A QUALITATIVE STUDY EXPLORING THE EXPERIENCE OF WOMEN SEEKING CARE FOR BREAST CANCER IN HAITI

NADEGE BELIZAIRE

A Thesis Submitted to the Faculty of

Harvard Medical School

in Partial Fulfillment of the Requirements

for the Degree of Masters of Medical Sciences in Global Health Delivery

in the Department of Global Health and Social Medicine

Harvard University

Boston, Massachusetts.

May 2015
A Qualitative Study Exploring the Experience of Women Seeking Care for Breast Cancer in Haiti

Abstract

Objectives: This study elucidates factors that affect access to care and the journey from first symptoms to treatment for Haitian women diagnosed with late-stage breast cancer. This study identifies structural barriers that women with late-stage diagnosis faced. Identification of these barriers can inform interventions that facilitate prompt diagnosis and lead to improved outcomes.

Methods: In this qualitative study, we selected participants from the Hôpital Universitaire de Mirebalais. We conducted and audio-recorded 18 interviews in Haitian Creole. Data were transcribed and translated into English. Qualitative data analysis examined multiple viewpoints using narrative analysis and grounded theory.

Results: The findings highlight the patients’ pelerinaj (journey): they visited several health facilities—expending considerable time, energy, and money—before being able to access appropriate breast cancer care. Patients experienced delays in their care trajectory which resulted in a loss of income and autonomy. Nevertheless, patients reported receiving important inputs—accompaniment, hope, moral and economic support—from their caregivers who were family members or friends.

Conclusion: Without structural interventions to improve access to high-quality and affordable breast-cancer care, the lengthy, complex care-seeking pelerinaj for women with breast cancer in Haiti is likely to persist, with continued dire consequences.
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>vi</td>
</tr>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Methods</td>
<td>7</td>
</tr>
<tr>
<td>Results</td>
<td>10</td>
</tr>
<tr>
<td>Discussion</td>
<td>41</td>
</tr>
<tr>
<td>Limitations</td>
<td>46</td>
</tr>
<tr>
<td>Conclusion</td>
<td>49</td>
</tr>
<tr>
<td>Recommendation</td>
<td>50</td>
</tr>
<tr>
<td>References</td>
<td>52</td>
</tr>
</tbody>
</table>
Acknowledgements

A number of dedicated collaborators made this work possible. The author would like to thank the following individuals and organization for their collaboration. First of all we thank God, my mentors Carole D. Mitnick, Arlene M. Katz, Annie Michaelis, and Hannah Gilbert for dedicating time to this study; Stephen Kahn from the Abundance Foundation and Leona Brenner-Gati for providing financial support; Paul E. Farmer, Joia Mukherjee, faculty and Christina Lively of the department of Global Health and Social Medicine at Harvard Medical School; Ruth Damuse, staff members from the Oncology Department of the Hospital Universitaire de Mirebalais; Kobel Dubique, Yolande Philogene, Fritz Belizaire, Adam Frange, Janey Ronxhi, and Anabel Dubique.

This work was conducted with support from students in the Master of Medical Sciences in Global Health Delivery of Harvard Medical School Department of Global Health and Social Medicine and financial contributions from Harvard University. The content is solely the responsibility of the authors and does not necessarily represent the official views of Harvard University and its affiliated academic health care centers.
Introduction

Ideal care for breast cancer

Early detection of a breast lump and/or changes in the breast is important to improve survival because the tumor or breast can be removed before the cancer spreads (Mitchell, Mathews, & Mayne, 2005; Ryu, Heo, & Kim, 2010; WHO, 2007). Such detection requires regular targeted breast cancer screening or physical examinations as part of routine preventive care. Women can also perform their own detection through careful self-examination of the breast and lymph nodes. Upon identification, an abnormal lump is then further examined through a mammogram or ultrasound. Results are read by specially trained radiologists. Any concerning findings result in referral to a specialist who confirms the diagnosis, and then may perform a biopsy. The biopsy allows the specialist to confirm a cancer diagnosis, and also provides insight into the types of cancer (Laronga, Cagpar, & Katheryn, 2013). Upon diagnosis, a comprehensive treatment plan is initiated, including surgical, medical, chemotherapeutic and/or radiation, psychological, and nutritional services (Payne et al., 2008). This multidisciplinary cascade of care represents an ideal which is rarely realized. The extent to which a system deviates from this cascade varies within and across populations according to access to care and other indicators of inequality. When the existing system bears no resemblance to the ideal cascade, a long journey for care often ensues, and disruptions emerge at various points along the care journey. This results in significant delays in breast cancer diagnosis and treatment, and often hastens and increases mortality among breast cancer patients.

Breast cancer worldwide

Worldwide, breast cancer is the most common cancer diagnosis among women and is the leading cause of death (Al-Azri, Al-Awisi, & Al-Moundhri, 2009). Approximately 1.4 million diagnosed cases and about 8.2 million deaths are reported (WHO, 2015). In rich countries breast care cancer mortality is declining because of early detection and improved care. In these countries
the health system tackles the cancer burden by supporting research, training, and dissemination of information about cancer detection, diagnosis, treatment, and prevention (Brown, Kerr, Haoudi, & Darzi, 2012). In limited resource settings with weak health systems, breast cancer incidence is relatively low but the majority of women with breast cancer experience delayed care (WHO, 2015). Breast cancer is a significant problem in developing countries, and both incidence and mortality are expected to increase by up to 50% in developing countries by 2020 (Anderson et al., 2011).

The incidence of breast cancer in the US is 23.5/100,000 females per year, with about 19% relative mortality (Phillips et al., 2007). In contrast, Haiti has a lower estimated incidence of 2.0/100,000 cases per year but higher relative mortality, 45% (Phillips et al., 2007). The high burden of cancer mortality is attributable not only to lack of access to care, but also to lack of adequate healthcare infrastructure in developing countries (Akinyemiju, 2012) (McEwan, Underwood, & Corbex, 2014) and medical malpractice (Barber, Jack, & Dixon, 2004). McEwan argues that lack of awareness is not the key factor for delay. The role of beliefs, although an oft-cited explanation for disparities in access to care and outcomes, is contested, according to Good (2012). Instead, these authors point to structural factors, such as weak health systems and financial constraints, as drivers of disparity.

The elevated cancer mortality in a place like Haiti begs the question of what structural factors need modification in order to eliminate or reduce these disparities. The varied experience of ethnic and economic groups in other countries (Lillie et al., 2014) reveals that certain risk factors for poor outcomes or delayed diagnosis may be modifiable. For example, a study conducted in the US found that preventive screening for breast cancer increased among Haitian women, with the behavior change occurring after longer time spent in the US (Brown, Consedine, & Magai, 2006). The present study examines the reported experiences of women seeking care for breast cancer in Haiti in order to identify which structures may be modified to improve outcomes.
Haiti overview

Haiti shares the island of Hispaniola with the Dominican Republic. Haiti was one of the most prosperous French colonies. In 1804, Haiti escaped from French colonization and slavery through a series of wars and became the first black republic in the world (Bellegarde and Lherisson, 1906; Independence of Haiti, 1852). In 1825, France asked Haiti to pay 150 million francs ($21 billion in today’s dollars) as indemnity, a debt that the Haitian government ended up paying until 1922, in fact Haiti became impoverished (Kleinman, Farmer, Becker, & Keshavjee, 2012) (Haiti says economic restitution from France would end poverty, 2003). Many perceive that although Haiti’s revolution may have brought Haiti’s independence, it destroyed many of the country’s resources (Henley, 2010). In addition, Haiti experienced decades of foreign occupation, dictatorship, political instability, violence, and environmental degradation (European Commission Humanitarian Aid, 2010). This history made Haiti the poorest country in the western hemisphere. Haiti’s GDP per capita was US $846 in 2014, and many Haitians live under the national poverty line of US$1.24/day (World Bank, 2014). The UN Human Development Index ranks Haiti as 168 out of all 187 countries worldwide, demonstrating Haiti’s poor health, education and economic conditions (United Nations, 2014).

Haiti’s medical profession, medical school and health care institutions were founded in the 1900s. In 1915, prior to the U.S. occupation, Haiti had a small community of well-trained physicians, a few state-run hospitals and medical professionals (Macbride, 2002). Currently, Haiti has an insufficient health workforce. Haiti counts 23 health care professionals (physicians, nurses and midwives) per 10,000 population, which is considered insufficient to ensure key primary health interventions recommended by the Millennium Development Goals (WHO, 2009). 40% of Haiti’s population does not have access to healthcare (World Bank, 2013). The European Commission Humanitarian Aid confirmed that 60% of Haiti’s hospitals were destroyed during the 2010 earthquake (2010). This loss worsened access to health care in Haiti. Poverty causes many Haitian people to struggle to pay for health care while doctors and hospitals often expect cash payment for
providing health services. Per capita, Haiti spends about US$83 annually on health care. Most of the rural areas don’t have access to any health care, making patients susceptible to treatable diseases (Global Security Organization, 2011) and requiring them to travel to seek care.

**Addressing breast cancer issues in Haiti**

Little has been written about breast cancer in Haiti. However, the International Agency for Research found that breast cancer is a leading cause of death from cancer among women in Haiti (International Agency for Research on Cancer (IARC), 2013). According to the WHO, breast cancer accounts for 0.49% of total deaths in Haiti and the age-adjusted death rate is 12.11 per 100,000 (WHO, 2011). There is no national cancer registry in Haiti. Oncological service is scarce, expensive and rarely available outside of Port-au-Prince, the capital city. Both patients and family members perceive breast cancer diagnosis as a crisis (Joulaee, Joolaee, Kadivar, & Hajibabaee, 2012). Unfortunately, the health care system fails where the health need is greatest (Walton et al., 2004).

