

Rural Patient Pathways to Care in the Egyptian Healthcare System
Renegotiating Breast Cancer in the Doctor-Patient Relationship

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In recognition of the privacy and rights to anonymity of certain individuals, doctors, and patients that have participated in this case study, their actual names have been replaced with pseudonyms within this text. This does not compromise the integrity of data collected.

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INTRODUCTION

ABSTRACT

The biomedical system is considered to possess the most advanced tools for battling breast cancer today. But in an area of the world where breast cancer accounts for 33% of all cancers in women and late stage breast cancer cases are on the rise, is it effective? ¹

In the rural Egyptian Delta Region, elevated incidence rates of breast cancer are attributed to contaminated local water and food sources.² This, however, does not explain why a majority of women from these particular rural communities are receiving late diagnoses and failing to adhere to prescribed treatment regimens.

In order to discern the reasons behind this anomaly, my case study has sought to explore how rural Egyptian women with breast cancer utilize the Egyptian healthcare system³. The Egyptian healthcare system is multi-faceted, containing not only bio-medical facilities, but also traditional healers, private organizations and NGO's, which are all accessible at various levels to rural patients.⁴ Over the course of a year, I conducted independent fieldwork at three breast cancer facilities in Egypt- the not-for-profit Fakous Cancer Center in the rural Delta Region, which served as the primary locus of my research, the government's National Cancer Institute in Cairo, and the Breast Cancer Foundation of Egypt's NGO clinic in Cairo. To map the pathways that rural Egyptian women undergo in their effort to seek treatment before, during, and after contacting a bio-medical facility, I analyzed three key variables- how doctors and patients conceptualize the disease, how these conceptions play out in the doctor-patient relationship, and how these two differing understandings impact ethics, treatment regimen compliance, and diagnostic timeframes.⁵

The current biomedical system incurs a palpable, physical, mental, time, and monetary commitment on the part of the rural patient. The effectiveness of the biomedical system in reducing advanced stage cancer rates and failed treatment regimens is contingent upon its ability to adapt to local healing structures and bridge differences in how doctors and patients understand cancer.

¹ Omar, S. et al. 2003. Breast Cancer in Egypt: A Review of Disease Presentation and Detection Strategies. *La Revue de Santé de la Méditerranée orientale* 9 (3): 448-463.

² Soliman, A. et al. 2002. Serum organochlorine levels and history of lactation in Egypt. *Environmental Research* 92(2003): 110-117.

³ Healthcare system as defined as "the constellation of beliefs, knowledge, practices, personnel, and facilities and resources that together structure and pattern the way members of a sociocultural group obtain care and treatment of illness," as Fabrega and Manning note (Stoner 1986:44)

⁴ Abu-Zeid, H A., & W M. Dann. 1985. Health Services Utilization and Cost in Ismailia, Egypt. *Social Science Medicine* 21 (4): 451-461.

⁵ Hahn, R. & Kleinman, A. 1983. Biomedical Practice and Anthropological Theory: Frameworks and Directions. *Annual Review of Anthropology* 12 (1983): 305-333.

A- A PPRESENTATION OF CASE STUDY RESEARCH

It was my first time in Fakous Cancer Center, a not-for-profit biomedical facility in the rural Delta Region of Egypt. A woman in her late 50's entered the physician's office for her examination. Her case was not unusual... TIII stage cancer of the breast, treated by chemotherapy, however, her treatment course was not fulfilled as recommended, and thus she was observing recurrent tumorous lumps. Nearly her entire right breast was gone and still she was not convinced that her condition was serious? After lecturing her of the imperativeness that she remain on the full treatment course this time, the doctor turned to me, flung his hands in the air in hopelessness and declared, "Ignorance, complete and utter ignorance!" I thought, "Ignorance of what? Ignorance of her suffering and condition?... Impossible. Ignorance of her illness? Her body bears the scars. So who are these women of rural Egypt and what exactly is preventing them from receiving their entire treatment course, fully recovering, and returning to a normal life?"⁶

Such was the impetus for my case study. In my first few visits to Fakous Cancer Center, I soon discovered that this woman's experience was not an isolated occurrence. It was actually representative of a majority of cases Fakous Cancer Center received, in which patients had come to the facility with late stage cancer and then failed to adhere to the treatment regimens doctors prescribed for them. I also realized that the outburst of frustration expressed by this doctor was something seeded in a difference in illness discourse as doctors seemed to talk about breast cancer differently than their patients. However, I was unaware of the breadth of the problem at hand. Only time could tell. When I returned to Fakous a year later after spending time in the States, I was first broached with news from one of the Cancer Center's long-standing physicians, Dr. Zuber. He alarmingly informed me that the number of breast cancer patients seen at Fakous Cancer

⁶ Alia Wahid. 2008. Fieldwork at Fakous Cancer Center: Personal Journal Excerpt.

Center since I was last there had risen by 15%. There was also an unprecedented rise in soft tissue carcinoma cases. More cases were in their advanced stages so the cancer center was performing more mastectomies as opposed to less invasive lymphectomy procedures. “I see now on average 150 follow-up cases a day!” he exclaimed. It was upon this realization that I was prompted to further investigate the nature and extent of impact that this particular dynamic in the doctor-patient relationship may have had on the current situation.

In this thesis I aim to determine the impact of the doctor-patient relationship on patient pathways to care. I discern the ways in which background disparities⁷ between doctors and patients influence their discourses about breast cancer. I demonstrate that differences in illness discourses between doctor and patient within the biomedical realm then perpetuate what I have deemed the “ignorance gap” and propagate different approaches to disease treatment and illness management. The detachment between doctor and patient illness discourses within this “ignorance gap” has in turn impacted various issues of morality and ethics within the biomedical⁸ system. Thus, my overarching

⁷ Background disparities between doctors and rural patients that I consider stem from issues of education, socioeconomic statuses, socio-demographics, geographical residence and work, place of origin, gender, and personal frames-of-reference through which doctors and patients regard illness discourse on breast cancer. From an anthropological perspective, I also consider the various “belief” and “cultural” systems doctors and patients belong to, as well as the distinct and overlapping spheres, symbols, relationship networks, and mentalities that shape their discourses on illness. (Stoner 1986)

⁸Biomedical System as defined as “a sociocultural *system*... asserts [that this] medicine consists of distinctive elements that interact in a manner which separates them from other systems in society... asserts that it is not simply a natural phenomenon buy an artifact of human society, founded in a cultural framework of values, premises, and problematic, explicitly and implicitly

argument is constructed as an interpretive lineage⁹ between plausible impacting factors and outcomes.

