Structural inequalities in the hospital system: rural and indigenous women’s experiences of cervical cancer treatment in Guatemala

Anita CHARY¹

Introduction

In recent years, cervical cancer, one of the commonest cancers among women, has been prioritized in the global reproductive health agenda. Although the disease is easily preventable and treatable at early stages, each year, 266,000 women die from cervical cancer worldwide. The majority of these deaths occur in low- and middle-income countries (LMICs) (Ferlay et al., 2013), where preventive and curative services are not widely available (World Health Organization [WHO], 2014). Mortality rates from this disease have increased dramatically over the past two decades and continue to rise (Cervical Cancer Action, 2012).

In Guatemala, a Central American nation with large rural and indigenous populations, cervical cancer is among the leading causes of death among women of reproductive age. Indeed, more Guatemalan women die each year from cervical cancer than from maternal mortality (Ferlay et al., 2013; Ministerio de Salud Pública y Asistencia Social [MSPAS], 2010). Poor Guatemalan women with advanced cancers who seek specialized therapy for cancer treatment have one option: the Instituto de Cancerología (INCAN), Guatemala’s only oncology hospital that attends to impoverished public sector patients. However, treatment success rates at the hospital are very low; according to hospital administrators, only one-third of patients complete recommended treatment after receiving a cancer diagnosis.

This article explores women’s interactions with the specialized biomedical system of INCAN. It shows that rural women with cervical cancer are often unable to navigate the hospital system and institutional policies. These problems are worse for indigenous Maya women and those with low levels of formal education, who generally lack the social skills and assets to negotiate the chaotic hospital environment. Women’s interactions with the hospital and its personnel illuminate how institutional bureaucracy

¹ MD/PhD Candidate, School of Medicine & Department of Anthropology
Washington University in St. Louis, Missouri, USA
Contact : charya@wusm.wustl.edu
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reinforces health disparities along existing lines of structural inequality and marginalization.

**Setting: Guatemala**

Guatemala is a lower-middle-income Central American country with a large rural population. Rural areas of Guatemala, dedicated to the nation’s agroexport economy, are neglected by the state and have minimal infrastructure and access to social services such as education and health care. Approximately 71% of the rural population lives in poverty compared to 53.7% of the country’s general population (World Bank, 2014). Notably, Guatemala’s rural areas are largely inhabited by indigenous Maya people, who have traditionally been identified by the use of indigenous languages and woven dress as well as the practice of subsistence agriculture (R. N. Adams, 1994). The nation’s 22 distinct Maya groups, which comprise approximately 60% of the general population (Elías, 2013), have been politically and economically marginalized throughout the country’s history of Spanish colonialism, forced indigenous labor policies, and a recent 36-year-long civil war (1990-1996) and state-sponsored genocide targeting Maya peoples (Carey, 2005; Comisión para el Esclarecimiento Histórico [CEH], 1999; Lovell, 1988). Though Guatemala has officially adopted a discourse of “multiculturalism” since the 1996 Peace Accords, which ended the civil war and aimed to offer state protections for indigenous peoples and cultures, Mayas continue to be subordinate to ladinos of mixed descent (Hale, 2006). In the national imaginary, indigenous and rural people are seen as backwards and regressive, in comparison to inhabitants of urban areas such as Guatemala City, who are viewed as more progressive and civilized (O’Neill & Thomas, 2011).

These legacies of discrimination, coupled with an inadequate public health care system, spell poor health outcomes for rural and Maya peoples today. Although the Guatemalan constitution guarantees citizens access to free government-sponsored health care, the Ministry of Public Health and Social Assistance (MSPAS) is severely under-resourced. The majority of its resources and personnel are concentrated in urban areas, and facilities in rural areas tend to be under-staffed and lack basic supplies, medications, and equipment (Garcés de Marcilla, 2004). Geographic, economic, and linguistic barriers (Glei & Goldman, 2000), as well as fears of mistreatment and discrimination (Berry, 2010; Chary et al., 2013), represent significant obstacles for rural and Maya people attempting to access care through the government public health system. Such problems are reflected in the health disparities endured by rural and Maya peoples. To provide only a few brief examples, the rate of maternal mortality quadruples, the rate of infant mortality nearly doubles, and the rate of chronic childhood malnutrition doubles among rural and indigenous populations in comparison to Guatemala’s urban and ladino populations (MSPAS, 2010).

