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# The Different Perceptions of Breast Cancer in Post-Conflict Northern Uganda

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*SIT Study Abroad*

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The Different Perceptions of Breast Cancer in Post-Conflict Northern Uganda

An ISP (Independent Study Project) for SIT Uganda: Post-Conflict Transformation.

By Karen Im

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School of International Training

13 December 2011

## Dedication

This project is dedicated to my mom who taught me much of what I know about character, perseverance, and hope through her journey with breast cancer.

### **Abstract**

**Objective:** To assess breast cancer perceptions in Northern Uganda for the purpose of informing necessary cancer initiatives.

**Methods:** Breast cancer patients and the Gulu District community development officer participated in semi-structured interviews. Interviews were analyzed using qualitative data analysis.

**Results:** The concept of cancer is relatively new in Northern Uganda. In conjunction with a lack of understanding and competing priorities, many women are often diagnosed in late and advanced stages. Most women go to the hospital when they feel distinctive pain in the body instead of getting regular check-ups.

**Conclusions:** Educating people on needs for more proactive health-seeking behavior could have a significant impact on cancer control in this community.

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## Introduction/Justification

Due to recent increases in breast cancer prevalence, the general public in Northern Uganda knows little about the new phenomenon and how to handle the situation. According to health experts “cancer kills more people in Uganda compared to Tuberculosis, Malaria and HIV/AIDS combined” (“Cancer killing...”). Moreover, the World Health Organization announced that breast cancer incidence is the highest cancer in women worldwide. This trend is disturbing for developing countries where breast cancer numbers are rising due to “increase in life expectancy, urbanization and adoption of Western lifestyles” (WHO). Even more worrisome is that many Acholi who accept Western lifestyle changes are not aware of the risks, prevention, and treatment for breast cancer. Many people may wait to go to the hospital long after the first sign of breast cancer, in which case, it is likely too late for any type of effective treatment. The inability for doctors to treat progressed cancers could cause patients not to trust the doctors and health institutions and cause patients to turn to traditional medicine and healers instead. This potential trend would perpetuate traditional beliefs and dependence on traditional healers that many Acholi already have.

Dealing with newer Western diseases, such as breast cancer, in a region where there is a cultural disconnect brings many challenges. Some are not fully able to understand the disease and know treatment measures for breast cancer, much less, go to doctors for screening. This study is aimed at understanding and exploring people's perceptions of breast cancer and health-seeking behavior. Studying perceptions of breast cancer in Gulu after the conflict is important for understanding the cultural challenges that hinder people and patients from pursuing effective breast cancer prevention methods and treatment so that those issues may be addressed in the community.

**Objective**

The objective of this research is to find out the community's perceptions and understanding of breast cancer. As people's perceptions of illness influences their behavior, knowledge of the perceptions can help design more effective programs to inform, educate, and even prevent the growing effects of breast cancer.

## **Background**

During and even after the 23 year long conflict, the international community placed much attention on Northern Uganda. This resulted in a flood of international organizations, people, and influence. Consequently, the influx subjected the Acholi to Westernization and globalization, which changed traditional perspectives on the world as well as lifestyles. Due to Westernization, the transformed behaviors of daily life and urban development of the Northern Uganda significantly increased the risk factors for cancers like breast cancer.

#### *Major Cancer Risk Factors*

According to the World Health Organization (WHO), there are ways to lower the risk factors of cancer and even prevent cancer through healthy lifestyle choices. Studies from WHO show that “at least one-third of all cancer cases are preventable.” Physical inactivity and unhealthy dietary practices are major risks for cancer. “Diets high in fruits and vegetables may have a protective effect against many cancers” (WHO). There is also a positive correlation to increased alcohol use and prevalence of breast cancer. Research shows that women in developed countries are more susceptible to breast cancer. Doctors speculate that Western trends to conceive fewer children later in life leaves women at risk due to high numbers of undifferentiated cells<sup>1</sup> in the breast. These cells are then more vulnerable to gene mutations and outside factors that could transform the cells into cancerous cells. Being able to make healthy lifestyle choices is an important determinant for fighting against breast cancer.

However, there are also factors outside of individuals which may affect cancer risks. “Infectious agents are a responsible for almost 22% of cancer deaths in the developing world” (WHO). In cases specifically for breast cancer, Dr. David Kitara Lagoro, the Head of the Surgery Department at Gulu University Referral Hospital, noted cases of patients operated on to

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<sup>1</sup> Undifferentiated cells- A cell that has not yet developed into a specialized cell type; stem cell.

remove benign tumors caused by fibroadenoma<sup>2</sup>. Some women returned to the hospital after their wounds became infected and later biopsies showed the emergence of breast cancer.