I present my thesis in the following chapter arrangement as it reflects most cogently this step-by-step interpretive process. The introduction includes a brief overview of the study population and locality, a description of the Egyptian healthcare system, as well as my fieldwork experiences, methodologies, and theoretical components. The first chapter provides an account of the patient biomedical treatment process from the doctor's viewpoint. The second chapter focuses on patient illness discourses, describing how patients' conceptions of such biomedical treatments, their disease, and their experiences outside the biomedical realm interact within the scope of their lives. Chapter three discusses the clash between doctor and patient illness discourses in the context of the doctor-patient relationship. Doctors and patients view illness through different lenses- one biomedical and the other experiential. The doctor's take on illness is typically the dominant and accepted discourse in the biomedical setting. Patients are typically attributed the stereotype of the "ignorant *falaheen*" (peasant) in the doctor-patient relationship and thus their discourses are, for the most part, disregarded. This leads to a schism in treatment approaches and health-seeking patterns of rural

taught by the communications of social interaction and then enacted in a social division of labor in institutional settings." (Khan & Kleinman 1983:306)

⁹ "Geertz [who] maintains that anthropologists should be concerned with meaning, and thus with interpretation, but not with causation," as Geertz notes (Hahn & Kleinman 1983:306). Causal relationships are prone to generalization and may be founded on incorrect or biased information and thus an associative relationship is better founded in the field on anthropology contingent on the frame of data collection and analysis.

patients within this medical pluralist setting.¹⁰ The fourth chapter discusses the implications of this “gap” from an ethical and moral standpoint regarding the ways in which treatment is then enforced. The final chapter pinpoints the doctor-patient relationship as a central issue within an epidemiological and developmental context. It offers a set of viable solutions for rural patient care to be better micro-managed within the doctor-patient relationship and macro-managed within the Egyptian healthcare system.¹¹

I selected Fakous Cancer Center as the primary locus of my case study as it was one of the most accessible and utilized biomedical cancer facilities in the Delta Region by rural women. Its status as the only not-for-profit¹² facility in the region also posed an interesting set of dynamics. A majority of patient care was either free or subsidized in this facility, thus decreasing the variability of cost in contributing to failed treatment regimens and late diagnoses plausibly present in other biomedical hospitals. Doctors worked either pro-bono or for a reduced salary. It was also the only facility in the region established specifically to serve this rural population; rural patients came from neighboring villages and even as

¹⁰ Medical Pluralism is “the existence and use of many different health care alternatives within societies... Medically pluralistic societies offer a variety of treatment options (physician, spiritualist, pharmacist...) that health seekers may choose to utilize exclusively, successively, or simultaneously.” (Stoner 1986:44)

¹¹ “The single most important concept for cross-cultural studies of medicine is a radical appreciation that in all societies health care activities are more or less interrelated. Therefore, they need to be studied in a holistic manner as socially organized responses to disease that constitute a special cultural system: the *health care system*.” (Kleinman 1980:24)

¹² Unlike an NGO which operates like a profit-making business, “the not-for-profit organization does not divide its extra funds between its shareholders, or owners, but uses them for the organization’s purposes.” (Ahmed & Potter 2006)

far as Gaza for care. Non-profit facilities, NGOs,¹³ and charity hospitals, like Fakous Cancer Center, are commonly implemented in developing nations to deal with epidemics¹⁴; thus Fakous Cancer Center provided an interesting setting within which to explore the issues of disease management in rural areas. Because Fakous Cancer Center was also specialized and equipped in a manner comparable with other governmental and university hospitals in the region and in Cairo, I also compared my observations at Fakous Cancer Center to that in the governmental National Cancer Institute in Cairo. (Landskroener 2008)

My work at the Breast Cancer Foundation in Egypt (BCFE), one of the most renowned NGO's in the country located in Cairo, also lent another perspective with which to examine the issues presented at Fakous Cancer Center. Although this NGO received very few women from rural areas, the socio-demographics of these patients were similar; a majority of female patients were working-lower class women, married with children. Services were subsidized by the organization contingent on income. In this smaller setting, patients only dealt with female counselors and doctors in small groups or individually. Issues of privacy were addressed more closely and patients were provided with services specialized in promoting early detection, aftercare physical therapy, counseling,

¹³ "A non-Governmental Organization (NGO) is created by legal persons who are not part of the government. Although NGO funds are mostly raised by the government, they maintain a non-governmental position..." (Ahmed & Potter 2006)

¹⁴ "The growing influence of NGOs in international health is occurring in face of major challenges and opportunities. These challenges include the continued increases in global poverty status, the growing influence of private-funded health systems, the need for sustainability of external-funded programs, and the clamor for community participation in planning and management of external-funded programs." (Akukwe 1998)

and prostheses fitting sessions. These services were typically unavailable to patients at Fakous Cancer Center. Although this NGO did not operate like a ‘hospital’ per se in that it lacked the capacity to treat cancer patients once they had been diagnosed, it did focus on early and post phases of the disease that were usually overlooked in larger hospital settings, like Fakous Cancer Center. Thus, in observing interactions at the National Cancer Institute in Cairo, the Breast Cancer Foundation in Egypt, and Fakous Cancer Center, I was able to construct a more diversified and detailed representation of the pathways to care experienced by rural patients as well as the dynamics of discourses fostered within the doctor-patient relationship.

There is currently little literature available on the doctor-patient relationship within not-for-profit biomedical facilities of developing nations like Egypt. Although deep disparities between the biomedical approach and local constructs of disease have been investigated, few scholars have questioned how the comprehension of illness by rural patients and their interactions within the biomedical realm influence their negotiation of treatment and care. Alternatively, I have sought to enhance the current literature on this topic by emphasizing patient discourse on illness through my theory of “streams of consciousness,” likening patient’s illness experiences to a series of interwoven threads cast within a sequence of life events. I also offer the term “ignorance gap” to describe the disparities between doctor and patient discourses of illness that ultimately impact patient care and the ethics of interactions.

Although this work is preliminary, I hope it will illuminate some of the key issues contributing to failed treatment regimens and late stage diagnoses amongst rural Egyptian women. It is necessary to realize that in the fight against breast cancer, patient illness discourses are not only relevant but also central to the treatment process. In order for the patient to become fully vested in the biomedical process a renegotiation of the relationship between the doctor and patient is vital. It is possible that once this is achieved patients will become designated allies within the biomedical system. Thus, patients can become key contributors increasing the effectiveness of patient outreach and support programs. Egypt has the distinction of representing a multi-faceted approach to breast cancer and it can serve as a model for other areas facing similar medical dilemmas. Ultimately, I hope this thesis will contribute to and inspire further research, governmental reforms, and systemic developments both within Egypt and other nations struggling to control diseases in rural communities.

B. A BRIEF OVERVIEW OF THE EGYPTIAN HEALTHCARE SYSTEM

i. The Sharkiah District and its Rural Communities:

Fakous, Egypt was a small industrial *markez* (center) encompassed by miles of peasant-run agricultural land part of Al-Sharkiah governorate, located about 60 miles north of Cairo in the Delta Region. The town of Fakous, in which the Fakous Cancer Center was situated, was a small impoverished area. Old

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concrete buildings were stacked along the dirt streets. Little *tuktuk* taxis zipped around the dust roads. Men sat in modest outdoor cafes, women window shopped and bartered with street vendors as children coming from school played in the street. This town was renowned for its mechanics that repaired various farming equipment and vehicles. Gigantic tractors, run-down trucks, and Mercedes from the 1960's were parked under straw-thatched enclosures outside the greased and blackened mechanic shops. (Fakous Cancer Center 2007; Fuad 1999; UNDP & INPC 2003; Landskroener, M. 2008)



Image 1. The Town of Fakous- Shed with Trucks.