Cancer care has long been neglected in developing countries (Kaul, Gralow & Atun, Bhadelia, 2012; Ginsburg & Love, 2011) such as Haiti. Personal informants and clinical evidence reveal that there are four mammography machines available in Haiti. Not all Haitian women can afford the cost of mammogram screening. Haitian women with breast cancer often present at advanced stages, which negatively affects their treatment outcomes (Sharma, 2013). The delayed presentation of breast cancer patients in healthcare services is not well understood, but is likely related to barriers that limit access to diagnostics, preventive care, and treatment. Such barriers include low socioeconomic status, poor health literacy, lack of access to healthcare, and the lack of oncologists (Sharma, 2013). Despite challenges such as scarcity of medical oncologists, lack of screening materials and timeline, and poor health infrastructure for oncological treatment, a few non-profit organizations with a global health perspective are trying to address disparities in breast cancer care and outcomes in rural Haiti.
Partners In Health/Zanmi Lasante (PIH/ZL), a local NGO founded in 1983, launched the first free cancer care program in 2011 in Haiti’s Central Plateau (now located in Mirebalais). The program validated that breast cancer was the leading cause of cancer mortality among Haitian women, and affirmed that women generally present with advanced stages of breast cancer, at which point therapy offers poor probability for survival. Advanced breast cancer results in social suffering not only for the patients themselves but also for their family members and akonpayatè/caregivers. Elucidating the reported experience of breast cancer patients, family members, and providers will help the researcher understand patient perceptions, emotions, and memories after overcoming barriers to seeking treatment. Accordingly, the objectives of this study are to understand the factors that contribute to delays in diagnosis of breast cancer and also to uncover the barriers that prevent Haitian women with breast cancer from accessing treatment for breast cancer when the diagnosis is made. Evidence-based strategies can then be developed to improve breast cancer care, and outcomes, among Haitian women.

Conceptual framework

In this study, the researchers elaborate three conceptual frameworks to explore the reported experience of women seeking care for breast cancer in Haiti. They are pelerinaj, social suffering, and akonpayatè.

Paul Farmer recounts the story of one Haitian woman’s attempt to seek care for breast cancer. She visited 14 health clinics to seek care for her breast problem. At the end of her journey, she had traveled about 248 km, from the most remote part of Haiti, Jeremie, passing through Port-au-Prince, the capital city, finally ending up in the Central Plateau where a foreign doctor found a big breast lump with a yellow fluid flowing from it (Farmer, 2010). She was diagnosed with advanced breast cancer.

In the narrative above, Farmer captures the challenges for women in Haiti seeking care for breast cancer. In our study, we use the term pelerinaj to describe the difficult and nonlinear journey that patients experience in an attempt to seek relief and treatment for their breast symptoms. The
most direct translation in English of the word *pelerinaj* is “pilgrimage.” Linguistically pilgrimage means “a journey to a special and unusual place” and frequently refers to a ritual journey of religious importance (Merriam Webster Dictionary). In Haiti, the term *pelerinaj* takes on a very specific meaning that departs from the conspicuously religious motivations entailed in the standard conception of the term “pilgrimage.” The local idiom of *pelerinaj* refers more broadly to an arduous, and notably circuitous, journey. During the journeys described here, the *peleren* or patients face many challenges and barriers that contribute to social suffering before accessing proper care.

Social suffering is a theory developed by the medical anthropologist and psychiatrist Arthur Kleinman in which he characterizes pain and suffering as social phenomena that is caused by social institutions, economic and political hardships (Kleinman, Das, & Lock, 1997; Das, Kleinman, Locke, Ramphele, & Renolds, 2001). He argues that poor people are subject to pain and suffering due to their social position. Social position is linked to health inequality: the more vulnerable a population is socially, the more limited their access is to health care and the greater their prospects are for poor outcomes from disease. The theory of social suffering illuminates the experience of women who seek care for breast cancer in Haiti. Patients have a feeling of having not a simple breast cancer (as providers diagnose), but a “generalized” experience of illness (Kleinman, 1988) that impedes them from staying physically active and affects them mentally. Social suffering is often expressed as social and psychological distress (Kellehear, 2009; & Gillespie, 2009). It is social because it is a junction between the illness experience in the human body (ill) and the society (Kleinman, 1988). Indeed, pain, metastasis, stigma, and suffering are the social reality for most of breast cancer patients in the study. This suffering has an impact on women with breast cancer, their community, their family members and also on their caregivers/ *akonpayatè* because of social interaction.

Kleinman defines caregiving as a moral responsibility and solidarity toward people or patients in great need. He calls caregivers people who care for a sick person with a sense of love and moral solidarity (Kleinman & Geest, 2009; Kleinman, 2012). Caregivers remain hidden
sufferers who share someone’s suffering, usually silently (Kleinman, et al. 2001) to give strength and courage to the ill person. In the Haitian culture we use the word “akonpayatè” instead of caregivers for people who devote time with responsibility, compassion, concern and hope to help another person seek better health. Partners In Health in rural Central Plateau, Haiti implemented the model of akonpayatè (Farmer, 2011). Akonpayatè are people from the community trained as community health workers who are responsible to link the community with the health facility. The akonpayatè perform home visits for health education and medicine delivery. In addition they are vital to provide moral and social support to patients (Walton et al., 2004). Our study explores the factors and the barriers that prevent Haitian women from accessing breast cancer care during their peleurinaj and also examines the role played by health providers and caregivers/akonpayatè in the experience of women with breast cancer.

**Methods**

In the present study, the researcher used a qualitative approach with open-ended interviews. The aims are to document the reported experiences of women seeking care for breast cancer and their caregivers. We chose grounded theory to derive insights directly from the words and reported experiences of the study participants and to demonstrate the meaning of those experiences for the individual.

The study took place at Hôpital Universitaire de Mirebalais (HUM), a hospital built by PIH and ZL in Mirebalais, in rural Haiti, Central Plateau. In 2011, these two organizations opened the first free public cancer center in Haiti (Rollins, 2013).

**Sampling**

We purposively selected participants who were likely to generate useful data for the study (Corbin & Strauss, 2008) by providing information about their experience seeking care for breast cancer in Haiti.
Women between 21-65 years of age who had been diagnosed with stage 3 or higher breast cancer in the previous 6-18 months, who were receiving medical care at HUM, and who were willing to give informed consent were eligible for inclusion. Patients in the study identified a supportive person who had helped/accompanied her during the process of identifying breast cancer signs/symptoms or when seeking care. These individuals were included in the study. We also interviewed health providers currently working with breast cancer patients at HUM.

**Recruitment and data collection**

Providers from the HUM Oncology Department introduced the researcher to potential study subjects: female patients who attended a breast cancer care appointment at HUM and who expressed willingness to participate. We selected those who fit the inclusion criteria. These women provided the researcher with their contact information. The researcher asked patients enrolled in the study if they had a caregiver, a person who had supported them closely during the process of noticing breast cancer symptoms, decision-making about seeking care, and/or receiving treatment for breast cancer. Each patient was given an invitation letter to give to the caregiver. When the researcher came to the patient’s community to conduct the patient’s interview, the invitation to participate in the study was also given to the non-professional caregiver. If the caregiver agreed to participate, the researcher scheduled a time and private place of his/her choice for the interview.

This resulted in 18 participants for face-to-face individual semi-structured interviews: eight women diagnosed with stage 3 or higher breast cancer; eight non-professional caregivers (one for each woman), and two healthcare providers. All interviews were audio-recorded and notes were taken, with the consent of the subjects. Data were transcribed and translated into English for data analysis.

The researcher traveled to different cities and communities across the country to reach participants at their chosen location (their home or other places) outside the hospital. The researcher ensured that the location was quiet and the conversation could not be overheard to protect the participant’s privacy. We conducted the interviews in Haitian Creole using three different interview
guides that were assigned for each group of participants containing specific open-ended questions. With these questionnaires we gathered data from patients, providers, and caregivers to capture the experience of patients seeking care for breast cancer in Haiti.

The participants provided oral informed consent before participating in the semi-structured interviews. The Harvard Medical School Office of Human Research Administration, the Zanmi Lasante Research committee, and the Zanmi Lasante Institutional Review Board approved the study.

**Analysis**

The data were analyzed through narrative analysis and grounded theory for the purposes of understanding the care-seeking experiences of women diagnosed with breast cancer in Haiti. After transcription and translation, the researcher manually coded the data. The coded data was then reviewed and regrouped into broader concepts. Using an iterative process that involved revisiting the data on a regular basis, these concepts were then used to formulate themes that reflected the experiences of breast cancer patients, their caregivers, and their health care providers. The researcher then compared and contrasted these multiple viewpoints, identifying common themes through narrative analysis. Finally, the researcher analyzed the data using inductive and deductive approaches to synthesize the diverse information from the participants into key ideas and themes. This in-depth study of cases was grounded in broader literature, specifically on the theory of social suffering. This theory is relevant in this context because the many obstacles—the delayed care, and lack of an organized health-care system—are experienced as social suffering by study participants. This is also experienced through pain and suffering that is not mitigated by the poor quality of care.
Results

Case Exemplar of Pelerinaj

A widowed mother of three children (two boys and one girl) one day in 2008 while taking a shower carefully touched her breast and noticed a lump ("ti boul") in her left breast but did not know what it was. At this time she communicated her breast problem to her boyfriend who accompanied her to see a doctor in Port-au-Prince a few months later in 2008. After evaluating the patient the doctor concluded that she needed to have surgery, and quoted a price. The patient could not afford that cost, so she and her akonpayatè tried to negotiate a price but the doctor did not accept the reduced price. So, the patient stopped going to see him because they could not afford this cost. In 2010, they went to another clinic where they had to redo all medical tests (mammogram and ultrasound), and then when they brought the results the doctor said that he would do a cleaning (which is like extirpation of the nodule(s)). This was delayed because of the earthquake. Without confirming the diagnosis by biopsy, the doctor insisted that it was not necessary to remove the breast. A month after the procedure, the patient started feeling severe pain and felt a mass; when she went to see the doctor, he prescribed pain medication. After 4 months without relief she went back to see the doctor again at his private clinic. He ordered repeat exams. Less than one year later, still without biopsy results, she went through surgery for a second time (again cleaning), but conserved the breast. Symptoms persisted; she was still in pain, and so this woman continued her journey and went to a clinic in Mirebalais. The doctor at Mirebalais said that it was nothing to worry about because she just had surgery and prescribed her drugs including pain relievers and advised her to put ice on the breast and to avoid chocolate, milk and other foods. She had not yet met any doctor who resolved her breast problem and her condition did not improve. At some point in this process, she had a biopsy but never received the results. Eventually, she received advice from her friend to go to seek care at a University Hospital in Mirebalais, Central Plateau. She traveled again from Port-au-Prince to Mirebalais and when she got there, she started over and had all the tests done there again. She was also advised to get the results from her previous biopsy.
Securing these required multiple interventions by the patient and her husband; the physician was reluctant to share them. Ultimately, in 2013, at HUM, she finally learned her real diagnosis. Unfortunately, it was too late, and they could not do much. She could not even have a mastectomy because the cancer had metastasized to her lung. At the time of the study, in October 2014 she was receiving palliative care—care only to treat the pain and symptoms, rather than to cure her breast cancer.

