed with his eyes closed and half of his face was covered with a piece of cloth. As the dressing nurse removed the piece of cloth from the patient’s face, a huge tumor at the patient’s left lower lip was revealed. The tumor almost covered the patient’s mouth, limiting the opening of his mouth. The weight of the tumor caused the mass to extend below the patient’s chin. At his cheek, there was a big hole through which the inside of his oral cavity was visible. The patient’s tongue, teeth, and internal part of his jaw were visible. As the size of the tumor appeared to be heavy, holding this weight seemed tiring, suffocating, and exhausting for the patient. On the outside, the tumor was black with necrotic tissue but inside the mouth, the tumor was ulcerated, bleeding, and oozing with secretions giving off a distinctive odor. In the inner side of the tumor were the small white bodies of maggots. He was in this state of suffering because he had delayed seeking healthcare attention and when he did the cost of the surgery was unaffordable for him and his family.

Later the patient’s wife explained the cause of the tumor. “We have been married for 19 years. All this time I see him chewing ghutka” (FM3). She explained that her husband worked in a small-scale shoe factory as a shoemaker. To provide for his family, he brought work home in addition to working in the factory. Thus, he worked day and night. To suppress his desire for food, and to concentrate and remain

focused on his work, he chewed ghutka. Healthcare providers described their personal distress, witnessing the suffering of their patients “who come to us full of maggots” (HCP4).

Other participants who talked about ghutka rationalized people’s use of it and other such substances to relieve stress, provide a boost of energy to work, and suppress their hunger. Ironically, these individuals had trouble affording food, but took advantage of the accessibility and availability of cheap substances such as ghutka, as this participant explained: “It [betel nuts and ghutka] is the cheapest thing and the—most amazing part—you can find it in every nook and corner of the streets...it’s so common, available, cheap” (HCP5). Most of the people who use these substances are from low socio-economic backgrounds. They experienced the short-term relief of hunger suppression and the benefit of energy boosts but were often unaware of the dangers of using these substances.

The healthcare providers explained that managing patients’ pain was their biggest challenge: most of their patients needed narcotics such as morphine, substances that were often not available in Pakistan. In its absence, they administered tramadol in conjunction with sedatives like midazolam to sedate their patients; however, managing pain with sedation often caused nausea, described as unbearable. One person put it this way: “At times it happens that [a] patient gets more sedated and feels nauseated.....[thus] the patient ... comes to the refusal phase [of the sedation]” (HCP4). In other words, patients must make a choice between pain or unbearable nausea. Healthcare providers explained that this situation caused patients to suffer and to die “due to unavailability of morphine” (HCP5).

Families desperate to relieve their loved ones’ suffering took risks and used illegal routes to obtain morphine. A healthcare provider relayed this story about this issue: “A female patient [who]... had breast cancer. Her cancer had severely metastasized to her bones.... She was in need of morphine but it was not available. Her husband said he would try to arrange it through the drug dealers to keep his wife pain-free” (HCP5). Cancer pain can cause suffering not only for patients, but for their families as well who must witness and support them as the disease and pain progress; this is also true for healthcare providers who witness patients’ severe cancer pain. In summary, the social and physical suffering that people experienced were often interconnected with and shaped by poverty.

Discussion

The key finding of this study was the depth of suffering these participants experienced, largely because of their late cancer diagnosis. Participants experienced cancer sequelae vis-à-vis several other factors: the social stigma

of having cancer, the financial burden, the social and cultural values related to seeking treatment, lack of understanding about cancer prevalence and prevention, healthcare system inadequacies and corruption, and most significantly, poverty. In this study, cultural values and beliefs about accessing healers at times obstructed individuals in seeking healthcare; in other cases, cultural values of philanthropy assisted individuals in accessing healthcare. Specifically, it is remarkable that the same cultural values and commitments about using healers—which often caused delays in cancer diagnosis and created further challenges to accessing healthcare—also encouraged families and neighbors to support participants in accessing the philanthropic hospital, sometimes, even paying for their treatment. The resilience of participants and their families, despite monumental barriers and suffering, is noteworthy.

Of note, poverty was at the root of most of the suffering described in this study and is largely the reason for late diagnosis. This is in keeping with our initial theoretical proposition about the social determinants of health that influence people’s experiences of health; these were low in our study, which resulted in poor access to healthcare and lack of understanding about the prevalence of cancer and early signs of cancer. Participants suggested that the following are needed: (a) policy-level change to enhance early diagnosis of cancer; (b) a focus on cancer prevention via access to health facilities with qualified healthcare personnel that could make an early diagnosis and treat people’s healthcare concerns; and (c) policy-level change to alleviate poverty, which would improve the social determinants of health ([World Health Organization, 2018c](#)).

Challenges within the healthcare system also contributed to late diagnosis. When participants accessed the healthcare system, they could encounter healthcare providers who themselves seemed to lack knowledge about the early signs of cancer; they also experienced inefficiencies and corruption in the public health system ([Khan & Puthussery, 2019](#)). Other scholars have noted that poor knowledge among health workers can cause delays that contribute to disparities in cancer diagnosis ([Ginsburg et al., 2018](#)). In this study, poor knowledge was evident in inaccurate diagnosis, false reassurances, and at times, inappropriate treatment.