Image 2. Streets of the Town of Fakous.



Image 3. Streets of the Town of Fakous- Vendors.

Immediately outside the town was a vast sea of greenery enclosed by stretches of desert. In light of the current food crisis, large pipelines strung their way through the sand in a government effort to create more arable land. This was where the *falaheen* (peasants) resided. With a population of over 68,600 people, of whom the majority depended on the production of wheat, rice, banana, oranges, watermelon, and various other crops to sustain themselves, about 20% of village residents remained unemployed. Electricity and clean running water were limited in this rural area. Fakous Cancer Center Down Staging Project¹⁵ revealed that about one-third of the women residing in rural Fakous had five children or fewer indicating the moderately average family size. Peasants relied on water from the Nile River and on small canals for hygienic and domestic purposes. These waterways were also used as dumping sites. Wastes discolored regions of the waterways and garbage was littered along many of the banks; a sharp contrast to the clean, rich green and golden fields located just inland. (Fakous Cancer Center 2007; Fuad 1999; UNDP & INPC 2003; Landskroener 2008, Mitchell 1990)

¹⁵ The Fakous Cancer Center Down Staging Project is a survey/questionnaire conducted in 2007 examining sociodemographic characteristics of a sample population of 181 females with breast cancer at Fakous Cancer Center. (Fakous Cancer Center 2007)



Image 4. Desert Camp between Ismalia and Fakous.



Image 5. Outside the Town of Fakous- The Fields. Image 6. Converting Desert to Arable Land.

It was along these banks that rural women were seen scrubbing pots and dirty shirts, feeding children in their homes, and hunched over in the fields gathering vegetables and cutting wheat with their male relatives. They were crucial to the functioning of this society as contributing and active caretakers and providers for their children, households, and farms. “The Delta differed from Upper Egypt in that more women were engaged in agriculture because of more flexible customs and traditions, which allowed women direct involvement in

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work. Some women farmers headed their households and were responsible for them. Nonetheless, they still earned less than men, although they work on a full time basis since childhood” (Fuad 1999:2). (Mitchell 1990; Salem et al. 2003; Toth 1991)

Despite their integral roles, only 4% of women are property owners in the village. Peasants from this area were very much involved in the violence and protests against the implementation of law 96 of 1992, when the government initiated its agrarian land redistribution plan.

“The law determined a five-year transitional period (that ended in 1997) after which tenants had to return the arable land to its original owners. The tenants had rented these properties for forty years with fixed rents determined by law (seven times the tax – about 100 LE per feden/acre) since the issuance of law 157 of 1952. In 1997, determining the rent of the arable land was left to the owners, whereby the rental of one feden reached 2000 LE, and in 2005, the yearly rental value of one feden amounted to an average of 3000 LE” [Saber 2006:1-6].

Today many farmers in Fakous still rent their land from large-scale owners. “The large prevalence of illiteracy among women farmers hinders their ability to further develop their lives and their children's. Also they find it hard to advance with their agricultural work particularly with regard to marketing, negotiations with owners and in making use of loans through the Agricultural Credit Bank” (Fuad 1999: 1-4). (Toth 1994)

There, however, had been no protests against the aftermath that years of tainted fertilizer and pesticide usage had caused in the region. The high incidence of cancer amongst rural communities was attributed to organochlorines found in

DDT pesticides and other chemical fertilizers that had leached into and polluted water and food sources.¹⁶ Many of these dangerous products were imported from Russia and China and banned by the Egyptian government the 1980's. However, organochlorines, classified as POP's (persistent organic pollutants), were resistant to pholytic biological and chemical degradation. Thus, when these harmful compounds were ingested, they built up in the fatty tissue of both animals and humans. (Amr 1999; Soliman 2003)

In the Al-Sharkiah district, cancer survival rate prognoses deduced from statistical analyses were heavily skewed. Lower grade and stage tumors generally received good prognoses and had better survival rates. They could be treated using less invasive forms of surgery and less intensive medication regimens. Higher grade and stage tumors had a worse survival rate and require aggressive surgical, radiation, and chemical regimens. According to the Down Staging Project conducted in 2007 by Fakous Cancer Center, 50% of patients seen at Fakous stated that diagnosis was not important and thus they do not seek treatment. The pathology of 60% of patients seen at Fakous had grade II, TIII, invasive ductal carcinoma (IDC) in 2008. T4 cases were said to be decreasing, but as of 2009 TIII stage cancer cases seen at Fakous were up by about 15%. (Abu-Zeid & Dann 1985; Fakous Cancer Center 2007; Fuad 1999; UNDP & INPC 2003; Omar et al. 2003)

¹⁶ Findings based on several studies conducted by the National Cancer Institute in Cairo. Breast cancer has been linked to organochlorines in rural areas in the following study including: Soliman, et. al. 2002. Serum organochlorine levels and history of lactation in Egypt. *Environmental Research* 92 (2003):110-117.

There was a great discrepancy between the U.S. and Egyptian five year relative survival rates for this disease. In the U.S. the five year relative survival rates for stage I cancer is 100%, but in Egypt patients with the same stage cancer only have a 60% chance of surviving. In the States stage II has an 86% survival rate and stage III has a 57% survival rate. Both the States and Egypt share a 20% survival rate for stage IV cancer. Interestingly, in Egypt the overall survival rates for women over age 40 were nearly two times greater that of women under age 35. These prognoses, strongly shaped by the assessment and treatment regimens outlined for patients in biomedical facilities, were contingent upon how closely patients adhered to their physician's plans. (Abu-Zeid & Dann 1985; Fakous Cancer Center 2007; Omar et al 2003; Soliman et al. 2003; Soliman et. al. 1999)

ii. **Navigating the System: FCC, BCFE, NCI and Other Facilities**

Over 57% of the female breast cancer patients who frequented Fakous Cancer Center were from rural communities. Fakous Cancer Center was established with the purpose of addressing the need for cancer medicine in the Egyptian Delta Region; prior to this institute's creation in 1990, "Al-Sharkiah governorate residents lacked ready access to healthcare and quite a large percentage of the population suffered from cancer, which consequently, had a high mortality rate, particularly among women and children" (Landskroener 2008: 1-4). Making the four hour journey to the National Cancer Institute in Cairo was

their only available option. (Abu-Zeid & Dann 1985; Fakous Cancer Center 2007; Landskroener 2008; Omar et al. 2003)

Dr. Sharif Omar, “professor of surgical oncology affiliated with NCI-Cairo, chairman of the medical committee in the Egyptian parliament at the time (and now chairman of education and the scientific research committee),” founded Fakous Cancer Center alongside his charitable foundation, The philanthropic Medical Society, to help fund the cancer free clinic. The hospital also received much aid from the Egyptian government and Ministry of Health subsidizing costs for patient treatment, medical equipment, and medicines. In 2005, Fakous Cancer Center was able to treat over 16,815 outpatients and admitted about 100 patients a month. (Fakous Cancer Center 2007; Landskroener 2008; Omar et al. 2003)