These disparities and long-standing problems with Guatemala’s health system are immediately apparent in the current state of cervical cancer prevention for rural and
indigenous women. Vaccination against the human papilloma virus (HPV), the sexually-infected transmission that causes cervical cancer, is not yet available through government health care. Free screening exams for cervical cancer, i.e., the Papanicolaou and visual inspection with acetic acid, are supposed to be available at government health facilities year round. However, health care coverage in rural areas is low, and rural health clinics often lack trained staff and basic materials to perform the exams (Chary & Rohloff, 2014). Recent large-scale surveys indicate that only 40% of Guatemalan women have ever been screened (Gakidou et al. 2008), in contrast to WHO (2006) recommendations of 80 % coverage for successful national screening programs. Women with abnormal screening results are referred to obtain more specialized exams, which are typically available only with gynecologists in urban areas. Women suspected to have cervical cancer receive referral letters to INCAN in Guatemala City. Systems to support women through such referrals are virtually non-existent, and loss of patients to follow-up care is common (Alvarez, 2013).

El Instituto de Cancerología (INCAN)

The MSPAS does not have the budget to operate its own oncology service and therefore relies on INCAN to attend to patients with advanced cancers. INCAN is a private entity that requires patients to pay for their own treatment. The hospital was founded in 1953 by the National Cancer League (la Liga Nacional Contra el Cáncer), a non-governmental association formed by wealthy Guatemalan cancer survivors. The majority of INCAN’s budget derives from the Liga’s fundraising efforts; the MSPA S offers comparatively smaller financial contributions. Patients referred from public-sector healthcare facilities who are deemed indigent, based on asocio economic assessment with social workers, may receive up to several thousand quetzals (~1,000 USD) of government financial support from MSPAS funds. These aid grants typically pay the costs of diagnostic tests and laboratory exams, but according to hospital policy, cannot be applied to cover the expense of chemotherapy, which ranges from several hundred to one thousand dollars per cycle. Government aid may subsidize but does not completely cover the costs of radiation therapy, the costliest component of treatment. The costs of treatment, which total several thousand dollars, are prohibitive for members of the working class. Though the national minimum wage is approximately USD 250 per month, in the face of labor exploitation and underemployment, few families, particularly in rural areas, earn this amount (Ministerio de Trabajo y Previsión Social, 2013).

As a hospital, INCAN is severely under-resourced. Approximately 300 patients attend consultations at INCAN daily. The majority of patients are poor, and their expenditures on treatment do not constitute a significant source of revenue. The hospital’s front windows, for many years, were covered with posters of protest about the nursing staff’s inadequate wages. All services are delivered in Spanish, the colonial language, but there is no budget for interpreters for patients who speak indigenous languages. Patients and their family members lean on the walls and sit on the floors of overcrowded waiting areas, which do not have enough chairs. The hospital’s radiation equipment is dated and decrepit and includes two nonfunctional cobalt machines, a facility for brachy therapy,
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and one machine for external beam radiation, which is in a constant state of disrepair. Treatments are often interrupted by machine breakdown, which not only compromises therapeutic efficacy, but also limits the number of patients who can undergo radiation annually. At any given time, there are 1200 to 1700 patients on the waiting list for radiation therapy. These patients typically wait anywhere from four months to one year before beginning radiation treatment, based on a triage algorithm that prioritizes patients with curable cancers.

INCAN lacks resources to operate full time. Rather, the hospital bustles with activity until noon, when most of the physicians head off to their more lucrative private practices. The physicians working at INCAN are largely non-indigenous upper-class Guatemalans of mixed or European descent who have completed oncology fellowships in other Latin American countries or in Europe. Salaries are not commensurate with those expected for medical professionals with a high degree of formal education. Physicians earn from 3-20 times more in their private clinics in Guatemala City, but they continue to work at INCAN out of a sense of obligation to the poor or to enrich their training given the varied pathology they see at the hospital.

INCAN is overwhelmed with women with cervical cancer each year. The disease is the commonest cancer among female patients and represented 36% of all new cancers detected among women in 2012, the most recent year for which statistics are available (Registro de Cáncer del INCAN Guatemala, 2013). More than half of those on the waiting list for radiation therapy and those receiving care in the palliative unit also have cervical cancer. Health care providers observe that women from rural areas, and indigenous women, are less likely to complete treatment. In this context, investigation was undertaken to comprehend the experiences of rural and indigenous women with cervical cancer attempting to seek treatment at INCAN.