Another factor includes environmental pollution. “Environmental pollution of air, water and soil with carcinogenic chemicals accounts for 1–4% of cancers” (IARC/WHO, 2003). Exposure to carcinogens may increase via contamination of food and water and use of domestic coal fires.

#### *Increased Risks Factors in Northern Uganda During the Conflict*

International NGOs began to have significant presence in Northern Uganda through the IDP (Internally Displaced Persons) camps. The war between Kony’s Lord’s Resistance Army and Museveni’s government caused the displacement of nearly 2 million citizens in Uganda. Around 80% of the Acholi population were IDPs, and up to 85% of these IDPs lived in government organized camps where the Ugandan army reportedly provided protection from the rebel group (Roberts). “As a result, most of the population of northern Uganda [was] now internally displaced, concentrated in ‘protected villages’ with extremely limited access to food and water and entirely dependent on food distribution through the World Food Programme” (Vikki). Foreign aid, like the World Food Programme, provided the camps with rations for basic necessities. The basic needs provided by the aid organizations had a great affect on lifestyle and especially dietary changes.

These dietary changes affected many parts of traditional Acholi life that greatly increased the risk factors for cancers. People were unable to farm and were dependent on aid. The younger generation lost opportunities to learn valuable farming skills from their parents. The packaged foods provided by foreigners taught IDPs the habits of using less healthy, processed ingredients.

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<sup>2</sup> Fibroadenoma- benign tumor of the breast made up of breast gland tissue and tissue that helps support the breast gland tissue.

“Traditionally, cereals, root and tubers, legumes, vegetables, fruits, meats and seasonal delicacies such as white ants made up the dietary system in Northern Uganda. With subsequent food aid interventions by WFP and International Non-governmental organizations (INGOs) agencies; such as ACDI/VOCA, Catholic Relief Services, Save the Children, Mercy Corps and World Vision, the diet systems of the local population greatly changed from a rich and diverse diet, to calculated food rations that include mainly maize, sorghum, beans, peas and vegetable oil enriched with Vitamin A... Cereals (maize, wheat and rice) constituted over 80% of food aid shipments into Uganda. The non-cereals (pulses, oils and fats and meat and fish) formed a smaller proportion (approximately 20 %) of food aid to Uganda” (Lawrence).

A diet once full of fresh foods now consisted of dried foods that were usually cooked in oils.

Long-term confinement in IDP camps also prevented many from being able to move physically. Men and women who once used their energy to farm lands and cook food were now limited to very small spaces in camp huts. In the camps, women used less energy to prepare food since aid organizations provided the hand-outs and there was no need for women to go out into the fields to gather crops.

#### *Increased Risks Factors in Northern Uganda After the Conflict*

After the 2006 Juba peace talks, there was relative peace in Northern Uganda as Kony fled to Sudan and the Democratic of Congo. The government did not need to force people to stay in the IDP camps anymore. Those who were able were allowed to return to their homes. Despite returning, many may not have been able to continue with the same lifestyles from before the conflict.

After the conflict a second wave of international NGOs perpetuated and increased Western influence on Northern Uganda that had begun in the camps. People from the IDP camps continued to prepare and consume the same foods. The focus on development brought rapid urbanization of towns. As Dr. David Kitara Lagoro mentioned, just a decade ago, very few in Northern Uganda owned cell phones but today, even an old lady in the remotest village is found with one. Similar to the Western world, there are problems with lack of exercise as more Acholi enter into white collar and service jobs. Appliances like the television and computer also promotes sedentary living. Unintentionally, the effects and the aftermath of the conflict have permanently changed Acholi culture and lifestyle.

Rapid cultural and behavioral changes expose many Northern Ugandans to increased risk factors for breast cancer. More educated women have fewer children later. Safer hygiene education and practices plays a role in longer life-expectancy, however, increasing age correlates to increased cancer risks due to the deteriorating effects of age on cells' proper function and replication.

There are urgent needs to raise awareness about breast cancer and to provide better access to screening and treatment. Breast cancer incidence in Uganda has more than doubled since the 1960s (Gwakaya). In Uganda, the five- year survival rate is 32% while the five- year survival rate in North America is more than 80% (Uganda Cancer & WHO). The survival rate in Uganda is low because 95% of breast cancer cases are already at an advanced stage when diagnosed ("Cancer in Uganda"). Many in Northern Uganda are not able to afford a visit to the hospital and so are left with no choice. The low survival rate may also be attributed to many who still depend on traditional healers. Many may have only a cultural understanding of the disease

which greatly impedes the individual from medical treatment resulting in fatal consequences (Nuwaha).