The 1,000 square meter facility contained Surgery, Radiotherapy, Radiodiagnosis, Chemotherapy, Urology, Pediatric Oncology, Histopathology, Clinical Pathology laboratory, Rehabilitation/Pain Clinic, and Data Registry units. There are also Internal Medicine, anesthesia, and ICU wards. Cobalt Radiotherapy unit (2D Planning System) and Digitizer technologies were used to assess and outline patient tumor growth and course of treatment. Five dialysis machines were also available as well as 54 beds. (Landskroener 2008; Fakous Cancer Center 2007)

Despite significant strides, Fakous Cancer Center still lacked many of the necessary technologies to better assess patient conditions. It did not have a CAT

scan machine, verification film in its cobalt machines or fixation solution used to develop films. Patients traveled to National Cancer Institute in Cairo and other hospitals in the Delta Region, like Zagazig University hospital, to receive such testing and returned to Fakous for treatment. These other biomedical facilities too lacked necessary treatment and often patients would be referred between them to receive a complete workup. The National Cancer Institute in Cairo was the only facility with all necessary treatments and technologies for diagnosing and treating breast cancer in the country. Patients from all over the Egypt flocked to NCI and thus it could take up to six months for patients from other facilities just to receive even an x-ray. (Fakous Cancer Center 2007; Landskroener 2008; Omar et al. 2003)

The Fakous district was also combating physician shortages and unequal distribution. It had one of the highest ratios of 12 physicians per 10,000 citizens according to the 2003 UNDP & INPC issued by Al-Sharkia Governorate. There were 45 doctors, 32 nurses and 17 technicians employed at Fakous Cancer Center. A number of volunteer doctors from the National Cancer Institute in Cairo also frequented the hospital by buses running from NCI to Fakous four times a week. Doctors worked either pro-bono or received a reduced salary. About 60% of the 250 people employed at this facility were women. Only 32% of women utilized doctors at the Cancer Center as their primary health-care providers. (Fakous Cancer Center 2007; UNDP & INPC 2003; Landskroener 2008)

Most NGO's; however, were much smaller and therefore the patient-doctor ratio was more equalized. At the Breast Cancer Foundation of Egypt (BCFE), patients receive one-on-one attention from a staff of all female doctors. This facility was one of the most renowned in Egypt. It was supported by organizations like the U.S. Komen Breast Cancer Foundation. Its mission was to "promote breast health through breast cancer awareness, education, and research and to facilitate services and support to women in all social and economic strata." (BCFE 2009) Like Fakous Cancer Center, patient services were free or highly subsidized; however very few rural patients had access to NGO's since most were located in cities like Cairo and Alexandria. (BCFE 2009)

NGO's played an important role in focusing on early and post stages of cancer, but they were not equipped to treat the cancer itself. Patients could resort to such facilities to learn to detect early stage irregularities using self-breast exams and other such techniques, but if an irregularity was detected, patients would be referred to a nearby hospital, usually NCI, to seek treatment. This contributed to the pressure on NCI. Even if a woman's cancer was detected early, she would not have access to treatment until later stages of the disease. At BCFE, patients were also provided aftercare services, like physical therapy, counseling, and prostheses-fitting sessions, that most hospitals in Egypt did not offer. It ran awareness campaigns, hosted the walk for breast cancer, provided patients an informational website in Arabic and English, pamphlets, and booklets. (BCFE 2009)



Image 7. BCFE Patient Care Room



Image 8. BCFE Physical Therapy Stress Balls to Help reduce Swelling for Lymphedema Patients



Image 9. BCFE Prosthesis Bra
Made in Egypt to Help Support Local Businesses



Image 10. Prostheses- Left- Imported Silicone,
Right- Cotton; Made from Local Egyptian
Businesses

This conglomerate of biomedical facilities within the Egyptian healthcare system consisting of not-for-profits, NGO's, private and public practices, and governmental hospitals played a crucial role in providing patients with a comprehensive treatment plan that individually each facility could not offer. Thus, the Egyptian healthcare system was established in such a way that it poses

overwhelming hurdles for rural women with breast cancer while also generating various pathways to care that patients are able to negotiate.

iii. **Extent of Localization of Biomedicine in the Egyptian Rural Communities**

The implementation of facilities like Fakous Cancer Center in Egyptian rural areas has been relatively new. The extent to which biomedicine has been integrated in such locales is significant to comprehending how patients' current views of breast cancer and their approaches to biomedical treatment have been shaped. Although traditional healing is typically juxtaposed with biomedicine, in Egypt this separation is not so clear-cut. "Egypt is... a contemporary society with ancient roots and a trajectory of recent change that gives it the unusual status of a once-developed society that is undergoing redevelopment in the current era." (Nelson 1977:20) "Modern-day" biomedicine has roots in Egyptian traditional approaches to healing. It is common for doctors in the biomedical realm to prescribe various "traditional remnants" like honey instead of cough syrup to cure a sore throat and other such herbal remedies instead of their biomedical counterparts when doctors believe them to be just as effective. There is a recognized and sanctioned crossing-over and recognition of the worth in ancient traditional healing techniques in Egypt by those both internal and external to the biomedical realm. (Hahn & Kleinman 1983; Morsy 1988; Nunn 2002; Saad et al. 2005; Shafik & Elseesy 2003)

The term “biomedicine” itself has evolved as science has developed, but today it refers to a primary focus on human biology, or more accurately, on physiology, even pathophysiology” (Hahn & Kleinman 1983:306). What has come to be known as “biomedicine” today is not simply an adjunct to “Western” medicine within Egyptian society. Some contend that “biomedicine may have its principal origins in Western civilization, and has even been a leading edge of modernism. It has incorporated and now penetrates other traditions as well” (Hahn & Kleinman 1983: 305). But biomedicine and modernism are not concepts exclusive to a Western platform. Egyptian society contends that “modern-day” biomedicine has its primary origins in Eastern civilization that predate Western advances. The West later adopted and augmented Eastern ideologies producing what is known today as “modern” biomedicine. “Modernism” is a relative term since Egypt has for thousands of years been considered a central hub of knowledge and has always participated in an international form. Today Egypt continues to maintain that reputation, hosting leading laboratories and conducting advanced research on topics like nanotechnology and competing and interacting on a common level with Western countries. (Landskroener 2008; Morsy 1988; Nunn 2002; Saad et al. 2005; Shafik & Elseesy 2003)