Methods

This article is based on fifteen months of ethnographic fieldwork conducted from June 2011-November 2014. During this time, I performed participant-observation at INCAN, where I observed and conversed informally with patients and health care providers in a variety of settings: waiting areas, the triage clinic, social work evaluations, the outpatient chemotherapy salon, inpatient surgery and radiation therapy wards, and the palliative care unit. I attended consultations with over one hundred women with cervical cancer. I also conducted semi-structured interviews with 5 hospital administrators, about hospital policy and experiences of providing care, and with 30 women receiving treatment for cervical cancer, about their experiences accessing INCAN and their interactions within the hospital. Of the 30 women formally interviewed, 24 lived outside of the capital, and 15 had traveled there from rural villages. Women identified as indigenous (27%), as descendants of indigenous people but no longer “indigenous” themselves (40%), or of mixed descent (33%).
Interviews were digitally recorded and transcribed or hand-written notes were taken throughout based on participants’ preferences. Field notes generated from participant-observation, interview transcripts, and interview notes form the basis of the ethnographic data. These items were coded inductively for dominant themes using the qualitative data analysis program Saturate App. The study was approved by the INCAN Ethics Committee as well as the Institutional Review Board of Washington University in St. Louis.

It should be noted that women interviewed in this study universally cited economic considerations as a major barrier to accessing care. However, unlike the majority of impoverished people with cancer who consult at the hospital, these women were obtaining care despite financial constraints. This article accepts the primacy of economic obstacles to care, based on these interview data, but does not explore them in depth. Rather, the results detail another important set of barriers to care related to poor women’s experiences of and within the hospital itself. First, information is provided about the social context of women’s experiences of cervical cancer. Subsequently, themes are presented about women’s interactions with the hospital system and how these encounters limit access to specialized reproductive health care.

Results

The Social Context of Illness

A recent hospital-based study performed by Moreno (2012) with a large sample of women seeking cervical cancer treatment at INCAN illustrates several important social factors that influence women’s experiences at the hospital. The majority of women seeking care for cervical cancer at INCAN are ages 41 to 60 (64%). Poor women of this generation generally did not have opportunities to attend school for more than a few years, if at all; Moreno found that more than half of women (52%) with cervical cancer at INCAN were illiterate. As explored below, this has bearing on women’s ability to navigate the institution.

Women’s ages also determine the social supports they count on, which in turn shapes hospital experiences. According to local social expectations and patriarchal patrilocal marriage customs in poor communities (Metz & Webb, 2013), the husband of a sick woman is economically responsible for curing her and accompanying her to medical consultations (Wehr et al., 2014). However, half of women with cervical cancer in Moreno’s study did not have a spouse at the time of seeking treatment. The civil war and ongoing violence have widowed many women (Zur, 2001), and men’s abandonment of wives and children is not uncommon (Ehlers, 2000). Additionally, in the context of poverty, husbands often cannot afford their wives’ treatment costs at INCAN alone or take time off of work to accompany them. This makes the contributions of adult children, both in terms of financing and accompaniment, very important to women with cervical cancer, the majority of whom are at the end of their reproductive years.
Also significant to women’s experiences at the hospital is the way that cervical cancer presents. The disease is asymptomatic in its early stages, therefore many women come to medical attention only after developing later-stage symptoms, such as vaginal discharge or bleeding, abdominal and pelvic pain, and urinary problems. Among women I interviewed, 28 of 30 sought care for vaginal bleeding. Half of these women – even those who were, from a biomedical perspective, post-menopausal – initially attributed the bleeding to menopause, and, thinking the problem would resolve alone, delayed care-seeking for anywhere from several months to years. Additionally, as many ethnographic studies have shown, in Guatemala, women’s health is generally deprioritized within poor households (Chary et al., 2011; Menjívar, 2011; Metz, 2006). Some interviewees reported needing to obtain their husband’s permission to seek care at the hospital, and others reported being too overwhelmed by childcare and domestic duties to seek care promptly. Taken together, these dynamics contribute to women’s presentation to the hospital at advanced stages, and shape the complex encounters that women must negotiate as a result. What follows is a presentation of four themes about women’s interactions with the hospital system.