## **Methodology**

### *Research Methods*

Qualitative data was collected using semi-structured interviews of breast cancer patients admitted or once admitted in Gulu University Hospital and St.Mary Hospital: Lacor Campus and of the Gulu District community development officer. Of the breast cancer patients, one was a nurse, another was a nun who works in the hospital and the remaining four breast cancer patients were primarily home makers.

Patients admitted in the hospitals were found by visiting the hospitals' surgery ward daily for about one week. Doctors, nurses, and health workers were asked if there were any breast cancer patients admitted in the wards. Once found, subjects were asked for participation in the research. Subjects were informed of the research, risks, and what kind of questions they will be asked. Subjects were informed that they are free to not answer any questions that are too difficult or make them feel uncomfortable. Qualitative data was collected by asking questions related to the topic. Questions may be found in appendix A. Persons willing to translate were used to help interpret the interviews. Subjects were given a half kilogram bag of sugar for their participation.

#### *Why I used these methods*

I chose to do semi-structured interviews for sensitivity and practicality. About 95% of breast cancer cases in Uganda are already in advanced stages at diagnosis making survival within a 5 year period unlikely ("Cancer in Uganda"). Knowing the likelihood of death, patients may have found difficulty in discussing their illness in groups. Although focus groups could facilitate interesting dialogue about breast cancer perceptions in individuals and in the community, focus groups would not have been practical given the short ISP period.

Breast cancer patients were difficult to locate in the hospitals. There were very few cancer patients in the medicine ward where health workers administer chemotherapy. Many breast cancer patients do not receive chemotherapy treatment or radiation due to late diagnoses or the lack of funds. Overcrowding pressures hospitals to release patients quickly who have received mastectomies to recover at home. I was unable to obtain knowledge for patients scheduled for mastectomies or patient contact information, so I could only visit the hospitals in hopes of finding a breast cancer patient.

Due to the relative lack of awareness in Northern Uganda, I chose to interview subjects who were directly affected by the disease. The patients would have more insight about perceptions before and after their diagnosis. They also would be knowledgeable about what people in their communities thought about breast cancer. I also chose to speak with the Gulu District community development officer to get more insight about the community as a whole. Since breast cancer had been a growing issue in Northern Uganda, I felt that the community development officer would understand how people in the community were handling the situation.

### *Challenges/Obstacles*

At the start, knowing where to look for breast cancer patients, specifically, in the hospital was challenging. Many nurses and doctors continually referred me to different wards and no one seemed to be able to direct me to the right place. I was unable to speak with any breast cancer patients for the first few days. The hospitals also did not have organized records of patients admitted. With no record system, health workers were unable to know about breast cancer cases unless a doctor or nurse had directly interacted with a breast cancer patient.

Due to the sporadic nature of finding breast cancer patients and having interviews, I was unable to depend on only one translator. I sought help from volunteers in close physical proximity to the patient. Interpreters were family members, other patients, and nurses. It was difficult to know if the translators were interpreting questions and answers accurately. Several times, the subject would give long answers and the translator would summarize the responses.

Some patients who had agreed to the interview were unwilling to answer the questions and seemed to not want to talk about their disease. One particular patient gave very short and abrupt answers. During the interview she decided that she “did not want to think about [the

disease].” Encounters with unwilling subjects made progress difficult especially given the few numbers of breast cancer patients found in the hospital.

### *Effectiveness of Methods/Lessons Learned*

Despite the challenges at the start, the methods were effective in finding breast cancer patients and collecting data. After interviewing one patient, asking that patient about other breast cancer patients proved helpful. Although tedious, asking each hospital worker if they knew any co-workers who may have or have had breast cancer was effective. These methods created a snowball effect where I was able to start with one interview and get connected with several other contacts.

I also learned the importance of flexibility in the interviews. Some subjects were not able to understand the questions and often began going on tangents. Follow-up questions were important for responses that were vague and did not answer the question fully.

## **Findings**

### *Individual Perceptions*

There were recurring themes throughout the interviews showing how individuals understood and responded to breast cancer. Patients shared their opinions about the possible causes and prevention methods for breast cancer. Views on proper health-seeking behaviors and priorities also gave insights on people’s comprehension of breast cancer.