This narrative case captures the journey and what is at stake for the women in our study.

**Lack of information about breast cancer, absence of preventive care, and consequences for symptom detection**

Patients in the study report not having access to routine preventive care. According to a doctor interviewed, there are no sources for adequate, accurate information about breast cancer in Haiti. Without this information, women were unaware of potential benefits of self-breast examination, did not know which symptoms warranted medical care, and made incorrect self-diagnoses. Although they independently identified breast problems such as lumps, itching, pain, and other changes in breast characteristics, they experienced them as passing, transient symptoms.

One patient from Fontamara, Port-au-Prince described:

“I just noticed a lump in my breast, which was already hurting me. And when I approached my period cycle, my breast used to be scratchy, but I never thought that it was a problem.”

Another participant disregarded her discomfort because she thought her symptoms were due to gas:

“I thought it was gas that was causing this pain, but when I looked at my breast it seemed that I had already been already operated on.” (Patient from Mirebalais)

In the absence of formal structures to permit evaluation of symptoms by trained healthcare providers, women assumed responsibility for these gaps. They internalized the lack of education and lack of preventive care as self-blame. Some patients invoked the words “neglect” or “lazy” to justify why they did not immediately seek help, to explain their ignorance of breast
symptoms and how serious they could be. One woman explained: “I've been a little lazy; I was never interested in seeking medical care...” (Patient from Clercine, Port-au-Prince).

This shortage of information on preventive care manifested as delays to diagnosis repeatedly at different points during the arduous journey that patients took in seeking care. A doctor providing free care at Hospital K explained:

“Only one thing, lack of information or misinformation: either the patient doesn’t know at all if it’s cancer... or the patient knows it’s breast cancer but won’t have any money to get treatment and must get it free. Or the patient knows if she comes that they would do a mastectomy for her, and believes that she’s dying and it’s the mastectomy that’s killing her and not the cancer, or else a bunch of other things. It’s always either the person doesn’t have all the information about cancer, or receives bad information.” (Doctor from Hospital K)

Since women did not have access to preventive care or education about breast cancer, and they did not know where to go for treatment of breast cancer symptoms, initial breast symptoms did not result in care-seeking. It was only when symptoms persisted that patients received advice to seek care. However, when a patient started seeking care, it was difficult to find a facility that could provide proper and timely care, for her health problems. One patient indicated the challenges of seeking care for her breast condition:

“Well, every time the doctors give me tests to do it’s not easy to get them done. When I come, it is very difficult for me to see doctor. Sometimes they tell me that they have already taken the quota of patients for the day, and they cannot see me. So I must return another day you understand. By this time now I feel discouraged.” (Patient from Delmas 3 Port-au-Prince)

Accessing health facilities did not solve the patients’ need. The flow of patients asking for help surpassed the health workers capacity. A lack of health professionals prevented patients from accessing diagnosis and treatment in a timely manner. A patient explained:
“...We visited several hospitals. We first visited the Hospital L, and some people told us that there are very good doctors working at a public Hospital E. So, there we went and saw the doctors. But sometimes, the doctors are not available because they have lots of cases to take care of.” (Caregiver, patient at Shada)

**Lack of access to appropriate oncological care**

In Haiti, at the time our respondents were seeking care, oncologists were scarce; in fact, few health facilities accessible to interview respondents provided oncological care. Patients often sought care for their breast problem at a primary care center, hospital, or private clinic where, unbeknownst to them, oncological services were unavailable. Referrals to centers with oncological services were often delayed. Frequently, non-oncologist providers spent a lot of time trying to make a diagnosis before making a referral; in the meantime, the symptoms and disease worsened. One of the doctors interviewed affirmed:

“... when the mass gets larger and [they] decide to go to the hospital, patients often did not go where they should go. That makes them waste a lot of time before seeing a specialist (oncologist), who would refer them where they’re supposed to.” (Doctor from Hospital K)

The lack of education and services led to delayed diagnoses of breast cancer with serious consequences. Many patients ultimately diagnosed with advanced breast cancer had experienced multiple health care encounters before their diagnosis. Another doctor explained:

“...the patient may have been going to the hospital without being referred to an oncologist. So, she gave up, all because she made 4, 5 trips to do surgery and when she got there no doctors would see her, or there’s a strike going on, so she can’t come.” (Doctor from Hospital K)

**Lack of health protocol**

Further compromising treatment and outcomes was the absence of a policy or protocol offering guidance for providers. This resulted in delays in treatment, failure to explain to patients the severity of disease, and possibly, inappropriate treatment for the extent of disease. In many
cases, diagnosis was made without knowing the stage of the cancer. Many patients had breast surgery while having distant metastasis. A doctor who was working at a facility that delivered free care explained:

“They usually go to another place, they have the right to go to any hospital, and you know there’s no protocol established. Far as us doctors at Hospital K, we more or less have our own protocol... We know once the patient comes what are the steps for “screening”, and what needs to be done. We have our protocol whereas other health facilities do not. The person can come and the procedures are not clear to her. And also, for example, I see there are patients who have breast surgery without the doctors giving them the staging while they had distant metastasis. So, you could still do surgery on them but at least they understand what it is. The fact that we follow a protocol, we clearly explain everything to the patient. We tell them 1, 2, 3, here’s what we’re going to do.” (Doctor From Hospital K)

Having guidelines or protocols can also avoid delivery of ineffective treatment: many patients had surgery without a biopsy. Two patients who had metastases, one in the lung and one in the femoral head of the thighbone, explained:

“I did one (ultrasound) before the first surgery. After the surgery, he gave me the specimen to take to Laboratory X for analysis (biopsy test). When I continued to notice the mass after the surgery, I went to see him (doctor A), and he said that it was nothing, that he had already removed the disease.” (Patient at Clercine, Port-au-Prince)

“At the beginning, I felt something in my breast; I just went to Port-au-Prince to see a doctor. When I had a surgery in my breast, Dr. B did not tell me anything about breast cancer. During the surgery, he (Dr. B) took a part from my breast and showed me a series of small lumps. After the surgical intervention, my husband and I came back for medical consultation. The doctor did not inform me of a breast cancer diagnosis...Six years after
having had surgery, my breast developed an open wound where I had had the surgery. I went back to see him (doctor. B) again. He “cured” it but it re-opened once again. Then, I went to seek care at the Hospital K...even after having a diagnosis of breast cancer from the hospital K, he [doctor. B] continued to tell me that I was not suffering from breast cancer. If I had kept going to see this doctor I would be dead and buried long time ago.”

(Patient from Gonaives)

**Delayed diagnosis**

**Impact of breast disease on patients’ economic livelihood**

In this study, patients experienced breast cancer as an illness that affected their whole lives. It prevented them from performing their regular activities and made their lives difficult and vulnerable. In some cases, the symptoms or treatment of breast cancer, or even the process of seeking treatment, prevented women from working. For some women who were able to and wanted to work, external forces (i.e., societal discrimination against people with cancer) caused them to lose their source of income. In both cases, the inability to earn a living resulted in dependency upon others—this makes breast cancer a collective issue.

Many of the patients were street vendors, living on a very narrow margin. Their living conditions became even more challenging due to the illness and its impact on their abilities to continue working and care for their families. For example, one patient noted: “I did not feel well. Everyone was telling me that I am sick in the breast; I should not work/do much with my body. And that was true because I did not have the strength and “courage” to do anything. I used to go sell things on the street but I had to stop to go to seek for care. And at home, I used to cook, clean, do laundry, but I now no longer do those things.” (Patient from Shada, Port-au-Prince)

They experienced this as a choice between health and financial life. The inability to continue working then reduced their ability to spend the money needed for the process of seeking care.
“Well, before I had a better living condition because I used to run a big business... And adding to my illness I could not have any money.” (Patient from Gonaives)

The study also found that many people in the respondents’ lives assumed that the person with breast cancer was not a productive person. Even in those cases in which patients with breast cancer had jobs which they wanted to maintain, some had been fired because of their illness. A patient explained:

“I moved to St. Marc to seek work. I found work but was let go while I was sick. On my way to the Hospital K I received a call from my supervisor, he said to me that they would not renew my contract, and I did not need to come to work anymore. I got a second job. When I had the surgery they fired me. They said to me that my health would not allow me to continue working.” (Patient from Saint Marc)

A caregiver described:

“...the first time we came back from Mirebalais [months before any intervention] they [employer] called her on the phone and said she couldn’t work anymore, but they didn’t give her a reason.” (Caregiver for patient from Saint Marc)

The challenge caused by the illness became a collective issue, not only an individual one because the economic consequences affected the patients as well as their family. A patient said:

“This affects my family a lot. I am the eldest in a family of 7 children. I am their eyes. When I had (money), I supported them in many ways. Now, I am sick, I am not working. I cannot continue helping them financially. They are unable to provide me money. This situation affects them a lot.” (Patient from Saint Marc)

A caregiver also noted:

"It had an impact on me because my wife had helped me a lot. Now, I don't have a father or a mother who can help me. That gives a lot of problem... Since we got married, we have been renting a house, we don't have our own house. She often helped me to pay the rent,
and spent money for other things in the house. As she got sick she could not." (Caregiver for patient from Fontamara, Port-au-Prince)

Thus, it was obvious that patients’ illness had a significant impact on daily life, disrupting their usual activities including work and routine activities such as cooking, and washing clothes. Patients felt the need to rely on their caregivers, making them dependent.