**Accessing the hospital**

Arriving at and entering INCAN pose many difficulties for women, and particularly for those from rural areas. Women living in rural areas reported journeying several hundred kilometers from their homes to Guatemala City by public bus, the most economic mode of transportation. Travel took from several hours to several days, for those whose villages lacked roads and regular access to public transportation. Bus fares represented a significant expenditure. Women reported that roundtrip fares equaled a family’s food budget or entire earnings for one week. On top of these economic problems, travel on the public buses is often uncomfortable in light of women’s symptoms. Typical public buses are brimming with passengers and crowded with cargo; there are no lavatories on board nor are stops for restroom breaks made. Women with vaginal bleeding found these conditions difficult to endure. Several described, in embarrassment, “emptying themselves of blood” or “spilling blood” on the way to the hospital. Additionally, rural women unfamiliar with the capital may become lost upon arrival in Guatemala City. Telma, a Q’eqchi’ Maya woman, was unaccustomed to leaving her natal village and grew disoriented and scared at the heavily-trafficked public bus stop closest to INCAN, which she referred to as “the place where there are many cars.” Telma had traveled alone to save money, and as she preferred to speak Q’eqchi’ to Spanish, found it difficult to understand directions those around her gave her to the hospital.

For many, problems do not end upon arrival at INCAN, where women must gain entrée into the hospital. Due to staffing and resource limitations, hospital administrators cap the number of new patients accepted into the hospital each day. A security guard, who patrols the locked hospital gates, hands out badges to a maximum of forty patients at 5:30 AM each day. Patients who have heard about this system arrive beginning at 4 AM, hoping to beat the crowd. Those who do not arrive early enough to earn a good spot in...
line are turned away, and the guards instruct them to try again the next day. This policy discourages those who have traveled to the capital from rural areas, at great personal expense, discomfort, and anxiety, from returning.

Once new patients enter the hospital, they are seen in a triage clinic by a physician, Dr. Mendez, and a nurse, Mayra, who perform a basic physical exam and review any referral letters and paperwork brought in by patients. The duo then sends patients to the specialty clinic within the hospital corresponding to their presumed cancer type – for example, to the dermatology clinic for a suspected melanoma, to the head and neck cancers clinic for a facial tumor, or, in the case of women with cervical cancer, to the gynecological oncology clinic. Each specialty clinic accepts only 5 new patients each day. Therefore, receiving a hospital badge and a consultation in the triage clinic is not enough to guarantee that one will be seen. For example, Merida, a monolingual K’iche’ Maya woman with cervical cancer, had been referred by a public sector physician to INCAN. She was among the last of the forty patients to be accepted into the hospital that day, and when she got to the triage clinic with her daughter, who was acting as her translator, Dr. Mendez informed the pair that five other women had already been admitted into the gynecological oncology clinic; Merida would have to return the next day. Merida’s daughter commented solemnly that it would be impossible for them to return, as they had traveled four hours to get to the hospital and she could not take another day off from work to accompany her mother without risking being fired by her employer. Dr. Mendez, who routinely encountered this type of situation, did not respond and simply called in the next patient. Merida and her daughter did not return the next day or over the next several months that I worked in the triage clinic.

On rare occasion, the hospital guards and Dr. Mendez bent the rules and accommodated an extra patient here or there. In these cases, the patients or their accompanying family members were relentlessly insistent about their needs or brought up the names of friends who were hospital staff. During my fieldwork, I only saw such exceptions made for ladinos. In general, due to long histories of discrimination, indigenous people tend to be deferent to non-indigenous authority figures and are less likely to talk back or argue with them in institutional settings such as the hospital. Some indigenous women, commenting on these dynamics, told me that they had “changed into pants,” or Western clothing, rather than traditional woven skirts that marked them as indigenous, in order to enter the hospital. Others had listed on their entry paperwork that they were from Guatemala City, rather than divulging that they lived in rural areas, as they thought hospital staff would treat them better, assuming that as urbanites, they “knew their rights.” A handful of people explicitly speculated that guards and gatekeepers were more sympathetic to the plights of ladino patients and discriminated against indigenous people.

“Vueltas”

Once women have managed to enter the hospital system as new patients, they and their family members must begin what they refer to as “vueltas,” or “errands.” Patients at INCAN are often sent from one department to the next – from the clinic to the laboratory...
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to the pharmacy to the cashier and back. “It’s impossible to go alone,” Isabel, a ladina woman with cervical cancer told me. At her first chemotherapy appointment, Isabel arrived at 6 AM to wait in line at the chemotherapy office. Around 7:30 AM, she received an order for laboratory exams and had to go to another department, where it was determined that she did not have an infection and could therefore receive chemotherapy that day. She then ran to the cashier to pay for the lab exams, returned to the chemotherapy department with her results, received approval to continue with treatment, and then went to the pharmacy to purchase the medications, IVs, and syringes to fill her prescription. Finally, Isabel returned to the chemotherapy department to have her medications administered. At each step, she had to wait in line and discuss her case with a department secretary, nurse, or cashier, who would process her request and redirect her. Even though Isabel was semi-literate – she reported she could “read a little bit” – and fluent in Spanish, she felt she could not manage all of the “vueltas” alone and enlisted a friend to help her manage the process for subsequent rounds of chemotherapy.