Challenges to healthcare services in Pakistan are caused in part by the government prioritizing spending on defense to combat terrorism, related to the country’s complex geopolitical position with neighboring countries ([Datta, 2018](#); [Raza et al., 2017](#)). This means that funding for health and education is significantly reduced ([Khaliq & Ahmad, 2018](#)). Moreover, in countries such as Pakistan, corruption in healthcare service delivery threatens attempts to institute universal health coverage ([Bruckner, 2019](#)), a key lack of coverage highlighted by the [World Health Organization \(2018b\)](#). Thus, an urgent need exists in Pakistan for improved cancer and palliative care services,

improvements in the infrastructure of the current healthcare system, trained staff to support patients and their families, a multidisciplinary approach for pain management, and access to morphine for cancer pain management (Kurji et al., 2019). Scholars also suggest that a public health approach to healthcare could assist in prevention, early diagnosis, treatment, and palliative care (Dempers & Gott, 2017). In LMICs, developing policy to integrate cancer and palliative care into the existing healthcare system also increases access and early diagnoses (Hannon et al., 2016).

Although Pakistan has made efforts to improve its healthcare delivery system (Kurji et al., 2016), critics report poor governance, lack of access to healthcare, unequal resources, poor quality of health information management systems, power-wielding bureaucrats, corruption in the healthcare system, lack of trained staff (Khan & Puthussery, 2019), and understaffed hospitals. In sum, these multiple factors reflect an insufficient health budget and a deteriorating healthcare system (Husseni & Ullah, 2019). What is needed in LMICs, such as Pakistan, are cancer prevention and screening strategies (Donkor et al., 2018), along with equitable access to cancer treatment and palliative care. Together, these aspects could improve survival rates and alleviate suffering. All this is urgently needed as, in LMICs, “90% of cancer patients are unable to access quality surgical care [and] a third of LMICs do not have functional radiotherapy services” (Donkor et al., 2018, p. 1047).

This lack of tools, skill, and resources helps to explain the struggle participants in our study experienced in their journey to being diagnosed with cancer and receiving treatment.

Similar to our findings, cancer is often diagnosed in the late stages of the disease in LMICs, and often palliative medicines are not accessible (Donkor et al., 2018; Hannon et al., 2016). This contributes to illegal marketing and sale of opioids in Pakistan and other LMICs (Stanos, 2017; United Nations Office on Drugs and Crime, 2018). This was also the case in our study, when family members would try to access opioids illegally to relieve their loved ones' cancer pain.

Limitations

Although rich in description, this study is limited as it focused on a small sample of individuals in a philanthropic hospital in a large urban center in Pakistan. Nonetheless, it provides a glimpse into the experiences of the poor as they navigated cultural ideas and sought diagnosis and treatment. Although participants shared their experiences in public hospitals, people who can pay for diagnosis and treatment in private hospitals may have quite different experiences. Our small sample size also leaves gaps in understanding the role of gender in patients, families, or healthcare providers' perceptions of suffering and late diagnosis. It is unclear if women and men received different treatment. More research that includes people from a variety of financial means and

exploration of gender differences is necessary to build a fuller picture of cancer diagnosis and treatment in Pakistan.

Implications for Practice

Providing sufficient training to healthcare professionals (Connor & Gwyther, 2018), both before and after they begin practice, is important to overcome a major obstacle to the provision of cancer diagnosis, treatment, and palliative care. Callaway et al. (2018) suggest that the deans from medicine, nursing, psychology, pharmacy, and social work schools, as well as education experts, review existing curricula for undergraduate and postgraduate medical, nursing, social work, psychology, and pharmacy education in Pakistan. Culturally appropriate core competencies of cancer diagnosis, treatment, and palliative care must be included in the curricula. Moreover, it is important to recognize that individuals' health and social practices are guided by their culture and tradition, which could be used to enhance health by approaching traditional healers. These healers could be educated about cancer prevention and health promotion, and could even be incorporated in some way into healthcare systems (Mwaka et al., 2021). Nurses need to advocate for health policy and health reform as well as cancer prevention strategies. They have a critical role to play in health education and thus have a responsibility to educate themselves and others to provide evidence-based cancer and palliative care.

Conclusion

This study provided a unique window into the experiences of people seeking palliative care in Pakistan. The participants in this study demonstrated that their poverty and cultural values obstructed their access to healthcare and contributed to late diagnosis and subsequent suffering as a result of a late diagnosis of cancer. They also described healthcare system failures embedded in corruption that obstructed their access to health. Health policy must be developed and implemented that improves access to healthcare, diminishes poverty, provides education for healthcare workers, and improves early cancer diagnosis, treatment, and palliative care. Collaboration with the WHO on the delivery of palliative care is another strategy that could assist cancer and palliative care services in LMICs. Finally, more research is needed in LMICs like Pakistan to better understand people's experiences with the healthcare system and to enable better planning and advocacy for appropriate healthcare resources.

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Supplemental Material

Supplemental material for this article is available online.

Notes

1. Obligatory Islamic poor tax of at least 2.5% per year on financial assets.

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