The “modern” biomedical approach to understanding the body and its ailments has many links in Western innovations of more recent centuries (15th-20th), but its roots remain firmly anchored in the Hellenistic and Eastern philosophies as well. Hippocrates of Cos’ is credited with the groundbreaking

contributions of the Hippocratic Oath and contentions that diseases derive from natural causes thus initiating the birth of medicine in the West (420 B.C.), but few Western medical practitioners are aware that the standard medical textbook they used in medical school today is based off of *The Cannon of Medicine* written by Ali Ibn Sina, (known in the West as Avicenna) in the 11th century. There had been centuries of knowledge exchanged between the Hellenistic and Eastern societies setting the foundation to fuel the creation of “modern” biomedicine. Hundreds of year’s worth of textbooks and discoveries in alchemy, mathematics, and biology written in Arabic were translated by the Westerners like the Greeks and Spaniards; however, today that crucial exchange is often forgotten. The West holds the idea that such advances simply sprung up from nothing; however, Egyptians have not given in to this contention generating for them a completely different conception of biomedicine today. (Brandt-Rauf& Brandt-Rauf 1987; Hahn & Kleinman 1983; Huff 2008; Morsy 1993; Nunn 2002; Shafik & Elseesy 2003; Smith 1980; Wolper 2005)

The Middle Ages (5th-16th centuries) were deemed the ‘Dark Ages’ in Europe, but they were the ‘Golden Ages’ in the Middle East. Arab-Islamic scientists led the scientific revolution and paved the way for Europe’s Age of Enlightenment. Baghdad, Egypt, and later Turkey during the Ottoman era became central hubs of knowledge- Arabs, Greeks, Romans, Chinese, Indians, Persians, Egyptians, North Africans, Byzantines and many others flocked to these metropolises. These centers also housed some of the most advanced medical

practitioners and medical technologies in the world at the time. While Europeans were barbarically lopping off arms and severing legs to treat minor or unrelated ailments, the physicians in the Middle East were advancing clinical and surgical medicine, innovating surgical instruments including the first unique to women that we continue to use today (ligature, scalpel, curette, retractor etc.) and incorporating the first anesthesiologists into the “medical team.” (Gabrieli 1967; Huff 2008; Nunn 2002; Shafik & Elseesy 2003; Smith 1980; Sullivan 1998; Wolper 2005)

One renowned medieval Syrian Muslim diplomat, Usama ibn Munqidh, traveled to Europe during the 12th century and he wrote:

“They took me to see a knight who had an abscess on his leg, and a woman with consumption. I applied a poultice to the leg, and the abscess opened and began to heal. I prescribed a cleansing and refreshing diet for the woman. There appeared a Frankish doctor, who said: ‘This man has no idea how to cure these people!’... The doctor supported the leg [of the knight] on a block of wood... and there, before my eyes, the fellow struck the knight one blow, and then another... The marrow spurted out of the leg, and the patient died instantaneously. Then the doctor examined the woman and said: ‘She has a devil in her head who is in love with her. Cut her hair off!’... He took a razor and cut a cross on her head, and removed the brain so that the inside of the skull was laid bare. This he rubbed with salt; the woman died instantly. At this juncture I asked whether they had any further need of me, and as they had none I came away, having learnt things about medical methods that I never knew before” [Gabrieli 1967: 76].

Egypt has fostered countless skilled and advanced medical practitioners throughout history and the many contributions of this nation remain present in the minds, relics, and healing practices of many Egyptians today. It is a misconception that magic or superstitious healing practices have inundated all

ancient, present-day, urban, or rural Egyptian understandings of illness. In fact, the first physician known by name in history is the third dynasty (2600 B.C) Egyptian pharaoh Imhotep who recorded various ancient Egyptian medicines, methods of diagnoses and treatment for over two-hundred diseases. (Brandt-Rauf & Brandt-Rauf 1987; Huff 2008; Nunn 2002; Shafik & Elseesy 2003; Sengers 2003; Smith 1980; Sullivan 1998)

Herbal remedies from ancient times till the present-day have also remained central to Egyptian medical practice, although they have become more associated with “rural” or “traditional” healing methods than with the “biomedical.” Yeast was used to cure ulcers, swellings, and it was ingested for other digestive disorders as well. Ashoma is an eye disease that was treated using animal liver, which today has been proven to contain compounds effective for curing certain types of cataracts. Honey and milk were frequently prescribed for treating respiratory and throat ailments as they typically are today. (Huff 2008; Nunn 2002; Saad et al. 2005; Shafik & Elseesy 2003; Smith 1980)

Although the medical compositions used to treat patients today have transformed drastically in the biomedical realm, Egyptian doctors do not shun the correct usage or deny the healing properties of natural elements. The Western notion of biomedicine often schisms “natural” remedies from pharmaceutical/pill-form remedies. In the West, a pill exists for everything. Although there are slivers of the population who do resort to natural healing methods, the majority

still rely strongly on these drugs or artificial healing compounds. In Egyptian, natural medicines and pharmaceutical drugs occupy the biomedical realm collectively with particular emphasis situated on the merit either one has to cure. (Huff 2008; Husain 2003; Nunn 2002; Saad et al. 2005; Shafik & Elseesy 2003; Smith 1980)

It is a common misperception amongst Westerners that the modern *mustashfah* (hospital) or *saydalah* (pharmacy) is a foreign concept to Egyptian society. The “hospital” and “pharmacy” have remained a typical part of the Arab and Egyptian medical setting for centuries. Hospitals were integrated into large complexes with schools, masjids, and mausoleums. Some even had separate, closed areas for quarantine that were used during outbreaks of infectious diseases. Hospitals also contained state-run apothecaries from the time Egypt was ruled under the Abbasid Caliphate (750 A.D.). Many of these historic monuments remain standing today and had set precedence for those in other parts of the world. The Bahri Mamluk Sultan Qalawun’s (1222-1290) Ophthalmology Hospital was built in Cairo over seven-hundred and fifty years ago and till today it remains an open and functioning treatment center for local Egyptians, like many of these historic monuments. The technologies may have changed to become more conducive with those used in the “biomedical” realm, but the idea of treating patients in a medical center is not new. (Al-Ghazal 2003; Hillier 2001; Huff 2008; Husain 2003; Nunn 2002; Saad et al. 2005; Smith 1980; Yeomans 2006)

Like “biomedicine,” what has become known as traditional healing in rural areas of Egypt is not necessarily a stagnant or aberrant approach to the body as is typically the contention; it is changing just as the “modern-day” biomedical realm is changing with every new discovery. Techniques used today have links to some early Islamic forms of holistic medicine from around the Prophet Muhammad’s time (632 A.D.) and others date back even further to pharaonic times in Egypt (2000 B.C.). Some ancient remedies have adopted new roles in treating “modern” illnesses. Breast cancer is considered a modern-day pandemic, but it is certainly not a new disease. Traditional healing techniques that address this specific illness have changed over time. The oldest known medical record and treatment of breast cancer dates back to the 1600 B.C. Edwin Smith Papyrus, part of an ancient Egyptian textbook on trauma surgery. This script describes eight cases of breast tumors that were treated by cauterization. Although Ancient Egyptian healers were able to remove the tumors or destroy them, they could not impede the progression of the disease. The author of the papyrus wrote that no treatment exists. (Al-Ghazal 2003; Brandt-Rauf & Brandt-Rauf 1987; Hahn & Kleinman 1983; Huff 2008; Husain 2003; Ibrahim 2003; Saad et al. 2005; Shafik & Elseesy 2003; Smith 1980)