Others do not fare as well. Illiterate patients often get lost, as they cannot interpret the written signs in Spanish marking routes between the departments. Patients are often unaware of the information desk as a potential source of guidance. They are wary of being brushed aside by providers walking through the halls in scrubs and white coats who are not directly involved in their care. For example, I met Sara, a K’iche’ woman with cervical cancer, and her husband Ines, who had traveled from hours away for a chemotherapy treatment. They were standing at the main doors of the hospital, visibly confused. Nervously fumbling his wife’s hospital appointment card between his fingers, Ines asked me, “Miss, can you tell me where we are supposed to go?” After I helped them find the appropriate clinic, he remarked, “Last time, we didn’t know what to do or how to be seen [by the doctor], so we just left.” They had missed that appointment, months ago. Sara’s vaginal bleeding had since gotten worse, and they decided to try again.

Patients used the term “vueltas” not only to describe running errands between departments during a single visit, but also between the home and the hospital over the course of multiple visits as their tumors are classified and staged. Patients often make four or five visits before getting together all of the relevant pathology, imaging, and laboratory exams required for physicians to determine the appropriate course of therapy. For those with long journeys to the capital, each trip requires a significant investment of time and money for travel, lodging, and medical expenses. Sylvia, a KaqchikelMaya widow, had to travel about five hours one-way from a small village with no regular public transportation. After receiving her treatment plan after multiple visits, she started, but did not complete chemotherapy, frustrated that despite spending so much money, her hemorrhage and pain were not improving with treatment. One day, in a rage, she burned all of the imaging exams and records that had been sent home with her, as she felt all of her “vueltas” had been in vain. After a year of worsening symptoms, Sylvia returned to INCAN in desperation due to severe pain, and began to receive palliative services.
Communication

Due to time constraints, provider-patient communication tends to be inadequate. As INCAN physicians tend to be overloaded with consultations, discussions of diagnoses and treatment plans often take only three to five minutes. Patients are often confused by these conversations and the new terms they employ – biopsy, pathology, chemotherapy, radiation. For example, after a team of physicians examined Marta, an elderly K’aqchikel Maya woman with cervical cancer, and described the follow-up exams she would need before beginning cancer treatment, she smiled nervously and said in broken Spanish, her second language, “I don’t know how to read.” The physicians on the team exchanged glances, unsure why she was bringing up her illiteracy at that moment. In rural areas, this trope is often used to communicate that one did not understand the explanation given. The medical team did not grasp this, however, and sent Marta out of the room without further conversation. During a number of consultations, both indigenous and ladina women, as well as family members accompanying them, brought up illiteracy not only to indicate the incomprehensibility of information delivered, but also as a way of expressing that they felt they were incapable of understanding it however it was delivered.

Sometimes, patients and their family members actively attempted to elicit further explanations. For example, one morning, the gynecological oncology team of several physicians evaluated Zoriada, a ladina woman from Guatemala City. Zoriada’s adult son Jaime, who was accompanying her, asked a variety of questions as Dr. Sanchez, the middle-aged physician leading the team, laid out the plan. Jaime spoke comfortably with the team of mostly male physicians and addressed Dr. Sanchez as “usted,” the formal and respectful pronoun for “you.” Physicians commonly address patients as “vos,” a more informal pronoun for “you,” and in this case the term functioned as a display of camaraderie, as it is used widely between male friends in urban settings.