"When I cook food at home, I bring her some. I used to buy soap to wash her clothes, and I usually wash them for her." (Caregiver for Patients from Debrosse, Port-au-Prince)

“Since my husband died, I felt my family was my children, you understand. They are my only family members. It’s my son who replaces him (my husband)! I could say that my son is my family; all my problems are his problems, you understand. When I have something that is hurting me it’s him I tell what is wrong with me. I communicate everything that I feel with him. So that is why when you asked me who is taking care of me I said to you that my son. My son is the person who is in charge of me. I belong to him. Because I have two children, my daughter doesn't have a job. It is my son who is helping me in my illness, going back and forth for treatment." (Patient from Mirebalais)

Lack of money can delay medical exams

The loss of income had a direct impact on care. Although some patients were facing particularly persistent poverty, all of the patients interviewed suffered from a serious medical condition that required a large amount of money for care. The full range of health services required lab tests, consultations, drugs, and surgery, as well as fees for transportation to access all these services. When patients were able to afford transportation and medical consultation fees, the health providers ordered lab exams and then prescribed medicine to buy. Patients had to pay out of pocket for all these expenses; the disease experience and absence of any public cancer service exacerbated the illness. Lack of money was a barrier to diagnosis and adequate care. Multiple patients described how expensive lab tests were problematic. For example, one patient noted:
“...He [the doctor from Hospital E] asked me to do a very expensive exam. I did not have money to do the exam. My friends put money together to give me in order to do it. This caused a delay. The breast problem became serious. It started to be stiff, ulcerative.”

(Patient in Debrosse, Port-au-Prince)

Additionally, lack of money forced many women to choose between two necessities: pain relief and diagnostic tests. For some patients, relief took precedence over medical exams simply because they did not have enough money for exams, but they had enough to buy medicine for pain. Indeed, patients in pain did not understand why doctors did not prescribe painkillers while ordering further exams. Often patients experienced long delays before being able to get tests as they struggled to find money. As one patient affirmed:

“It was not easy because the cost of a mammography was $300 and at the time, my husband had just paid for the funeral of his dad. It was difficult to find the $300. So I went to see doctor C; I explained that I could not afford to do the exams, and I asked him to prescribe a pain reliever. He refused; he said that he was not going to give me any medication. But at the end, while he urged me to take my case very seriously, he prescribed something. I bought it at the pharmacy, and took it whenever I was in pain. It took me some time before I was able to do the mammography.” (Patient at Fontamara, Port-au-Prince)

Responses like this illustrate a mismatch between doctors’ realities according to their professional experience in diagnosing breast disease, and patients’ social realities in finding relief for their illness. This tension was one factor that drove patients to seek care at other health facilities. A patient affirmed:

“When I went, he (doctor A) asked me for exams, and after he received the results, he said that I needed surgery, and asked for more exams. I said to him: “why I am in pain you ask me for exams and you never prescribe me medication” he said “No, I will prescribe you medication after getting the results.” I left. Then, I went to Sainte Catherine Hospital.”

(Patient from Clercine, Port-au-Prince)
This disconnect between the doctor requesting more tests as a condition for pain relief and the patient requiring immediate pain relief caused a breakdown in the doctor-patient relationship. The patients went elsewhere to seek help because the doctors did not satisfy their need for pain relief.

Support from akonpayatè

As patients were unable to continue their economic activities and required funds for medical care, caregivers were a financial resource for them. Akonpayatè was a word respondents used to refer to people who help them as breast cancer patients in different ways. Here we discuss the economic support akonpayatè provided to the patients during the whole process of seeking care. Akonpayatè money was spent on medical exams, consultation fees, and transport during the care-seeking journey. Patients identified a range of akonpayatè: spouses, family members and community supports, and indicated how they assisted them:

“When I couldn’t afford to do the exams, she (my daughter) gave me money to do them.” (Patient at Shada, Port-au-Prince).

“He (a brother from my church) helps me all the time, I can’t say otherwise. He came here this afternoon and gave me 250 gourdes. You see that’s how I’m living. This brother who cares for me is a member of the church, but not everyone is that way. When sometimes I’m going to Mirebalais to my medical appointments and don’t have any bus fare he often gives me 500 gourdes.” (Patient at Canapé Vert, Port-au-Prince)

Despite this support, after patients had spent multiple years seeking care, they became impoverished. Family members and/or caregivers were so invested in patients’ care, they used the word “we” to convey that the costs affected not only patients but also their family and other persons surrounding them, such as caregivers who were willing to spend money for them.
Experience of “bothering” people for money and borrowing

Despite support from akonpayatè, patients needed additional funds and were forced to ask other people from their extended social networks for money. Therefore, patients did not have any other options other than “borrowing” and “bothering” people for money in order to find solutions to their illness. Others did not borrow because they thought that they would unable to repay.

“Well, I live by faith; sometimes I don’t have anything in my hand. And, don’t have money to pick up my medicines, and go to my health appointments. Sometimes I ask my brother for money. But, I feel uncomfortable to bother people”.

(Patient at Debrosse, Port-au-Prince)

“No. Thanks to God, I do not borrow money from people. God always gives me a way. I would never borrow money from people because neither my husband nor I is working. And no one would ever lend me money because they would believe that I would not be able to reimburse. With God’s infinite compassion and love, he always helps me. A friend would just stop at the house to give me some money. When I face difficulties, and that I am concerned not to be able to attend my appointment, I just have to pray.” (Patient at Fontamara, Port-au-Prince)

“A lot of money. People that I owe money to, so I can pay Dr. D. I still haven’t finished paying the doctor. Since he’s a Christian brother he’s patient with me.” (Patient at Canapé Vert, Port-au-Prince)

“Oh! a lot. There were times I couldn’t buy medicines, for 2,500 to 3,000 gourdes, I couldn’t afford it sometimes, and I didn’t have any money. I borrowed from the kids sometimes but now they’re not working.” (Patient at Canapé Vert, Port-au-Prince)
**Sacrifices to save money for medical expenses**

Despite the financial support patients received from their caregivers and others in their journey/pelemanaj, it was not enough. Patients were still struggling. Patients were unable to afford recommended lab tests immediately after medical consultations. Because patients had to save money little by little, patients had to wait a long time to access necessary medical care. As one patient described:

“...when you expect to do the exams, you do not have the money; or you just have part of it; so you have to wait until you collect the whole amount. You can’t do the exams without money.” (Patient from Shada, Port-au-Prince)

“That is also the reason why I stopped going to Dr. G because I knew that I would not be able to find the money; those who are helping me are really making big sacrifice. A session of chemo was reported to cost $1,500. I didn’t know where I would find the money.” (Patient from Shada, Port-au-Prince).

To gather the money for their pelemanaj, sometimes patients and caregivers sacrificed themselves. They opted not to cook and remained hungry so they could reserve funds for their medical appointments or to buy drugs, or pay for lab tests. As several patients described:

“Yes, sometimes the little that you have you squeeze it so you don’t spend it all on food. Even when you need to take your medication sometimes, you can’t because you haven’t eaten anything since morning, you can’t take the medication on an empty stomach, it would send pain in your heart. That happens.” (Patient from Canapé Vert, Port-au-Prince)

"I never miss my medical appointment. When I have even $50, I kept it. Even though I am suffering, I would not use it." (Patient at Debrosse, Port-au-Prince)
Delayed adequate treatment due to “doctor carelessness”

The most effective treatment could not be accessed as expected. Some patients realized that if doctors had removed the breast from the beginning, their “health condition would be different today.” Mistreatment resulted in recurrence of signs and symptoms. Later, when symptoms reappeared some women realized that they had been improperly diagnosed. Thus, cancer got worse and became a very serious medical condition. The consequences of doctors’ “carelessness” of having mistreated their patients was to allow the disease to spread and affect other organs (metastasized). Patients said:

“I had been seeing Dr. I for a long time. Now the water flows on me (liquid flowed on the breast wound and wet her dress). If I arrived at this point, it is not my fault; it is the Dr. C fault. They were careless with me.” (Patient from Débrosse, Port-au-Prince)

I told him (my partner) that I was not going to live a long life because doctor from Hospital G said that I could not be operated; and that the disease had already attacked my lung. I said that it was Dr. A’s fault because the doctor who did the ultrasound told me that I needed to remove the breast; but Dr. A insisted that it was not necessary. I blame him because I realized he did not really care. (Patient from Clercine, Port-au-Prince)

Distrust in health providers’ diagnosis

Many patients and caregivers distrusted the health provider’s diagnosis, and therefore left the first facility to start over at another one. Patients who misunderstood their diagnosis often consulted other non-professional persons for information. The lack of information on the diagnosis led patients to question the doctor's professional capacity and generated distrust in provider diagnosis. Even when the diagnosis was confirmed by medical tests, patients could not rely on it because the pathology was new for them. Some said that they knew that people had fibroadenoma in other organ but not in breast. Distrust delayed patient diagnoses and made them consult other doctors.
A patient said:

“I went to another hospital. Doctor J asked me to do an ultrasound. When I got the result, I brought it to the doctor and he said that it was a breast “fibroma” [a non-cancerous lump]. So, when I spoke to some people, they said that it doesn’t exist to have in breast.” (Patient from Mirebalais)

“Doctor L decided to send her for radiology exams. Before getting the results the doctor drew blood samples from both of my mom’s breasts. When he got the results, he said that my mother had breast cancer in one breast and, in the other breast, fibroma. I was surprised about my mom’s diagnosis. I asked myself if this doctor could lie to me because I have never known that people can have fibroma in the breast. I was asking people for information about fibroma in the breast. Finally, someone explained to me that it is possible.” (Caregiver for patient in Mirebalais)

Many times care was disrupted without knowing the diagnosis because patients were dissatisfied with treatment provided by the doctors. When patients perceived that their breast condition had worsened instead of getting better, it became obvious to them that some doctors were not able to treat them. Thus, they decided to seek care at a different health facility. Sometimes they went to more than one before finding one they trusted enough to feel they were getting quality care.