Every breast cancer patient interviewed either did not know or shared different thoughts about what may have caused their illness. One teaching member at Gulu University’s nursing school was unsure of the direct cause. Being HIV+, she deduced that HIV had predisposed her to have cancer. Another woman who had lived in an IDP camp reasoned that “these NGO’s

thing are causing cancer,” specifically referring to the oil given to cook the food. Many women seemed unable to give reasons saying that “it came by itself.” Another patient in her 60s was unwilling to answer questions about what may have caused the disease. Even though she had agreed to participate in the interview, she gave short and hasty answers, ultimately deciding that “I don’t think about it. I don’t want to.” In one interview, a patient mentioned people from her village may believe that cancer comes from bewitched spirits. These curses may have been sent by colleagues; however, none of the interviewees applied this belief in spirits to themselves but always referring to others.

Consequently, having no definitive explanations for the cause of cancer would elicit differing perceptions on prevention methods. Individuals believed that avoiding the occurrences they perceived to have caused cancer would be adequate. For example, the teaching nurse advised to protect oneself from HIV while the woman who had lived in the camp suggested that living outside of the camps would have prevented breast cancer. There were also several women who believed that receiving tablets and injections early on would have prevented the onset and growth of the tumors. Others expressed that prevention was impossible because they had not even heard or known about breast cancer before their diagnosis.

The patients’ health-seeking behaviors showed a lack of understanding about the disease. All the breast cancer patients did not go to the hospital until there was pain. Even the experienced nurse assumed that the lumps came from irritated axillary lymph nodes along the side of her breast and believed the lumps would eventually disappear. It was not until a year after she first noticed the lumps that she went for a biopsy. Another woman did not consult doctors even when one breast had swelled twice the size of the other. She waited until pus began to come out from white lumps that had also grown.

Once patients are finally diagnosed with breast cancer, many women may also have competing priorities that delay treatment even more. For instance, the teaching nurse worried about getting treatment not only due to the costs but also because she knew the treatment process would have been very grueling. Recovery required much time off of work and she wanted to “keep working and avoid a long recovery period.” She was the sole provider of a family of 6 children. So the nurse was diagnosed with breast cancer a year after she noticed the lumps and also waited until the end of the school term to start treatment.

Another complication that makes treatment difficult originates from the limited capacity in health facilities. According to the community development officer of Gulu, many doctors in Northern Uganda refer their patients far away to hospitals in Kampala. A St. Mary’s Hospital nurse working in the medicine ward explained how different hospitals offer different treatments for breast cancer. Even though many hospitals in Northern Uganda are able to perform mastectomies and other minor surgeries, St. Mary’s Hospital offers chemotherapy while the hospital in Mulago offers radiotherapy.

When asked when they would be cured and able to go home, most patients in this study said their progress would wholly depend on the doctor. No one mentioned any possibility of death. One patient seemed to completely trust the doctor’s and the drugs’ abilities to cure the disease. She believed that as long as she obeyed the treatment directions, everything would be alright. Even a patient receiving palliative care expressed her hope in the doctors.

### *Community Perceptions*

An interview the Gulu District’s community development officer, Okech Goretti, affirmed and explained the individual breast cancer perceptions in the context of the community. There have been many changes in lifestyle, food, and environment. Goretti mostly pointed to the

fact that “life is not as organic as before.” However, cancer is still a “new” disease. Many people do not understand cancer because it comes in so many forms in the body. There is not a consistent occurrence and even treatment for all cancers. Individuals still have many different stories about breast cancer because “the whole concept is totally new.” There have been few programs that have thoroughly informed people of breast cancer. According to Goretti, people need in-depth desensitization to be able to understand the complexity of the disease and for early detection and treatment.

### *Other Findings*

While speaking with Dr. David Kitara, the research advisor, an interesting dimension for the topic emerged. Research points to a definite correlation between breast cancer risk and age at first birth. Women who wait to have children or do not have children at all have increased chances for breast cancer. Due to the dominant Catholic culture in Northern Uganda, there are many nuns who devote their entire lives to serving the church. According to prior research, since nuns do not give birth, there should be higher prevalence of breast cancer among nuns than the general population.

Obtaining statistics comparing breast cancer frequency in the two populations was difficult due to the qualitative nature of the project. However, I spoke with a nun who also worked in the hospital. She knew of one other nun who had recently died from breast cancer and one who was going through treatment in the Opit District. There were also two other nuns who had died from other cancers. Although the nun working in the hospital did not feel that breast cancer is more prevalent among nuns than the general population, it is an interesting aspect of breast cancer study in Northern Uganda.

I was able to have an interview with one nun who was receiving treatment in Opit. Her perception of breast cancer was similar to the other patients. She did not have any opinions about what may have caused that cancer. Before her diagnosis, she had known about breast cancer, but there was never any cancer in her family. Like the other patients, the nun trusted that strict adherence to the treatment prescribed by the doctor would be the only way to survive.