The subsequent consultation with Leticia and her daughter Sandra, both K’iche’ Maya women wearing indigenous clothing, contrasted sharply with Jaime’s experience. Dr. Sanchez asked Sandra if she was “in charge of her mother,” again using the form “vos.” In many indigenous communities outside of the capital, such as Sandra and Leticia’s, it is uncommon, even disrespectful, for men to address women with the intimate “vos.” Using the formal “usted” with Dr. Sanchez, Sandra confirmed that she was overseeing Leticia’s care; Leticia spoke only K’iche’, and as there are no interpreters for indigenous language speakers in the hospital, she would not have been able to access services without bringing a family member with her. Dr. Sanchez informed Sandrathat Leticia had stage III cervical cancer and would require chemotherapy and radiation. He referred to Leticia as “a girl” (niña), a term that some physicians use as a caring term of endearment for elders, but it simultaneously reflects disparaging attitudes about the presumed simplicity of indigenous and peasant women. These verbal cues served as reminders to Sandra of physicians’ positions of authority within the clinic. Sandra waited for Dr. Sanchez to finish the whole explanation before thanking him and timidly asking what the radiation would entail. He briefly responded that the treatment would “burn
away the tumor.” Sandra opened her mouth to ask another question, but by that time, the medical team had already signaled to the nurse to bring in the next patient from the unending line. When Sandra and Leticia stepped outside of the consultation room, they conferred in rapid-fire K’iche’, eyes wide and full of doubts.

“Not Being Attended”

Women commonly levied complaints against INCAN that “here, they don’t attend to you.” These statements reflect two facts: first, patients often do not receive medical services they expect, and second, they do not fully comprehend the procedures and processes of the institution.

As previously mentioned, salaries for health care workers at INCAN are relatively low. Nurses who work at INCAN typically work multiple jobs to make a living, and often come to work from overnight calls at national hospitals. Some are conscientious and hardworking despite being tired when they arrive at work, and described that they chose to work at INCAN in order to support a vulnerable patient population in need of affection and support. Others, however, have little motivation or incentive to work hard for little pay. As a result, routine nursing services are sometimes hard to come by. For example, one morning, on the women’s inpatient ward, which is mostly comprised of women with advanced cervical cancer, Bilma, a woman with stage IV cervical cancer, was crying out in pain and discomfort for several hours. Her bed was immediately adjacent to the nurses’ station, but, according to the patients on the floor, none of the nurses on duty went to her bed to check on her. Rather, Bilma’s wardmates, who attempted to soothe her themselves, accused the nurses of “playing on their cell phones,” “not attending to patients,” and “not wanting to work.” Similar complaints were lodged by Irene, a young K’iche’ Maya woman who was staying in the hospital for several weeks with her mother, who was receiving radiation therapy for cervical cancer. Irene had been very happy with the care her mother was receiving during the first week of her stay. However, the nursing team subsequently shifted to new staff. Irene described that she often ended up performing the new nurses’ work, such as taking her mother to the toilet and bathing her, because they neglected to do so in a timely fashion. “They do not attend to her,” she said. Some patients and their family members remarked that they resorted giving food or small gifts to nurses in hopes that they would perform these services.

Complaints about “not being attended” also related to the long waiting list for radiation therapy. Because over one thousand patients are on the list, they can expect to spend upwards of four months waiting for their appointment. Interviewees reported that during this waiting time, their symptoms, such as vaginal bleeding and pain, worsened. Some of these women called the hospital repeatedly to see if their appointments could be moved up. Few women reported that their phone calls were answered; those who did get through were told nothing could be done to advance their cases. Some interviewees, rather than calling, visited the hospital in “desperation,” hoping to be admitted, but were
turned away. Although the hospital has a triage algorithm to prioritize some patients for treatment, interviewees were unclear about this process, leading to complaints such as “they don’t want to attend to me.”

“Not being attended” also described instances in which women were turned away from specialty clinics by hospital staff. For example, Mirna, an illiterate ladina peasant experiencing severe pelvic pain from cervical cancer, was sent from the chemotherapy salon to the palliative care unit to obtain a same-day appointment. She was uncertain, however, about the referring physician’s instructions or what she was supposed to do with her files at this new destination. The departmental secretary took Mirna’s paperwork from her, but, overwhelmed with an already long waiting line, began to snap at Mirna that appointments were scheduled weeks ahead of time and refused to allow her to enter the clinic. “They didn’t attend to me,” she told me. Rosario, another ladina peasant, was more successful at obtaining a same-day appointment when she received a similar in-hospital referral. Rosario was accompanied by Celeste, a friend who was a cancer survivor, who had previously received treatment at INCAN. Celeste did not back down after the secretary’s stern admonition; she was dogged and persistent that Rosario be seen and refused to leave. The secretary eventually gave Rosario an appointment. As Celeste later told me, “This is how this hospital is. You have to fight to be attended.”