“I spent 6 years seeking care in Port-au-Prince at this private doctor’s clinic. At the beginning I did not feel any pain and my breast was not opened. But after, when I started with pain and my breast developed an open wound, it became obvious to me that he could not treat me and I decided to go to Cange where I was referred to Mirebalais.” (Patient from Gonaives)

**Poor health care management**

“I had a lump in my breast before. In 1998 I had to get surgery done in Leogane...when I got to the operation room the doctor felt my breast and didn’t notice any lumps, he asked
me where the lump was, I told him I didn’t know, then he asked where’s the lump he’s supposed to remove. I told him I don’t know. He (doctor) called another doctor, who also didn’t find anything. Since 1998 none of the doctors was able to detect any lumps in my breast.” (Patient at Canapé Vert, Port-au-Prince)

Some patients (like the one above) reported seeking care very early but still experiencing delayed diagnosis, as they did not receive adequate services. Their situation worsened. Despite the intensive investment in care seeking, the care was insufficient to heal the patient. For example, one patient expressed feelings of frustration and grief:

“I have seen the lump. I know breast disease is not something simple. I sought care very early. I thought I would find a solution (for the illness). But nothing has improved for me. I am an unlucky person.” (Patient from Debrosse, Port-au-Prince)

A doctor shared the experience of a patient who had a delayed diagnosis because of poor care management. This woman had been diagnosed somewhere else with inflammatory breast disease (mastitis). She received antibiotic therapy, when in fact, she had inflammatory breast cancer:

“It was a young woman who had inflammatory breast cancer. There was no lump; instead, the whole breast was affected. It looked like orange peel, and the nipple was retracted. She had previously seen doctor L, a doctor who speaks only Spanish. Later, she came here, and showed me her medical record. In her medical record I saw that she received intramuscular antibiotic therapy called ceftriaxone over 6 months ...She showed me all the monthly receipts and I understood her situation. She had seemed like an educated person who at that moment realized that she hadn’t received proper medical treatment. Her breast condition had deteriorated, then she decided to come to us.” (Doctor at Hospital K)
**Lack of trained and qualified health professionals to diagnose and treat breast cancer**

A provider confirmed that limited access to mammography and limited training of health care workers to refer for mammography delayed access to diagnosis even when they sought care early. Mammography, despite its high cost, is recognized as a key diagnostic tool for breast cancer. Adequate training on when to refer for mammography was lacking. Lack of tools, proper training and proper management were structural weaknesses in the system for breast cancer care.

Untrained technicians who misused the tools or misunderstood the operating procedures contributed to making patients lose the benefit of a timely diagnosis. In fact, tools and training remained a challenge for health care providers to confirm the breast cancer diagnosis. Doctors who provided free oncology care shared their experience showing how patients often lost the opportunity to get treatment on time:

"There was a 32 year-old patient, who had seen a "boul" (lump). She did not neglect it, she went to hospital within a month [of detecting it]. The doctor ordered mammography. But the technician said that the patient should wait until she was menstruating to conduct the mammography. Each time she went, during or after her menstruation, he always said that it was not a good time to conduct the mammogram. Indeed, she spent 8 months going back and forth without able to complete the mammography. Ultimately, she decided to go to another health facility and see another doctor. This doctor ordered mammography and other lab exams. She tried to do it and spent another 3 months going back and forth to the laboratories without having any mammography... Someone she knew advised her to go to Hospital K. When she came, it was too late because she had already spent 1 year seeking care for the mass in her breast elsewhere. The disease was too advanced because they made her do a lot of back and forths." (Doctor from Hospital K)

Many patients who relied on their doctors for a diagnosis didn't think that they could have cancer since their doctors had ruled out cancer. After visiting a multitude of health facilities, patients were surprised to know their real diagnosis, although they patients had asked whether
cancer might be a possible diagnosis. Doctors sometimes gave patients incorrect explanation. A patient from Clercine, Port-au-Prince explained:

“I did not really think about cancer. When the doctor said it was a mass, I asked if that meant cancer, he said no. He explained it was kind of a combination of blood and breast milk. They never mentioned cancer to me before. I was only informed it was cancer at the Hospital K.” (Patient from Clercine, Port-au-Prince).

She learned about her true diagnosis 5 years later.

A patient, who was reassured by her clinician that her breast problem was not cancer got her breast cancer diagnosis from a hospital located in rural Haiti after 6 years seeking care at a private clinic in Port-au-Prince. She stated:

“He never told me that I had cancer. He always says that I don’t have breast cancer. It was when I went to Hospital K, they diagnosed my breast cancer...” (Patient from Gonaives)

**Psychological effects of the diagnosis**

Breast cancer diagnosis gave rise to stress, emotional upset and mental health issues. After the diagnosis of breast cancer, learning about the disease made them feel ill. Knowing their diagnosis and realizing that they had missed the opportunity to be diagnosed and treated on time had complicated their case made patients feel vulnerable, near the end of life. A patient from Fontamara in Port-au-Prince said to the researcher: “I am very happy that you came to get information on my illness. I would like to ask you one question that I had: Can cancer be cured?” Cancer patients commonly asked this question. Many patients in our study spoke of time spent on fruitless searches for healing and how it was very difficult for them to overcome the uncertainty they felt about their lives. This uncertainty affected patients physically, emotionally and mentally. Knowing that the diagnosis was breast cancer gave rise to other serious mental and physical health issues. Following diagnosis, patients and their caregivers experienced depression, stress, and loss of weight. This diagnosis led many of them to seek alternative solutions.
A patient from Saint Marc said:

"For me this (the diagnosis) was really a problem ... I lost weight, stress invaded me. I have lost my hair." (Patient from Saint Marc)

“When the doctor informed me about my situation, I was very depressed, I felt lost, and cars almost hit me on my way back home.” (Patient from Clercine, Port-au-Prince)

**Questionable expensive treatment**

The patients who were able to access a treatment had been charged in local as well as foreign currency, for demonstrated effective treatments as well as questionable ones. Some providers offered vaccines with no proven benefits. Indeed, patients and caregivers questioned the care they spent a lot of money on:

“She went to see a doctor who had studied in Israel. He ordered a vaccination for about $600 (Haitian) dollars.” (Caregiver for Patient at Canapé Vert)

“She started feeling "a ti boul" in 2005. We went to Port-au-Prince to see a surgeon doctor; he performed breast surgery. He removed a cyst in my wife's breast. From 2005 until 2011 she was able to perform her usual activities. In 2011, while in a communion, she felt a liquid under her arm; she passed her hand, and smelled it. It had a bad odor. Right away she informed me about the issue. In a week, we came back to Port-au-Prince to see him. He saw the wound, and asked for medical exams. The doctor said that she had an attack of cancer. He said that the advice he could give us was to have her vaccinated in order to prevent the disease. I gave him the money, he bought the vaccine. He vaccinated my wife.” (Caregiver for Patient From Gonaïves)

“Well, we have spent a lot of money. It is one of the reasons that we (patient and family) became impoverished. He (the doctor) prescribed me some vaccines (to prevent the patient
from getting breast cancer) and every time I went to Port-au-Prince, I had to pay for medical consultation and the vaccine. One vaccine could cost between USD 2,000-2,600… And also I had to buy the drugs that had been prescribed in Port-au-Prince.” (Patient From Gonaives)

This patient from Gonaives had traveled 152 km to seek care at a private clinic in Port-au-Prince for a lump that was not big at the beginning. She had started seeking care in 2004. After 6 years of traveling she had decided to switch health facilities. It was only then that she got the breast cancer diagnosis.

A physician from a free oncological care department explained how providers had asked patients for money to remove cancer from a diseased breast, while the breast cancer was too advanced to warrant resection. In these cases, the doctors inappropriately prioritized conservation of the breast. The questionable professional decisions of some providers delayed patients from receiving proper treatment on an appropriate moment:

“I remember one patient that was going through chemotherapy and at that time this patient had a sort of sacrum of the breast that couldn’t respond to chemo and it was a huge and hard lump and we applied chemo. We determined that we also had to do mastectomy. She said that she had gone to a private doctor who had told her, if she had had money, that he would have removed the cancer for her. He said that she wouldn’t have to lose her breast and the cancer would never come back. The lump on the breast was different from other breast cancer patients, the lump on her breast was 2 or 3 times bigger than the actual breast, yet the doctor had told her that he would only remove the lump.” (Doctor from Hospital K)

**Lack of information about the benefits of treatment**

Patients, family members, caregivers and friends or acquaintances were under the impression that whether or not a breast cancer patient had surgery, she would die. This impression held patients back from accessing diagnosis and treatment. This was the consequence of the absence
of information provided by health leaders about detection of symptoms, signs, and about the
disease. They did not have the correct information they needed that could alert them to how
treatment could be effective. Some providers claimed that mastectomy was stigmatized in society.
It was equated to death. That was why some patients often asked for another option of treatment
when no other option was available. A doctor said:

"I think that it is taboo of the society; removing breast is seen as the biggest loss that can
happen in a woman’s life, and that a woman cannot live without her breast. It is like the
end of life. Sometimes husband has the same reaction." (Doctor from Hospital K)

When patients finally got the proper information about breast cancer and the benefit of
treatment, patients sometimes started blaming themselves for being negligent and not seeking
medical care earlier. The reality was the lack of services precluded access to quality care. And
women who had sought care early often received misdiagnoses and ineffective treatment. A patient
who ultimately required a double mastectomy had sought care at different health facilities
previously. She had received a fibroadenoma diagnosis. The patient, from Delmas 3, Port-au-Prince
who moved to Mirebalais to seek treatment at rural University Hospital at the time of data collection
said:

“It’s been 10 years since my husband died, but it has been 11 years that I have been feeling
this problem in my breast. At first it used to cause me to itch. Five years after my husband
passed away I felt a ‘boul’(lump); it hurt me a lot... I used to shake my breast when it hurt
me. Now my ‘negligence’ caused me to lose both breasts. When I felt it was hurting me
very bad, I should have gone to the doctor’s office to see what was wrong with my breast!”

(Patient from Mirebalais)

This patient blamed herself, despite having sought care and having had an incorrect
diagnosis and poor followup.