Early Islamic medicine centered on a holistic approach. The teachings of Islam contend that “for every illness God created, He also created a cure,” as narrated in Hadith by Abu Huraira (Sahih Bukhari 2007: 7:71:582). Today Egyptian traditional healers advise the ill to recite certain prayers for health and to

take specific herbals to remedy ailments as instructed by the Prophet Muhammad. These ailments vary from epilepsy to eye diseases. Prescribed medicines consist of various seeds such as cumin, different fungi, physical therapies, and relaxation techniques. Ibn Abass is recorded in a Hadith as stating that Prophet Muhammad defined early Islamic medicine in the following way, “Healing is in three things: cupping, a gulp of honey, or cauterization, but I forbid my followers to use cauterization” (Sahih Bukhari 2007: 7:71:585). (Husain 2003; Ibrahim 2003; Sahih Bukhari 2007)

Since cauterization was forbidden in Islam, a new treatment approach was instituted. Today, one of the prime traditional treatments for breast cancer is honey, which the Prophet described as the purest substance on earth. Since the Prophet’s time, honey was used as a natural remedy for incontinence and stomach trouble, but today traditional healers have latched onto it as a “cure” for breast cancer as well. It is not quite clear the exact reasons behind this phenomenon, but it is evident that many rural Egyptian women, Muslim and non-Muslim, today do believe that this treatment has an effect and many regard it in greater esteem than the treatments offered in the biomedical realm. (Al-Ghazal 2003; Husain 2003; Ibrahim 2003; Saad et al. 2005; Sengers 2003)

Although Islamic tradition and ancient Egyptian teachings are highly regarded by physicians, most doctors also believe that the usage of such traditional remedies beyond their original and intended usage is a clear act of

ignorance and backwardness. Islamic and Ancient Egyptian medicines have always had a scientific basis and goal to make sense of the body in order to remedy it. But according to doctors, the usage of honey to “cure” breast cancer is an unfounded aberration more closely linked to a distortion of traditional Islamic healing methods. (Al-Ghazal 2003; Husain 2003; Ibrahim 2003; Saad et al. 2005; Sengers 2003)

Like the pyramids, the historic and monumental contributions of the ancient and Islamic civilizations have been preserved by Egyptians today. Egyptian doctors, *baladi* (commoners), and even *falaheen* (rural people) are aware of this religious and national history. Many “biomedical” approaches stem from this region of the world and thus “biomedicine” cannot be considered an isolated and implanted Eurocentric or new-age way of contemplating the body and illness in Egypt. When analyzing how “modern” biomedicine manifests itself in Egyptian society, it becomes clear that the dichotomy does not lie so much in “Eastern” and “Western” but more so in “technological” and “natural.” It is this dichotomy that defines and limits the extent to which modern-day biomedicine has been localized in rural communities. (Al-Ghazal 2003; Hahn & Kleinman 1983; Husain 2003; Ibrahim 2003; Malti-Douglas 2001; Morsy 1988; Saad et al. 2005; Sengers 2003)

The extent to which “modern-day” biomedicine has been localized is contingent on access to a specific knowledge and discourse. Although Egyptians

have to a great extent defined “modern-day” biomedicine according to its historic roots, this has also presented many difficulties in their grappling with the irrefutable changes that have come to compose biomedicine today. Thus, the “modern” biomedical realm is still to some extent an unfamiliar entity within rural communities. Those who have access to knowledge within the “modern” biomedical realm, and are therefore more likely to comprehend its language, are those in high standing positions like doctors, professors, government officers. The biomedical realm has become normative in such circles. Most of Egypt’s rural and lower class communities; however, do not have access to such information as readily. Although rural communities may relate to the “modern-day” biomedical system to some extent through their historic and traditional healing methods, the “modern-day” biomedical system has also diverged from its Egyptian roots in many ways, thus generating a channel of differences in illness discourses and conceptions of the body. (Hahn & Kleinman 1983; Husain 2003; Ibrahim 2003; Malti-Douglas 2001; Morsy 1988; Saad et al. 2005; Sengers 2003)

C- FIELDWORK METHODOLOGY & THEORETICAL FRAMEWORK



Image 11. touregypt.net/egyptallmap.jpg

i. Access:

Its 4 a.m. and I am in *Medan Tahrir*, our usual meeting spot. “*Ramadan Mubarak ya Aam Hussein wa as-salam-wa-a’alaykum.*” (Happy Ramadan Uncle Hussein and peace be upon you) As I hop out of the Fakous Cancer Center van for the last time, *Aam Hussein*, the facility’s driver, responds with the formal, “*Wa a’alaykum-as-salam wa rahamatalahi wa barakatu.*” (And may peace, mercy, and blessings be upon you). I slam the door shut and turn to wave goodbye to the small teary-eyed elderly man. *Aam Hussein*- we called him this as a sign of respect, but over the past two years of traveling back and forth to Cairo and Fakous, he truly did become like an uncle to me.

Tomorrow would be Monday, but unlike every other Monday, Wednesday, Thursday, or Sunday, *Aam* Hussein would not pick me up at 7:30 a.m. for the arduous drive from Cairo to Fakous Cancer Center. *Aam* Hussein was the proprietor of the Fakous Cancer Center van that serviced every doctor that wished to go to the center. His days and mine would begin with the simple goal of being able to escape Cairo's boundaries. But, as the song Hotel California intones, "You are welcome to come, but you can never leave..."

There are few benefits to being an Egyptian doctor, but if there is one, it is that others have to wait on you. Dr. Aziz, was always the first call on our trip. He would tell us to pick him up at one stop or another, and at one time or another, and then, like many of the other doctors, would not show up, show up late, or change his point of origin. Several hours later our over-heated van would hobble off the highways of Cairo and past the toll booth that marked the exit leading onto what we had deemed the "road of death." Immediately, after taking the turn onto this beaten up, dusty, pot-holed, slice of a two-lane road which strung its way along the Nile, in a final tribute to *carpe diem*; Oum Kalthoum, a famous Egyptian singer, would blast from the old tape player, cigarettes would light up the air, talk of taboo politics which Dr. Aziz just a road ahead eluded to as "sshhh... they are listening," and *Aam* Husein in a defiant move against the tractors, donkey carts buses and large tractor trailer trucks which barreled toward him would floor the gas pedal and in a cloud of smoke and fumes would weave his way along the Nile toward Fakous Cancer Center.

As I jostled from seat to ceiling and side to side, I thought of how I, a naïve American student at AUC, in the spring semester of 2008, under the guidance of Dr. Hanan Sabea, my anthropology professor, and with the support of a close school friend would find myself proposing a vague study on women, breast cancer, and the Egyptian medical system to Dr. Hussein Khalid, the Dean of the National Cancer Institute of Egypt. Dr. Khalid quickly recommended that I meet with Dr. Sharif Omar in Cairo, the founder of the Fakous Cancer Center. I must admit I did not know at this time how my study would be refined, but Dr. Omar was kind enough to give me access to his facility.