Discussion

This article has examined the experiences of rural and indigenous women with cervical cancer seeking treatment at INCAN. Arriving at and entering the hospital, performing “errands” between departments, communicating with health care providers, and attempting to be “attended to” pose difficulties for women. The extent to which women can navigate these problems depends on the cultural capital they or accompanying family members possess. Bourdieu (1977) describes cultural capital as social skills or assets that allow for advancement within particular institutions. Within INCAN, accessing treatment requires a variety of social, cultural, and linguistic competencies. Speaking Spanish comfortably, if not fluently, eases patients’ interactions with gatekeepers and health care providers, while those more comfortable in indigenous languages are at a disadvantage that can only be addressed by bringing bilingual relatives along. Literacy helps patients navigate the hospital complex; a lack thereof leads some patients to underestimate their capabilities to comprehend medical information and justify inadequate provider-patient communication, rather than trying to clarify treatment plans. Because of patriarchal social norms and discriminatory linguistic cues, men and ladinos tend to have an easier time than women and indigenous people communicating with authority figures such as physicians. Familiarity with the culture of the hospital system also offers women advantages – for example, awareness, based on hearsay or previous experiences, of needing to show up at dawn to enter the hospital, or offering incentives to nursing staff to be attended to. Finally, and very significantly, willingness and ability to advocate for oneself become crucial, especially in the face of dismissal, hostility, and mistreatment from hospital personnel. In some cases, patients or loved ones who persist about their needs manage to bend the rules of the hospital. More
often than not, such self-advocacy is easier for ladinos from urban areas than for indigenous and rural people. Western, rather than indigenous dress, and claims of residence in Guatemala City make one likelier to be taken seriously by gatekeepers and health care providers. All of these forms of cultural capital, and their availability, are shaped by structural inequalities. Women who are indigenous, illiterate, rural, and unaccompanied by men encounter greater difficulties accessing services in the hospital, reflecting broader ethnic, geographic, and gender discrimination.

Significantly, in many cases, what cultural capital helps women overcome are situations inherent to institutional bureaucracy, or the system of administrative controls and personnel governing the hospital. At INCAN, bureaucracy includes hospital policies that cap numbers of new patients, send people on “errands” between departments, and place them on waiting lists, as well as the gatekeepers – guards, secretaries – and health care providers, who unpredictably grant or deny access to information and health services. Such bureaucracy is common to hospitals and biomedical institutions (Kohrman, 2005; Sullivan, 2011). Ethnographic accounts of social welfare and development settings (Fassin, 2011; Gupta, 2012) and in public disaster relief programs (V. Adams, 2013; Petryna, 2002) similarly make clear the ways that institutional bureaucracy restricts access to social services among the poor. These studies also demonstrate how one’s cultural capital, and particularly, one’s familiarity with a specific service system and discoveries about how to manipulate it, shape one’s ability to cut through “red tape” (Gupta, 2012) to obtain care.

At the same time that bureaucracy and the biomedical culture of INCAN restrict access to specialized health services for some women with cervical cancer along extant lines of inequality, they function to reinforce hegemonic power relations. Perceptions of “not being attended” are revealing here. In a study of indigenous Maya people’s interactions with a hospital in a rural department of Guatemala, Nicole Berry (2008) locates patients’ complaints about “not being attended” as reflecting contrasting sets of therapeutic expectations between physicians and indigenous patients. While this analysis applies to the setting of INCAN in some ways – for example, when patients unfamiliar with hospital policies express disappointment about not receiving services – the experiences of waiting in line, running errands without a guarantee of receiving services, and dealing with uncertainty about how one obtains a timely radiation appointment, create a sense of powerlessness among women. Similar phenomena are documented by Javier Auyero (2012), who describes Argentians’ experiences of waiting for services in state welfare offices. In Guatemala, INCAN as a biomedical institution, and urban ladin no authority figures and gatekeepers within it, exert control over patients, and, in doing so, reproduce dominant unequal relations between physicians and patients, urban and rural inhabitants, ladin o and indigenous peoples, and men and women. Only those with certain forms of cultural capital may resist these dynamics and fight for access to health services in an overwhelmingly disempowering biomedical system.
Conclusion

Rural and indigenous women’s interactions with INCAN and its personnel illuminate how bureaucracy in biomedical institutions both relies on and reinforces health disparities along existing lines of social marginalization. Poor women with cervical cancer, particularly those from rural and indigenous communities, tend to lack the cultural capital to successfully navigate the hospital environment. Those who successfully obtain specialized health services and treatments either possess characteristics allowing them to overcome institutional barriers to care, or they must enlist the help of family members and loved ones who do. In these ways, structural inequalities of ethnic and geographic discrimination, present more broadly at the national level, become apparent in and are refracted through the biomedical setting.