Thus, misinformation about breast cancer signs, symptoms, and treatment, resulted in fears
among many participants.
**Fears of mastectomy (“Koupe tete”)**

Fear of mastectomy emerged from anecdotal reports about the outcomes of the surgical intervention. Mastectomy or “koupe tete” was thought to induce death rather than prolong or improve life. These fears had a negative impact on patients and caregivers. Many patients were reluctant to have a mastectomy and took time before accepting this treatment option. But some took the chance, bolstered by faith in God, and agreed to have it. Participants said:

“It has an impact on her because people kept telling her that whether or not she had surgery, she would die. They said to me not to let her have the operation because people with cancer just die. My mother is a Christian. She believes in God. She said that ‘The will of God would be done. I will not put everything people say in my head.’ She decided to have surgery.” (Caregiver for patient in Mirebalais)

"At the beginning I did not understand it. I believed that if someone was sick in her breast, whether or not she removed the breasts she would die. But, after participating in a seminar at Hospital Mirebalais, I had a better understanding of the disease. Now, I believe that my wife might not die." (Caregiver for patient from Fontamara, Port-au-Prince)

**Role of faith in patient treatment decision-making**

Faith played a key role in patient decision-making. Before receiving treatment, patients prayed, asking God if they should have surgery. They asked God to show signs that he wanted them to remove the breast. In contrast, some believed that acceptance of mastectomy indicated a lack of faith in God. A patient from Fontamara stated:

“I prayed and asked God to give me a sign to let me know whether I should remove the breast. One day, I dreamed of a pastor at my church, and in the dream he told me that he would have already taken me, but he had 2-3 other persons to take care of first. Another day, I dreamed that I removed the breast, and I could see the hole that remained after the surgery. After this dream, I told myself that God wanted to show me that I needed to get
surgery, and I decided to be operated. People told me that: I lack faith, and I have to believe that God can heal me.” (Patient from Fontamara, Port-au-Prince)

When treatment was finally available, patients were scared of having a mastectomy and waited for a final decision from God. Meanwhile others didn’t have a chance to get adequate diagnosis in order to plan for a mastectomy.

“God would have a solution to this disease”

After unsuccessful outcomes, some patients retained their faith and others developed a faith that had not existed before the pelerinaj. Their journey was informed by both the clinical and the spiritual. Participants tried to overcome their disease ordeal by seeking God. They hoped and trusted in God to do everything that was outside the reach of humans. They believed that God could heal their illness, when it was impossible for the doctors to do so. Yet, their breast healing was in good hands because they “left it in the hands of God.” Some patients who had even not noticed improvement at all hoped for healing from God, they “left the rest in the hands of God.” “Leave it with God” and “leave it in the hands of God” meant healing was possible. In the meantime “God would have a solution to this disease.” Others who noticed progress during treatment said: “he starts, I believe, he can finish.” The way that patients conceived of God increased their hope. It was not just a spiritual belief but a confidence that God, as a doctor, had the right treatment for their illness. Patients experienced strong belief thinking that they would be cured one day thanks to God.

“I lived upon God’s will, and constantly attended prayer sessions, and that’s where I heard about the Mirebalais hospital.” (Patient at Shada, Port-au-Prince)

“Well, my experience is that I sought care from doctors to doctors but I did not find any solution, I leave it with God. There is nothing God cannot do. I know I will go one day. I leave the rest in the hand of God.” (Patient at Debrosse, Port-au-Prince)
“I hope, I still hope God is thinking about me, I can find a solution, because he starts, I believe he can finish... I believe he can do everything.” (Patient at Debrosse, Port-au-Prince)

“Yes I believed it. I believed that God could help me heal.” (Patient at Canapé Vert), Port-au-Prince)

“When we arrived at Hospital E we found out that the breast problem was cancer. Now, as we are Christian, we went to pray to God, because God would have a solution to this disease. (Caregiver for patient at Fontamara, Port-au-Prince)

One patient described how her pelerinaj to Mont Carmel had resulted in reduced pain in the breast:

“I was going to the celebration of Mont Carmel (an annual feast) Mariaman in Petion-Ville, there, I have a friend and I told her how the breast was hurting me. I told her do you think its gas that is causing the pain. I started shaking it and saying ‘God I don’t understand,’ and it stopped hurting me. I asked God to do something for me and I returned home.” (Patient from Mirebalais)

Experience with “simen kontra” a natural intervention

“And besides doctor’s prescription, I always encouraged her (my mother) to drink lots of juice, mainly papaya, for I had heard that it is good for lungs, and since the lungs are close to the breast, I had advised her to eat papaya, watercress, and a medicine called “simen kontra” that they say is good for cancer, and I must say it is not easy to find.” (Caregiver for patient at Shada)

Part of the pelerinaj included exploration of alternative interventions. In addition to doctors’ care and prayers to God, patients and caregivers/akonpayatè agreed to use simen kontra. Simen kontra was the most common remedy that patients had tried during their pelerinaj to seek
treatment for breast cancer. Despite undergoing medical care, patients boiled simen kontra and took it as “tisane” (herbal tea). Simen kontra has the scientific name Henopodium. Henopodium is a leaf that Haitian people use for various ailments, and one of the remedies that people recommend to patients with breast cancer. They say: “It is good for cancer.” It is sold on the street. Some patients bought it from herbal tea sellers and others raised it at home. Its purchase represented an additional expenditure on top of patients’ daily expenses. “Simen kontra is rare” patients said.

Figure 1. Simen kontra from a patient’s yard

“I often hear people saying that it is good for cancer. Many people are looking at it crazily. They drink it a lot. I often see people who have this kind of disease taking it. They buy it. People say that it is good. Sometimes, I have someone who sometimes bring it to me. I used to dry it. Then boil it as a tea.“ (Patient at Debrosse, Port-au-Prince)

“No, I’m going to take it [my medicine], you know. The reason I didn’t take it this morning is because I boiled simen kontra. I drank it. It’s good for me because after I drink it, the pain in
my body eases. But, there is still acid in my body. When the acid reaches my throat I boil tea...

After I drink simen kontra I don’t feel pain in my body or the acid but I’m going to take my pills anyway because Doctor A told me not to skip any. I never skip my medication.” (Patient at Canapé Vert, Port-au-Prince)

Motivation to continue seeking healing for illness

Healing was the motivation for continued care seeking. Illness encompassed the feelings that patients experienced such as pain, itching or some signs that scared them (wounds, changes in breast, etc.) when they arrived at doctors’ office. When symptoms disappeared, patients thought that they had been cured. That was why many patients who had been misdiagnosed and mistreated waited longer to come back to see a doctor—they didn’t return until symptoms reemerged. In contrast, when symptoms persisted even after treatment, patients kept looking for healing, even if health providers said that the disease could not be cured. Palliative care was all that could be offered responsibly for late stage breast cancer patients, even though patients were still hoping for healing because they felt ill and needed healing. A provider explained:

“The biggest challenge is to get patients to understand the disease. Because when you explain to them that they have cancer, it seems like they (patients) don’t understand. Even when you have explained to them that the chemo won’t cure them and surgery is not an option, they still hope that they can have surgery and will be cured anyway.” (Doctor from Hospital K)

Supports that mitigate illness-related hardship

Role of doctors in supporting in patients’ illness

While some health workers delayed patient care, others played an important role in the recovery of the patients. They became more than providers; they were caregivers or caretakers in their attitudes. The way that these health workers took care of their patients represented another source of caregiving. When patients received what the perceived to be good care, the providers’
attitude played a key role in the treatment of the patients’ illness. It relieved their symptoms by making jokes, bringing joy and a smile to their lips. It made patients feel comfortable, at home. Patients revealed that counseling, the time spent in the company of health providers during chemotherapy sessions, and access to treatment were some of conditions that made them feel safe, comforted, and hopeful. It was much more than breast cancer treatment. Patients said:

“The other hospitals are different because they do not take your case into consideration. When you learn that you are sick, you are lost; you feel that you are going to die; you do not think about life. But since I discussed with Miss. X; it’s like she has given me some medication. I am very comforted.” (Patient at Clercine, Port-au-Prince)

“When I went to the Hospital K I felt at home. The service was so good when I started chemotherapy I didn’t want to move back to Gonaives. They made me laugh and I forgot that I was sick. You feel that you are living. For example Miss X and Miss Y are very polite and genial when they are taking care of us. They joked and talked with us. Even if you were in pain, you would feel better and your mood would be changed after chatting with them. Dr. A is a very good doctor who gave us a lot of encouragement.” (Patient from Gonaives)

“I can say it is a good hospital. I had spent a lot of money in doing exams, but when I listen to how much other people spent in seeking care for breast cancer, I know that I would not be able to afford care on my own. It is a good hospital that God has provided for us to take care of such a disease of us and help us overcome it... I pray and I ask God to take care of the doctors at Hospital K. I do not regret that I decided to go to there because I have found great services.” (Patient from Fontamara, Port-au-Prince)

**Role of akonpayatè caregiver supports as non-professionals in patients’ illness**

While patients felt comforted at the clinic, it was not enough. At home, on their way to clinic, they felt that they needed at least an akonpayatè. The akonpayatè provided support to the
extent possible. Akonpayatè/caregivers were friends, daughters, sons, people at church and husbands. The caregivers’ akonpayatè support was very important; they provided patients with food, money, and moral support. The caregivers/akonpayatè, as non-medical professionals, supported and “pushed” patients to seek care once they were informed about their breast problems. They also gave advice to patients and pushed them to seek care for their breast disease. akonpayatè/caregivers “encouraged” patients to continue seeking care after they noticed patients feeling discouraged, for all the reasons previously described, and “ease their suffering.” Akonpayatè were vigilant and participated actively, insisting that patients seek doctors. Caregivers were not only present at home. They often accompanied patients to appointments: when patients had made “10 back and forth trips to the hospital, they [akonpayatè] made the same number of trips,” unless there was no possibility to pay transportation for two people. They took part in the whole life of the patients, and, akonpayatè, husbands, and other family members participated in decision-making around care.