After I received permission from Dr. Omar to visit his facility my progress came to a sudden halt. I needed government permission to visit and do research at the hospital. Like the donkey cart we sped by that sat struggling at the side of the road, unable by sheer force to propel itself out, I too sat for three months, waiting by the side of the road, for government permission. Once I received government clearance, for seven months I worked mainly between Fakous Cancer Center and NCI. At Fakous Cancer Center, I shadowed the doctors, observed patient visits and surgeries, and interviewed patients, doctors, and nurses. At the conclusion of each interview I also gifted patients a hand- crafted jewelry in gratitude for their participation.

It was during this process of conducting interviews and observing the doctor-patient relationship at Fakous Cancer Center that it became clear to me that

there was a difference between the patient and doctor discourse about breast cancer. I then returned to the U.S. where I spent the rest of the school year doing research on the issues presented in my fieldwork findings. In spring of 2009, I was awarded a WEED scholarship from Mount Holyoke College and received I.R.B. approval to return to Egypt where I then proceeded with my fieldwork at Fakous Cancer Center and to also do fieldwork at the Breast Cancer Foundation in Egypt (BCFE), an NGO, for an additional two months. At BCFE, I was able to instruct physical therapy sessions, participate in prostheses fitting sessions, update their online outreach website and write informational articles for their monthly newsletter. After three months in Egypt, I then went to Morocco where the rest of my summer was spent translating interviews with a native Arabic speaker.

ii. Bias:

Interviewing Patients:

It is necessary to establish an awareness of the influence or plausible bias my personal convictions and character may have posed in my fieldwork setting. Initially I conducted interviews with patients in front of doctors, immediately following their appointments, before I had any inkling of the extent to which the doctor-patient relationship was compromised. I found patients were often very shortcoming with answers and visibly shy. Also, patients were reluctant to express any complaints against the hospital or treatment they were receiving.

Thus after a few months of conducting interviews in this manner, I requested a private room in which to stage my interviews. I found that in this setting, patients were more relaxed and their stories started flowing.

Even after I had switched the location of the interviews, however, patients seemed mainly concerned with my affiliation to the hospital. Was I a doctor, administrator, or in any way affiliated with the hospital? After asking one woman what she thought we could do to better assist the women in rural areas with breast cancer and spread awareness, she became silent. She then asked me if her story would be published in the newspaper. I assured her that all her information would remain confidential; however she appeared a bit nervous through the rest of the interview. Another woman responded with short, complacent answers, until I told her she did not have to worry because I am not affiliated with the hospital. I was simply a researcher hoping to understand the situation better. After stating this, she laughed, and stated, “I know, *ya benti* (my daughter),” and then the truth behind her hardships came to unravel. It was of primary concern to most patients that I not be in a position of power where I could take away or forestall their treatment in anyway. I found that patients were more forthcoming with their stories after I made it clear that I was in no way associated with the hospital.

It also helped that I was young and they could treat me or speak to me as a daughter or even rather informally. Few addressed me as *doctora*, instead

calling me *benti* (daughter), *habibti* (my dear), or *setti* (my lady, or miss). As a woman, though, they felt more comfortable sharing their personal stories. Our small informal meetings consisted of my friend Meriam who lived in Fakous, the patient, and me. I arranged the chairs in a circle, so as the patient would not feel uncomfortable with all the attention focused on her. The conversation was informal, often sharing jokes and other hilarities, between which I inserted the serious questions I wished to focus on.

Patients were curious about my ethnicity. Although my parents were born in Guyana, South America, my heritage is actually quite complicated. My relatives were taken as slaves by the British to Guyana from what is today Pakistan, India, Iran, and Afghanistan. I was born in the U.S. and was raised amidst a conglomerate of these different cultures. When Egyptians asked me about my ethnicity, I usually claimed to be Iranian, not out of any real deception on my part as I am part Iranian, but in order to alleviate any politics which may rear its ugly head if I said, American. Being American had less to do with any prejudice against Americans and more to do with an association with the Egyptian government. Egypt is a highly nationalistic and politicized country. My attempts at discussing Egyptian politics with doctors even concerning issues about the healthcare system were often futile. Criticizing the government even inspired a sense of fear in doctors, and patients were even more reluctant. Whatever Egyptians may feel about Americans or politics they do not want to insult the Egyptian government. For the rural patients I interviewed, as an American I was

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a possible threat. Revealing their complaints to me as an American may have meant to them that the Egyptian government would find out and they would receive no more medical treatment.

In declaring my Iranian ethnicity, patients always responded warmly. Some even outright stated “O.K. good, you are one of us! The Iranians are like us. Welcome!” Others exclaimed, “I love Ahmedinejad! Welcome to Egypt!” Ironically, their reactions hinted at the notion that they were more likely to trust someone whose government was just as staunchly outspoken about the oppression of the West and Israel as their own government and yet also just as oppressive to its own people. In these shoes they felt I understood what was at risk for them with any annoyance they mustered to disclose.

Some patients also guessingly labeled me as *Hind* (from the Indian subcontinent), which I am part as well. They had a good opinion of Indians; however, patients also did not associate Indians with Islam and thus deemed me an outsider before discovering I too was Muslim. I would typically try to steer clear of the ethnicity-trap due the confusion it often prompted and due to the incumbent politics it may ensue, and usually simply stated that I was Muslim. This seemed to put people at complete ease, as it is the dominant religion of the area. Also, regardless of ethnicity, Muslims belong to one *ummah* (community) and thus there was no need to deem me an outsider.

Before coming to Egypt, I had a very strong background in Arabic. I am both literate and well versed in the language. I have more than ten years of experience with classical Arabic, five years experience with Moroccan Arabic, and three years experience with Egyptian Arabic. It is important to understand though that Arabic is an extremely versatile and dynamic language. In fact, upon moving to Morocco when I was in high school, I discovered that few Moroccans even understand Egyptian Arabic. Basically, the entire Arab world has their own distinct dialect *daarijah*, diverging to the point that most could be considered entirely different languages. Classical Arabic *fusha* is the only common denominator which can be understood almost anywhere. It is the language of the news media and other such outlets; however, if spoken on the street, be ready to receive a look of amusement or even a burst of laughter, as speaking Classical Arabic in common social spheres could be easily be equated with speaking Shakespearean English with a store clerk in Boston. Thus, in my first month or so in Fakous, language posed a slight difficulty. As a resident and student of Cairo, I had mostly picked up the dialect in the city. The dialect spoken in the rural areas of Egypt are distinctly different from the Arabic spoken in Cairo carrying with it its own nuances. I needed to become accustomed to these differences. It was this aspect that posed me as an outsider to patients as someone clearly from the city; however, patients were overjoyed that I shared the Arabic language with them as an “Iranian Muslim” and as the “language of the Qur’an and *deen* (religion).” Language served as bridge between us and drew us closer in our conversations.

Interviews with Doctors:

I presented myself to doctors as a pre-medical college student from America hoping to conduct research with the aim of helping the local population. Certainly this fed into some stereotypes they had of Americans and certainly inspired a degree of cynicism. Few Egyptian believed that I would come all the way from America to help anyone in the rural areas of Egypt with my country's terrible track-record weighted against me. Many Egyptians equated America with the current invasion in Iraq, its destruction of Afghanistan, and the ongoing handouts to the Israelis to eradicate the Palestinians.