#### *Comparison with Other Researchers' Findings*

Although there is not much study done on breast cancer perceptions specifically in Northern Uganda, there were similar findings in studies done primarily in low-income neighborhoods in the United States. In one study, "knowledge of breast cancer was poor among the women... Moreover, the women in the sample did not perceive breast cancer as a fatal disease" (McDonald). Almost all the breast cancer patients in this study had little knowledge of the disease before diagnosis. Some had heard of the disease over the radio or from a neighbor who had been diagnosed but had very little understanding. Women seemed fearful not necessarily because of the cancer diagnosis but more because they were not sure how breast cancer would affect them.

According to other studies, the level of education was a significant determining factor in an individual's cancer perception (Price). "Patients with little secondary education were significantly more likely to underestimate the seriousness of their condition" (Mackillop). About half of the breast cancer patients in Gulu were illiterate and only able to communicate in Luo. Lack of education hinders an individual from fully understanding breast cancer, much less its urgency for medical attention.

Contrarily, different studies have also shown dissimilar findings. Research done on the African-American community revealed misperceptions of the nature of cancer and its treatment.

“Groups discussed the pervasive fear and stigma associated with cancer... and were also acutely concerned about community distrust of the healthcare system” (Shankar). In contrast, the Acholi patients seemed to show a lack of knowledge, and therefore little fear and stigma associated with breast cancer. Also, the breast cancer patients generally had complete trust in the doctors and the healthcare system.

## **Recommendations/Personal Opinions**

### *Recommendations*

The most important initiative for the increasing breast cancer prevalence in Northern Uganda is desensitization. There needs to be reforms in traditional health-seeking behaviors. The survival rate of breast cancer cases is so slow largely due to late diagnoses. More programs need to include education on early breast cancer detection. Education in early detection gives opportunities to treat the cancer before reaching advanced stages where treatment is mainly palliative. Education could also help create a culture where women get regular and routine check-ups as opposed to going to the hospital for pain.

Currently, the most rampant cancer in Ugandan women is cervical cancer so there are relatively many programs offering free screenings. Instead of performing screenings solely for cervical cancer, programs could carry out breast cancer examinations simultaneously. It would be beneficial to also teach women to perform frequent self-examinations.

Due to the array of breast cancer risk factors, the community should educate the population about the many risks and promote healthier lifestyles. Since many students may not reach the university level, information on cancer risks may be added in primary schools' curriculum. Many educated women who delay their childbearing years should know and understand the risks. Frequent screenings are necessary especially for women choosing life as a nun. Since Catholicism is the dominant religion in Northern Uganda, it could be helpful to

initiate more research on the breast cancer for nuns. This research could support or disprove the correlation between breast cancer and age at first birth.

### *Opinions on the Project*

I was surprised that more patients did not talk about traditional healers. I attempted to bring up the topic during the interviews but the women never discussed the beliefs in reference to themselves. I expected patients from the village to have strong views or experiences on traditional healing practices. However, every patient agreed that belief in spirits exists but disregarded any personal relevance. It is difficult to measure the reliance on spirits because individuals may lie. People could feel uncomfortable sharing these views especially since they go against Christianity. Others may not actively pursue traditional healing methods, but may resort to the practices if nothing else seems to be working.

From the interviews, the patients seemed that they wholly trusted in western medicine. Their trust is surprising because most breast cancer cases are incurable due to late detection. So it seemed reasonable to deduce many patients may turn to western medicine at first but eventually go to traditional medicine.

### *Limitations:*

There were several challenging areas in the project that may have had an effect on the findings. Due to the time restraint, it was difficult to obtain a completely accurate perception from the community. I interviewed only breast cancer patients who were women even though there are men who also suffer from breast cancer. The language barrier was also an issue.

### *Future Research:*

Given more time and resources, it would be interesting to gain perceptions from people who do not have breast cancer. All the interviewees also were receiving treatment from hospitals close to the town. Going to the villages to collect data from people with breast cancer would provide a more complete picture of the perceptions.

Another potential area for future research would involve breast cancer patterns among nuns. The research could look at the prevalence of breast cancer among nuns in different parts of the world and in different times. This study could show how much childbearing actually affects breast cancer occurrence.

## **Conclusion**

Cancer is a relatively new concept in Northern Uganda. The subjects in this study demonstrate misconceptions on ideas of acceptable health-seeking behavior. Individuals seem to measure health by the level of pain. Due to competing priorities, like providing for the family, people delay hospital visits until the pain becomes too distracting from daily activities. These breast cancer detection behaviors directly affect chances of survival. Educating people on needs for more proactive health-seeking behavior could have a significant impact on cancer control in this community.