Participants expressed:

“I told her (my friend) she had to go to a hospital, but she didn’t want to go. She thought that God would help her. She is a real believer. Anyway, I forced her to go to the hospital.”
(Caregiver for patient at Canapé Vert, Port-au-Prince)

“Once I told him (my husband), he said that breast disease is very sensitive. He really pushed that I go see Dr. A. If it wasn’t for him, I would not have gone to the hospital.”
(Patient from Clercine, Port-au-Prince)

“My older sister accompanies me every time I go to my appointment at the hospital. If I go 10 times, she also has been 10 times. She paid her own fee for transportation. She also fed me when we got there.”
(Patient from Debrosse, Port-au-Prince)
The akonpayatè/caregivers in this study were also the Good Samaritans, who, even though they did not have much, shared what they had to support patients. Generally, the patients did not need to ask akonpayatè/caregivers for anything. The caregivers could sense the need, and knew when to act. Caregivers took care of their patients with love and compassion. They were involved in all steps of the medical processes in order to see their patients recover their health. Participants testified:

“She (my sister) has a husband, but sometimes she comes to my house, to wash clothes and also clean the house for me. She really supports me.” (Patient from Debrosse, Port-au-Prince)

“He (my husband) gives me all kind of help. Since he was informed that I am sick, he is constantly watching after what I am doing; he makes sure that I am not lifting any heavy materials, boxes. He does not even want me to cook…” (Patient from Fontamara, Port-au-Prince)

Some caregivers believe that God wanted them to take care of their friends and ill relatives. As non-professional caregivers, they had the sense to know that patients were psychologically affected and provided them with moral and psychological support. Patients did not need to tell providers that they needed money to get medical exams because some of them were aware of how serious breast cancer is and as one patient said “how important [it is] to take immediate action.” Caregivers acted like mothers who were taking care of their children, and they helped just as much as they possibly could. In addition to other support previously mentioned, they provided money, food, and also helped with bathing, household chores, and washing clothes. They did not want patients with breast disease to exert any physical effort. The main objective of the caregivers was to see their patients feel better and heal. Caregivers affirmed:

“She (my friend) went to the Dominican Republic where she couldn’t find any solution. Perhaps God wanted me to help her and when she arrived at my house, it was God who led her to talk to my daughter about her breast problem. Then we looked for a doctor to
perform the surgery. After that, she stayed home with me.” (Caregiver for patient from Gonaives)

“First of all, I gave her (my mother) financial support because I know that cancer is serious, and that you need to take immediate action. So I assisted her, and accompanied her (to the laboratories) for the tests. When I learned that she has breast cancer, I did not want to tell her; I started to provide her moral and psychological support.” (Caregiver for patient at Shada)

“Well, I did as much as I possibly could because after breast surgery, as I told you, she (my friend) didn’t live with her mother. I supported her as much as possible, like her mother would. When it was time to take a bath, I bathed her. I fed her like a baby. When she went to have the surgery, I did my best for her. I took the place of her mother because she was not with her and I did everything I could for her.” (Caregiver for patient from Saint Marc)

Akonpayatè were not defined by providing financial support to patients. They were non-health professionals who took care of the patients, by making sure that the patients follow doctors advice concerning diet, preparing food and feeding patients, insisting that patients take their medication as prescribed. The caregiver for the patient from Saint Marc explained:

“I do not give her money for her treatment. She makes some savings from her job salary. When she goes to the hospital, she only needs money for transportation and to pay to get her medical file to the doctors. My support is that I take care of her: I feed her, give her juice as requested by the doctor, give her milk. I have already prepared boiled milk for her; she has medication to put in it, but she is saying that it tastes like clay, blood. I insist that she drink it. That’s my support to her.” (Caregiver for patient from Saint Marc)

**Pain, psychological distress associated with patients’ illness**

The pain and psychological distress that patients experience impact the patients and their akonpayatè/caregivers. It is challenging to care for patients with chronic illness such as breast
cancer. Caregivers often made a major effort to provide care for patients. They suffered in silence, hiding their pain to give strength and courage to patients. However, sometimes witnessing the suffering of patients and experiencing their own inability to help the caregivers made them cry. Caregivers and patients were also affected by psychological factors such as stress. Fears, uncertainty, and other emotions overwhelmed the patients and their caregivers. Frequent questions about “what is going to happen” were painful topics. There were a lot of doubts about mortality behind this question that remained unanswered. Thinking about death generated anxiety and morbidity in caregivers. Women relatives who were caregivers even had the feeling of developing breast cancer. The experience was hard, painful and stressful as shown by these statements:

“I try not to cry in front of her so it does not affect her in return.” (Caregiver for patient from Saint Marc)

“And it is a lot of stress because, whenever I feel something, for example if I feel like scratching my breast, I am stressed because they said it is genetic. If a mother and another family relative had it, the daughter might have it too. So I am not feeling well. Whenever my phone rings, I am stressed. When she calls me, and tells me that she is in pain, I try to encourage her (my mother), but it is not a good feeling living with stress. You are always wondering what is going to happen. If she had died when this happened... but she is here suffering, and you cannot do much for her... the medication does not do much. It is a very tough experience. You are living with stress. I am constantly thinking. The consequence is that I am currently suffer from high blood pressure. It is a very, very hard experience.” Caregiver for (patient from Shada, Port-au-Prince)

“So seeing how big the breast was, this gave me lots of pain; I tried not to cry in front of
her, but I could feel that deep inside she was suffering. I tried to put myself in her shoes to feel how I would feel." (Caregiver for patient from Shada, Port-au-Prince)

Learning of their diagnosis was difficult. Patients who had not felt sick despite the signs and symptoms in the breast started feeling ill. Their disease seemed to progress much faster after getting a diagnosis. Going through all of the challenges and difficulties that the illness caused alone was not possible. Therefore, breast cancer patients declared that they needed an “akonpayatè” who not only accompanied them on the way to hospital but who also spent time with them.

**Discussion**

This study fills an important gap, illuminating the ruinous *pelerinaj* encountered by Haitian women with self-identified breast problems, who face a cascade of care in stark contrast to the ideal care pathway described in the introduction of this document. If they receive care, it is often too little and too late (Sharma, 2013), despite lengthy journeys to seek diagnosis and treatment, which often start at the first sign of a problem. In existing literature, delays are often attributed to “irrational” beliefs on the part of individuals who require care. This reflects a premium placed on individual responsibility rather than on structural constraints (Good, al. 2012). Our work found that the illness experience of women with breast cancer reflects a range of social, economic, and political forces that constrain access to health care. Implementation of an affordable, high-quality, linear and accessible cascade of care would subvert these structural barriers and have an enormous impact on the lived experiences of women with breast cancer in Haiti.

The term *pelerinaj* maintains some religious undertones of the concept of pilgrimage, and similarly denotes a singular focus. There are many important distinctions between the notion of “pilgrimage” and the concept of “*pelerinaj*” invoked here. In this paper the term *pelerinaj* is distinct as a local idiom that explains the process of an ineffective, nonlinear, frustrating search for a resource; rarely is it a voluntary journey. It also is different in that it is difficult to define when the *pelerinaj* started because patients did not think that seeking care for a breast lump would involve
journey. The patients in our study were forced to undertake the search for relief and treatment for their breast symptoms.

The present study documents the reported experiences of eight women with late diagnoses of breast cancer. These women experienced their *pelerinaj* as cycles, with repeated forays seeking appropriate care, which was denied by the presence of myriad obstacles and limited supportive structures for poor women with breast cancer in Haiti. They continued their search despite repeated disappointments. Believing that God can do what doctors cannot was the engine that motivated patients and gave them strength and courage to continue seeking care, despite structural barriers, and willingness to achieve this through any means. With courage and patience, patients still hoped that they would find healing.

Throughout the *pelerinaj*, study respondents often benefitted from the reliable presence of *akonpayatè*. In this study *akonpayatè* accompanied women along their journey, spent time with them at home and provided emotional, physical, logistical, and monetary support during their *pelerinaj*. Accompaniment has been identified as a key component of successful treatment of complex, chronic diseases (Lkhoyaali, Aitelhaj, & Errihani, 2014; Franke et al., 2008). In the Haitian culture we use the word “*akonpayatè*” (translated in French as *accompagnateur*) for a person who devotes time and life to give meaning to someone else's life with responsibility, compassion, concern and hope (Farmer, 2011). This is also a form of caregiving. Arthur Kleinman defines caregiving as a moral responsibility to and solidarity with people or patients with important health needs (2012). He called caregivers people who cared for sick people with sense of love and moral solidarity (Kleinman & Geest, 2009). Caregivers often experience substantial emotional and financial impacts (Hebert & Schulz, 2006); this was the case in the present study. Nevertheless, *akonpayatè* hid their suffering to give courage and strength to the ill person. A strengthened cascade of health services would support both the patient and her caregivers/ *akonpayatè*, acknowledging the role of the latter. *Akonpayatè* can still provide moral, social, financial and medical support that
a patient needs during the course of care. An ideal system would help akonpayatè to provide this care without requiring that they do it all, alone without additional institutional support.

The women in our study had traveled everywhere within Haiti and even abroad to seek care. In Haiti, patients pay for care out of pocket, in cash, at the time of service (Alfred, 2007). Yet, 60% of the population lives under the poverty line, US$2.44/day, (World Bank, 2015) which limits access to all forms of health care including oncology and preventive care. So women had to save little by little the money needed until they collected the whole amount for the required services. Sometimes patients left themselves and their family hungry to save money for health care and transportation. This burden added to the pain caused by the breast cancer. Informal discussions with a provider indicated that, even when care is received at the public hospital, patients are required to purchase chemotherapy at a pharmacy and bring it to the hospital for administration at each chemo session. Frequently, patients did not receive treatment due to lack of money. Even though patients received support from caregivers and other people, it was not enough to afford the health service costs.

Oncology care is expensive; in a market-based system, the cost of such care is well beyond patients’ means. Many of the patients in this study gained their livelihoods by selling things on the street. Some had to choose between financial stability and their health needs. Lack of money held patients back from accessing timely diagnosis and treatment needed. Patients could not perform physical work to meet their needs. As a result, as many of the patients faced chronic poverty, and most of them struggled to find money to pay for consultation fees, transportation fees, and medical tests. Spending resources on unsatisfactory health care services impoverished not only patients but also the akonpayatè/caregivers who experienced financial hardship during this journey.