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Résumé

Inégalités structurelles dans le système hospitalier : expériences de femmes autochtones et rurales dans le traitement du cancer du col de l’utérus au Guatemala

A partir d’une étude sur les difficultés d’accès aux soins spécialisés pour le traitement du cancer du col de l’utérus des femmes résidant dans les zones rurales du Guatemala, cet article analyse comment les inégalités structurelles se traduisent à travers la bureaucratie institutionnelle. La majorité des femmes guatémaltèques atteintes d’un cancer du col de l’utérus – le cancer reproductif féminin le plus fréquent – ont pour unique option de traitement l’Institut de Cancérologie, le seul hôpital oncologique public au Guatemala auquel les patients pauvres peuvent avoir accès. Au-delà des barrières géographiques et économiques dans l’accès à l’hôpital, lequel se trouve dans la capitale du pays, les femmes résidantes des zones rurales atteintes d’un cancer du col du l’utérus n’ont souvent pas la capacité de naviguer dans le système hospitalier et ses politiques institutionnelles. Ces difficultés sont accrues pour les femmes autochtones maya qui ont pour la plupart un faible niveau d’éducation, et qui manquent donc de capital social relationnel et culturel pour pouvoir négocier et se défendre dans un environnement hospitalier chaotique. Par conséquent, de nombreuses femmes abandonnent leur traitement. Les interactions des femmes avec l’hôpital et son personnel révèlent comment la bureaucratie institutionnelle renforce les inégalités de santé sur la base d’inégalités structurelles et d’une marginalisation existante.

Mots-clés

Abstract

Structural Inequalities in the Hospital System: Rural and Indigenous Women’s Experiences of Cervical Cancer Treatment in Guatemala

This article examines how structural inequalities are refracted through institutional bureaucracy by analyzing rural Guatemalan women’s attempts to access specialized health care services for cervical cancer treatment. The majority of Guatemalan women with cervical cancer, the commonest female reproductive cancer, have only one option for treatment: the Instituto de Cancérologia, Guatemala’s only oncology hospital that attends to impoverished public sector patients. In addition to facing geographic and economic barriers to accessing the hospital, which is located in the capital city, rural women with cervical cancer are often unable to navigate the hospital system and institutional policies. These problems are worse for indigenous Maya women and those with low levels of formal education, who generally lack the social skills and assets, or cultural capital, to negotiate and advocate for themselves within the chaotic hospital environment. As a result, many women drop out of cancer treatment. Women’s interactions with the hospital and its personnel illuminate how institutional bureaucracy reinforces health disparities along existing lines of structural inequality and marginalization.

Keywords
Resumen

Desigualdades estructurales en el sistema hospitalario: las experiencias de las mujeres rurales e indígenas con el tratamiento para el cáncer del cuello uterino en Guatemala

Este artículo examina cómo las desigualdades estructurales se refractan a través de la burocracia institucional, mediante el análisis de los intentos de las mujeres de áreas rurales de Guatemala de acceder al tratamiento para el cáncer del cuello uterino. La mayoría de las mujeres guatemaltecas con cáncer del cuello uterino, el cáncer reproductivo femenino más común, tiene sólo una opción para acceder al tratamiento: el Instituto de Cancerología, el único hospital de oncología en Guatemala que atiende a pacientes empobrecidas del sector público. Además de enfrentar las barreras geográficas y económicas para acceder al hospital, que está localizado en la capital urbana, las mujeres rurales con cáncer del cuello uterino a menudo no son capaces de navegar el sistema hospitalario y las políticas institucionales. Estos problemas son peores para las mujeres indígenas mayas y ellas con bajos niveles de educación formal, quienes por lo general carecen de las habilidades y de los activos sociales, o capital cultural, para negociar y abogar por ellas mismas dentro del ámbito hospitalario caótico. Como resultado, muchas mujeres abandonan el tratamiento. Interacciones de las mujeres con el hospital y su personal iluminan cómo la burocracia institucional refuerza las disparidades de salud a lo largo de las líneas existentes de desigualdad estructural.

Palabras claves

Cáncer del cuello uterino – Guatemala – cultura indígena – ruralidad – burocracia – hospital