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### **Interviewees' Information**

1. Name: Molly Acayo

Age: mid 50s

Occupation: Nurse, Teaching director at Gulu Clinical Nursing School

Children? Yes,

2. Name: Margret Laker

Age: 47

Occupation: house wife

Children? yes

3. Name: Aleti Ajiba

Age: 60

Occupation: house wife

Children? yes

4. Name: Atoo Marcellina

Age: 51

Occupation: house wife

Children? yes

5. Name: Okech Goretti

Age: late 30s

Occupation: Community Development Officer

Children? unknown

6. Name: Magret Aceng

Age: 32

Occupation: house wife

Children? yes

7. Name: Sister Virginia

Age: mid 50s

Occupation: nun

Children? no

## Interview Write-Ups

**Sister Molly Acayo**

Mid 50s,

We sat in a room in the dental ward of Gulu university referral hospital. The room was sanctioned off only by thin curtains. During the first half of the interview, a patient sat in the chair waiting to be treated. Later, Molly directed him to the next room to start treatment. Other nurses came to sit and listen in on what was going on.

We started with greetings. She did not want her voice to be recorded. She directed me to take notes while she spoke.

She is really involved. She teaches nurses and clinical officers in the school. She travels all around Uganda to train other health workers.

- Began by sharing her story. She described how she had found lumps on the side of her breasts in 2006 through self-examination. The lumps were along the side of her left breast. She did not think much about it. There was no pain. It took her a year to finally go to the hospital to get a biopsy.
- Occasionally wiping away her tears with a blue handkerchief, she explained her worries and fears about death. She was not ready to go yet, especially for her children. She worried about getting treatment because it was very expensive, she knew the treatment process would be very grueling. She needed to keep working and avoid a long recovery period. She was worried about her children. She was the sole provider, the father had been an avid drinker and died while the “last born was 6 weeks old in the uterus” of either liver cancer or cirrhosis. She tried not to be too traumatized or depressed by it because the stress alone can kill you.
- She couldn’t get treatment right away. She waited until she had the means of getting the lumps removed. Since she was a health worker, she was able to get a commitment form from the hospital to cover the surgery costs.

**1. What do you think brought your disease?/How did this disease come?**

I was told by my first surgeon that my HIV+ status may have caused the cancer to come. It is common. She had been tested for HIV in 2002.

**3. How did you come to know you had breast cancer? lump on the side.** I was taught in my training for nursing and in training in educating others about cancers so I was very conscious about cancer. **When did you notice? How long was it before you went to the hospital?** Still, it took over a year to visit the hospital for the lumps because the lumps were along the side of my breast, I did not think it was abnormal.

**4. What do people say brings breast cancer?** I didn’t tell anyone about my lumps until I got the excision biopsy results. I thought it had been something minor...didn’t want to tell others the wrong thing. I told my children first, then colleagues.

-Also took ARVs while getting treatment for cancer. it was very hard on my body.

**5. How did you respond when you found out?** I accepted really that I have these things, so I decided that I will take all these drugs.

**6. What do you think caused the cancer? How do you think it could have been prevented?**

Preventions could have been possible by early detection of the lump. HIV+ people are at risk. You should be HIV free to prevent breast cancer. You need frequent check-ups.

-currently, there are many programs for cervical cancer screening because it is more rampant than breast cancer.

**7. How is it dealing with the treatments? What do you think helps (physically, spiritually, emotionally)? What has been difficult to deal with?** I counseled myself. I was in constant prayers. Frequently attended the clinic without skipping any treatment.

**8. What did you know about cancer before you were diagnosed?** I was taught about cancer in nursing school, long time ago. I was taught that causes are not known but that there are factors that predispose one to cancer.

**9. Recently, there have been many stories about cancers in Northern Uganda. What do you say about that?** When people are diagnosed, the person is traumatized and stressed. They do not know what to do because the treatment is very expensive and many have to travel far to get treatment. Some go to the hospital to see if it's cancer but they can't do more than that.

-Traditional healers? Some people think that they are bewitched by spirits, curses sent by their colleagues.

**10. What do you think is the reason why the numbers have increased?** According to me, the HIV+ status of many here.

**11. With the increasing prevalence of breast cancer in Uganda, how is the community handling the numbers?** People in the community seek voluntary treatment and counseling. They get their blood work checked, their status. If HIV+ they get treated early to prevent cancer, infections, and other complications.