This is a manifestation of the inequality in Haiti and globally: wealthier individuals may survive with cancer while the poor die after a painful battle with the same disease (Knaul, Gralow, Atun, Bhadelia, 2012). The extremely limited access of the Haitian population to health care services and oncological care is a form of structural violence, reflecting huge gaps in society and
making effective therapy available to only a limited number of patients (Farmer, 2010). The provision of free care at a few sites in the country is not sufficient to address this gap. Because of the long pelerinaj, even for some of those fortunate enough to reach the provider of free care in Mirebalais, sadly, it was too late for surgical intervention: their breast cancer had already spread to other organs (metastases) while seeking for care elsewhere. This can affect the morale of medical providers as well. Good and colleagues extensively studied oncologists and described the “disempowering” and “overwhelming” experience for doctors who witnessed countless deaths due to HIV disease in Kenya (Good, Mwaikambo, Amayo, & Machoki, 1999).

A more equitable system of national insurance might prevent patients from having to make choices between work and health care or between pain relief and diagnostic tests. Pauly and colleagues found that national insurance can avoid substantial out-of-pocket expenditures for care (2006). Patients should not have to rely on support from family, neighbors or friends to access health care, which is a human right that should be guaranteed by the State.

In the experience of study respondents, often substantial fees were paid for interventions that were not supported by evidence, not guided by any national standard, and not delivered by providers subject to regulation. Existing structures harmed women by making them pay out of pocket for questionable care that delayed the search for appropriate care.

Structural barriers resulted in the absence of a range of services that could accelerate diagnosis and access to appropriate treatment. These include health campaigns that could raise awareness about information on self-detection of a lump, the significance of breast signs and symptoms, and preventive care that could avoid delay of health care, even after women notice breast changes. The structure of the public sector reflects little appreciation for the social determinants of the disease (Farmer, 2010). Health care in Haiti focuses disproportionately on curative care or treatment—with little attention to prevention—for diseases such as malaria, diarrhea, respiratory infections AIDS, etc (Knaul et al., 2012; Farmer, 2010; Hicks, 2011). This is despite documentation of an increasing burden of non-infectious diseases in resource-poor settings.
Chronic diseases are often considered unaddressable or not cost-effective to address in settings such as Haiti which continue to suffer a high toll from treatable and curable infectious diseases (Murray, 2015; Murray & al., 2007). And research on the subject is even more absent than care. Thus, the health system fails to provide information to women about alarming signs and symptoms of breast cancer through health promotion and prevention program. Indeed, having proper information about breast cancer is essential for patients to be aware about the benefits of seeking care for breast lumps. And knowing where to go is another important type of information that patients need in order to seek care early for breast disease. Yet, the Haitian health structure is not linear. Clinics, pharmacies, and laboratories are often located in different places. Despite the cost, women take multiple trips, often characterized by repeated visits to the same unsatisfactory venues to access medical consultation, medical tests, and drugs. A 2008 study found that lack of an integrated system of care, for instance when health care is delivered in many small practices, can contribute to a perilous journey through a health care system and makes it challenging to coordinate proper care (Bodenheimer, 2008). The journey of Haitian breast care patients is the product of an unorganized health system where access to care is limited and the quality of care is a serious challenge for the health sector. As noted in other studies, care coordination is practically impossible without a solid base of primary care in the health care system (Smith, Nicol, Devereux, & Cornbleet, 1999).

There is no regulation to control the services that the health markets are providing to patients. In the absence of regulation, providers were free to prescribe expensive solutions for which there was no evidence base, without fear of consequences. Several women reported being asked to pay for vaccines that would “prevent breast cancer.”

Consequently, our respondents spent a lot of money in inappropriate treatment, resulting in further impoverishment. Such questionable care should be regulated. Law could be an effective instrument for safeguarding the public’s health (Gostin & Mary, 2008). Regulations should both prohibit fraudulent services and promote evidence-based services. Guidelines should be developed
to prevent harm to sick people and promote health (Gostin & Mary, 2008). These should be implemented in public and private settings. Training in the protocols and other opportunities for continuing education for providers may enhance the speed and quality of breast cancer diagnosis and treatment. A study conducted in the UK found that significant delays in breast cancer diagnosis were caused by providers’ medical malpractice, radiological misinterpretation and pathological error (Barber et al., 2004). In our study, lack of providers’ skills and training resulted in poor health care management, misdiagnosis, and distrust in the diagnosis of such doctors. This delayed patients from accessing breast cancer diagnosis.

A study conducted in 2010 found that the Ministry of Health does not produce national, hospital or primary care standard treatment guidelines (STG) for major conditions. (Ministry of Public Health and Population of Haiti, State University of Haiti-Faculty of Medicine and Pharmacy/School of Pharmacy University of Carolina, San Francisco/WHO collaborating Center for Pharmaceutical Research and Sciences Policy, Pan American Health Organization, World Health Organization, 2010), and each health facility has its own protocol for care delivery—some more effective than others. This lack of standardization resulted in a wide range of care: some patients had surgery (lumpectomy), but without any diagnosis. The perceived poor quality of the health system resulted in limited confidence in solutions that might be provided there. Trust in the system or providers can be jeopardized, further creating obstacles to screening and care. Lack of trust of the providers was identified as a major barrier to community colorectal cancer screening in the US (Lasser, Ayanian, Good, 2008). In the present study, mistrust opened the door to impressions among respondents, which were based on anecdotal experiences others had related to study participants. For example our study participants reported reluctance to pursue mastectomy as treatment in light of reports that mastectomy—rather than inadequate or delayed breast cancer treatment—caused death.

In this study, the accumulated information (interviews, field notes, etc.) indicates that the perpetual pelerinaj—the repeated cycles without care—is a consequence of fragmented,
unregulated health care delivery that makes patients willing to accept other health services and alternative and unproven treatments such as Simen Kontra, prayers, and vaccines.

Study participants experienced their breast cancer disease, which starts as a specific and localized pathology, as a feeling of illness, something generalized throughout the their bodies (Kleinman, 1988) and lives. Patients’ illness extends through stress, depression, and loss of weight, appetite and finally metastasis. This process impeded them from staying physically active and affected their morale. This has previously been described as social suffering (Kellehear, 2009; Gillespie, 2009). It is a social phenomenon that is caused by social institutions, economic and political hardships (Kleinman, Das, & Lock, 1997; Das, Kleinman, Locke, Ramphele, & Renolds, 2001; Farmer, 2003). These authors argue that poor people are subject to pain and suffering due to their social position. Health inequality reinforces the disparities in social position: wealthy people in rich countries more often have the possibility to live healthy and productive lives after cancer (Knaul et al., 2012). The women in our study, with the same human characteristics and diagnosis as their counterparts elsewhere, became dependent, without energy or capacity to move forward.

Limitations
This study has several limitations. First, there was political uprising by the in the country during the study. This political situation limited the time the researcher was able to spend with participants and, consequently, data collection. Longer, more detailed narratives may have been possible if this constraint had not occurred. Additionally, we selected participants from only one hospital in rural Haiti, with a relatively small sample of patients and caregivers. However, because it is one of very few studies conducted to-date on breast cancer patients’ experiences in Haiti, this paper adds important knowledge that can be used to inform evidence-based health system improvements.
Conclusion

Interviews with women suffering from advanced breast cancer revealed a number of structural factors that compromised timely access to high quality, curative care. These barriers can be summarized as lack of access to adequate preventive, diagnostic, and curative care; financial constraints; and failure to appropriately train, equip, and regulate providers. These factors ultimately led to delays in breast cancer diagnoses, and overall poor prognoses for the women in this study.

The impact of these delays on women’s lives was nothing short of devastating. Women traveled long distances over extended periods of time, engaging in an extended *pelerinaj*, as they sought care and healing for their illness. This circuitous, care-seeking journey came at a high price. Patients paid large sums for ineffective treatments, and were often forced to abandon work and responsibilities within the home in an attempt to pursue care for their breast symptoms. Despite incredible effort to reach health facilities, and the extensive search for proper diagnosis and treatment, the women who participated in our study were not able to access needed care on time, and their journeys often ended with metastasis.

It is essential a national breast cancer program be established to avoid the lengthy *pelerinaj* that left study respondents impoverished “panicked with the illness” and “worried for the sake of their children.” This infinite *pelerinaj* had social implications that put undue stress the life of breast cancer patients as well as their *akonpayatè*/caregivers and engendered human suffering.

This paper adds important knowledge that can be used to inform evidence-based health system improvements.
**Recommendation**

A National Breast Cancer Early Detection Program in Haiti is essential to reduce suffering and the number of premature deaths from a disease that is curable. The program should be developed in such a way that it addresses barriers in health accessibility, while promoting appropriate screening, widespread delivery of educational information on breast cancer signs and symptoms, and the promotion of breast cancer services.

This program could be established through a partnership between NGOs already providing breast cancer care in the country and the public-private health sectors, with the help of community participation, including the akonpayatè model in Haiti. This could build on the structures for community participation already set up through community health workers in many developing countries for such communicable diseases such as HIV/AIDS (Bhutta, Lassi, Pariyo, & Huicho, 2009).

Patients in our study in the course of the pelerinaj have identified the social and public health problems that impeded them from accessing proper treatment. For some women, having good care closer to home would avoid long distance traveling and additional spending in transportation when seeking care. And, they proposed recommendations:

"So, I am very happy if there are decisions to help the patients and prevent them from going to Hospital K, which will avoid spending money on transportation. So, I would be very happy if there could be a place nearby where we could go for appointments. It would be in our interests; because it is very difficult for me to go over there.” (Patient from Fontamara, Port-au-Prince)

“Things need to change in the country. We need to have good medication available, and also have doctors available to take care of the patients to avoid them from travelling that far to get care and treatment.” (Patient from Shada, Port-au-Prince)
References


http://www.globalsecurity.org/military/world/haiti/health.htm


http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2206003/