**12. How much do you think the community knows about breast cancer?** There are cancer programs broadcasted on the radio. They teach that cancer can affect any part of the body so many more are checking for cancer but not specifically breast cancer.

**13. What are the cultural challenges of educating the community about breast cancer?** there are none.

**14. How do you hope to prevent breast cancer in the community?** Early check-ups, teach about it in schools, teach how to do self-examinations

-she showed me her scars from taking out the auxiliary lymph nodes. She showed me her radiotherapy scars on the left side of her chest. She let me feel the scars. The scars were very stiff. The flesh in the area had been burned off. She described how it was difficult to lift anything heavy because it would stretch the scar.

-I asked her if she could introduce me to other breast cancer patients she knew. She had 3 friends who were patients but they all died. One had passed away just 2 weeks ago.

### **Laker Margret**

age 47

Sat on the floor holding bandages to her right breast.

Did not know how to write, got her thumb print. Did not smile throughout the interview

Said she just got the first part of the operation today and will get the 2<sup>nd</sup> part later.

#### **1. What do you think brought your disease?/How did this disease come?**

I was confused about what brought it. I only heard about it.

**3. How did you come to know you had breast cancer? When did you notice? How long was it before you went to the hospital?**

It started paining. I went to the village health center then got transferred and then got referred to Lacor. I felt pain for 2 years but didn't know it was cancer. I found out it was November 8<sup>th</sup> this year.

**4. What do people say brings breast cancer?**

Staying in the camp. "these NGO's things are causing cancer."

Was in the camp since 2002. Went home finally last year.

**5. How did you respond when you found out?**

**6. What do you think caused the cancer? How do you think it could have been prevented? I** don't know how to prevent because it was from the camps. Breast cancer was not there until camp life.

**7. How is it dealing with the treatments? What do you think helps (physically, spiritually, emotionally)? What has been difficult to deal with?** They still need to operate more. Pain is still there, can't tell if there is change. God and medical workers are the ones that help her. I trust the doctors. (white doctors are there doing rounds behind us as I am interviewing Margret)

**8. What did you know about cancer before you were diagnosed?**

I did not know of cancer. I thought it was just a minor disease.

**9. When do you think you will be cured and able to go home?**

I don't know. It depends on how the drugs help me.

**Thoughts and reflections after the 2 interviews:**

While I was leaving, I saw a boy with a left arm stub with badly burned skin. Made me cringe. So far, I am surprised that no women have talked about traditional ways of dealing with breast cancer.

**11/21/11**

**Notes:** I talked to the nurse in the medicine ward. Breast cancer patients are only in the surgical ward if it's only a tumor.

Only metastasized breast cancer patients go for chemotherapy.

There is no radiotherapy at Lacor, patients need to go to Mulago.

**Aleti Ajiba**

60 years old,

Yombe district

Never lived in a camp, lived in town during the conflict.

**1. What do you think brought your disease?/How did this disease come?**

I don't know. I thought it was just selling and not serious.

**3. How did you come to know you had breast cancer? When did you notice? How long was it before you went to the hospital?**

At first, I didn't know. The 1<sup>st</sup> examination was negative then the 2<sup>nd</sup> exam took 2 weeks and the results said it was cancer.

(She proceeded to show me her chest.) Her left breast was very swollen. Twice as big as the right breast. There were large bumps on the side of her left breast and near her armpit. There were white bumps around the larger bumps.

I had the disease for one year. Before, I was healthy.

**4. What do people say brings breast cancer?**

if it swells then you need to cut it.

**5. How did you respond when you found out?**

People were doubting it was cancer. The swelling started very small. So I got different injections at the clinics. The swelling got very big but without pain. When it first starting paining, I went to the health units.

**6. What do you think caused the cancer? How do you think it could have been prevented?**

The swelling pulls the skin very hard. (To prevent) take tablets before swelling gets big even though it did not work for me. It came by itself.

**7. How is it dealing with the treatments? What do you think helps (physically, spiritually, emotionally)? What has been difficult to deal with?**

Drugs: feels a bit ok when swelling goes down after taking drugs.

I did not have an operation yet. They excised some to figure out what kind of operation is needed.

I worry about the tumor but I get calmed by getting treated.

**8. What did you know about cancer before you were diagnosed?**

There was swelling 10 years ago which was operated on (probably fibroadenoma). I did not know about cancer before.

Breast cancer is not common in my village. I knew one neighbor who got her breast cut. But I've never seen this (pointing to herself) kind of cancer.

**9. When do you think you will be cured and able to go home?** I am waiting for decisions from the doctors.

**Atoo Marcellina**

51 years old, did not live in a camp ever

Toilet mastectomy procedure: 11/16/11, 40K surgery, 25K admission...TOTAL:65K

From chart:

1/6/11: ceftriaxone

1/26/11: biopsy

2/12/11: admission

3/4/11: skin graft, class II

10/3/11: paracetamol, cloxacillin

10/27/11 biopsy, 10k UGX, blood test 4K, x-ray 4K

**1. What do you think brought your disease?/How did this disease come?**

I don't think about it. I don't want to.

**3. How did you come to know you had breast cancer? When did you notice? How long was it before you went to the hospital?**

Not from here. I was in the hospital for 2 weeks. I had it for 2 months. I don't know when I first noticed.

**4. What do people say brings breast cancer? i don't know.**

**5. How did you respond when you found out? Very fast.**

**6. What do you think caused the cancer? How do you think it could have been prevented?**

There is nothing I can do to prevent it. It just comes.

**8. What did you know about cancer before you were diagnosed? I didn't know anything.**

**9. When do you think you will be cured and able to go home? I am just waiting for the doctors.**

Even though she said she was willing to answer the questions, it did not seem she wanted to talk about her disease all that much. She kept her response short and hasty. Little patience.

**Okech Govetta**

Very busy office. Was interrupted 4 times throughout the 15 minute interview.

**Community Development Officer**

**1. Recently, there have been many stories about cancers in Northern Uganda. What do you say about that?**

There are many stories. The numbers have slightly increased in frequency compared to the past.

**2. What do you think is the reason why the numbers have increased?**

Lifestyle. There are changes in food, environments. "life is not as organic as before."

**3. With the increasing prevalence of breast cancer in Uganda, how is the community handling the numbers?**

I don't know how it's been handled. Health facilities try to help but their capacity to help is small. Many doctors refer their patients to other places like Kampala.

**4. How much do you think the community knows about breast cancer?**

Not much. People need in depth sensitization still.

**5. What are the cultural challenges of educating the community about breast cancer?**

Cancer is almost a "new" disease. People might not understand cancer comes in various forms. Because there is not consistent occurrence and treatment for all cancers some call it witchcraft.

**6. How do you hope to prevent breast cancer in the community?**

Hard to know about lumps to come to terms with the disease. The whole concept of cancer is totally new.

**Aceng Magret**

Toilet mastectomy on right breast, lived in the camp

From chart: 32 years old

Invasive medullary carcinoma of the breast

10/31/11 ultrasound

11/18/11 gen admission 25K, class III mastectomy 40K

**1. What do you think brought your disease?/How did this disease come?**

I don't know.

**3. How did you come to know you had breast cancer? When did you notice? How long was it before you went to the hospital?**

I saw lumps and came to the hospital. There was also pain. The lumps came 6 months ago.

**4. What do people say brings breast cancer? I was not told.**

**5. How did you respond when you found out?** Fears.

**6. What do you think caused the cancer? How do you think it could have been prevented?**

[You prevent] by being told by the medical personnel. Health center did not tell me it was cancer.

**8. What did you know about cancer before you were diagnosed?**

I knew about it, that it could come and attack any part of the body.

**9. When do you think you will be cured and able to go home?** I don't know

She then proceeded to ask me what the cause of cancer is.

I responded by telling her the exact cause is unknown but there are factors that affect the chances of getting cancer: food, environment, lifestyle, age of first pregnancy.

Later, on my quest to find a nun or nurse with breast cancer, I spoke with Sister Josephine. She told me 2 sisters died from cancer this year that she knew of. One cervix and one pancreas.

There was one other sister she knew that died from breast cancer only 2 weeks ago. There is 1 in Opit still getting treatment. Her name is Sister Virginia and I got her contacts.

### **Sister Virginia**

Oral Consent- telephone interview

Works at Opit Health Center. 077 559 0551

Phone interview. She agreed to the interview.

### **Breast cancer patients**

**1. What do you think brought your disease?/How did this disease come?** I don't know.

**3. How did you come to know you had breast cancer? When did you notice? How long was it before you went to the hospital?** I got a biopsy and they confirmed it was breast cancer. 1 year ago I got the operation. There was never any pain.

**4. What do people say brings breast cancer?** Some say it's incurable, some say curable.

**6. What do you think caused the cancer? How do you think it could have been prevented?** I don't know.

**7. How is it dealing with the treatments? What do you think helps (physically, spiritually, emotionally)? What has been difficult to deal with?** Chemotherapy, 6 doses every 3 weeks, themoxiphin daily. There is no pain anymore.

**8. What did you know about cancer before you were diagnosed?** I knew about it, but there was never any cancer in my family.