But it helped that I was Muslim. Upon hearing that I was Muslim, doctors would say, "Oh that is good. You have come to help your Muslim brothers and sisters in Egypt from America." Some doctors simply could not believe that I was American and Muslim. One doctor even asked me to recite a *surah* from the Qur'an. Doctors were also welcoming to my Iranian ethnicity, though this immediately conjured images of the Shi'ite violent and often bloody tributes to Ali. Doctors would look at me questioningly and boldly inquire, "Are you Shi'ite or Sunni?" When I responded that I was Sunni, doctors would sigh with relieve, shouting *elhamdulillah* (Thank God) and some would even go on a diatribe denouncing all the practices of the Shi'ites as against "real" Islam. This often generated some interesting conversations in our four hour car rides to Fakous. Overall, I would say that doctors were pleasantly surprised by my boldness as an

outsider to brave the difficult journey in a quest for knowledge in a remote area of the world they considered to be *asl* “my origin”. Upon receiving the news that I was to travel to Egypt to conduct fieldwork, my grandfather in the States bid me farewell with the Prophet’s saying, “You should always be in search for knowledge, even if you must go all the way to China.” I set foot in Fakous Cancer Center and was welcomed with the same phrase.

iii. **Conducting Interviews, Collecting Data, and Analyzing Information:**

In conducting fieldwork at Fakous Cancer Center NCI, and BCFE, I acted as a participant-observer. I conducted 40 interviews with patients and doctors and observed over 100 patient visits. At Fakous I observed surgeries and at BCFE I observed counseling and prosthesis-fitting sessions. At BCFE, I conducted physical therapy sessions and updated their informational website and wrote informational articles about breast cancer to be included in their newsletter or published in online pamphlets. I analyzed data using the computer program Atlas T.I. to code, categorize, and create correlations and elucidate relationships between several of concepts. Amidst a number of subcategories, the key codes investigated and used to generate relationships were: 1) Patient health-seeking behaviors: perceptions/responses/experience in diagnosis, treatment, and recovery processes within the healthcare system 2) Social aspects of illness discourse: role of family/community/patient status in society 3) Patient methods of coping with

illness 4) Natural and traditional healing 5) Doctor-Patient Interactions 6) Stigmas against breast cancer reinforced by doctors, patients, and society 7) Patient somatization of illness and their descriptions of symptoms and etiologies associated with breast cancer 8) Doctor descriptions of breast cancer. The associations that arose from this data gave pointed towards several alternative theories I use to explain the current situation within the doctor-patient relationship.

“STREAMS OF CONSCIOUSNESS” THEORY- RURAL PATIENT DISCOURSE ON LIFE AND ILLNESS:

An exhausted middle-aged woman rocks gently back and forth in her wheelchair parked in front of me. She and her husband left their village in the Egyptian Delta at sunrise to attend a follow-up visit with a physician at the Fakous Cancer Center this afternoon. They lingered in the sultry waiting room gazing desperately at the fan overhead. It swung lazily around barely able to cast a breath of coolness through the thick hot air. A doctor approached them and they suddenly snapped back from their languid states. “Are you the doctor here to see us?” the husband asked with a sigh of relief. “No... but we were wondering if your wife would be willing to answer some questions about her illness for a study a student is conducting.” The wife nodded her head in agreement, but her husband became irate. “We are here to see *the doctor!*” he exclaimed angrily. The doctor haggled with him over the soonest available slot that their case could

be seen. The husband finally acceded to allowing his wife to participate, and in return, immediately following our interview the physician would see them. The husband happily returned to his reposed state as the doctor wheeled his wife into a corner room.

The doctor hands me her chart and leaves. My friend Mariam is with us. She is a 30 year-old, college-educated woman living in Fakous with her husband and two young children. We introduce ourselves. The woman fidgets with her *hijab* that neatly frames her fair, oval face and high-cheek bones and she adjusts its simple loose knot under her chin. She timidly engages in some small talk with us, mostly about Mariam's children, as I quickly flip through her file. The medical diagnosis is metastatic breast cancer in the bone marrow of her legs. The cream-colored *djellaba* draped over this woman's delicate frame stops above her ankles revealing severely swollen limbs. Her medical history includes a biopsy in her right breast and a radical mastectomy. The chatter lulls as I close the file and discreetly place it on the table next to me. The woman peers at me with her large brown eyes inquisitively. "What would you like to ask me, *ya setti*?" she asks me in a soft tone of voice. "If you don't mind, *ya khalti*, I would like to begin by asking you to tell me about your life."

The method of recruitment and pre-interview interactions this particular patient experienced, as well as her age, medical history, and diagnosis were fairly representative of the many women I spoke with at Fakous Cancer Center. However, it is this seemingly simple yet vague and complex question that I

initiated each interview with, asking patients to tell me about their lives, which individualized each woman not only in relation to the other patients but also in relation to her illness. This question never failed to incite a wide array of reactions from my interviewees, and rightfully so. This particular woman countered my query with another question, “That means I will talk about what?” Another woman interpreted the question as a cultural linguistic idiom. She responded jokingly with another cultural parlance, “You want me to cry? We have the whole day!” Yet another woman simply chuckled, threw her hands up in the air with a sigh, and exclaimed, “*Ya Habibti!* Where should I begin!”

Conducting interviews always conjures, for me, memories of a game we used to play as kids. Someone would say a word and impulsively you would shout out all the things that popped into your mind induced by that single term. Let’s say we called out the word “illness.” Some words and images that may instantly leap to mind are: hospital, sick, tired, exhausted, dead, disease. If we called out the word “life,” however, different terms may burst into mind: happiness, death, vitality, music, family. The question in this situation then becomes how often the word “illness” springs to mind when someone calls out the word “life.” More specifically, how often is “illness” correlated with “life” in the mind of a person with a chronic ailment. When these two words are connected in a phrase, such as “How has your life been affected by your illness?” the interviewee is automatically situated in a specific mindset to correlate these

two terms, and thus their response follows the trajectory of what Kleinman (1988) calls an “illness narrative.” (Das 2006; Kleinman 1988)

I initially approached interviews by asking patients to tell me about their illness. I would receive a bombardment of complaints about aches and pains. Giving me what they believed I wanted to hear as a “pre-medical student” conducting interviews in a biomedical setting, the conversation would cut short and they would ask me when they could see the doctor. By asking this one-dimensional question, I was projecting on them a biomedical lens. It later dawned on me that this question was usually asked by doctors. I fell into the trap of Kleinman’s (1988) “illness narrative” approach which limited and only allowed patients to speak in directly to the ways in which illness affected their lives. This approach thus provokes a deceptive idea of the extent to which illness is made important in a person’s life. In the Kleinman (1988) “illness narrative” context, it is then difficult to understand then why rural patients would delay or cease seeking treatment if their lives appear to be so completely inundated by their disease. I realized that to comprehend how patients actually experience their illness and the extent to which it is made important, my lens needed to be expanded to encompass the ways in which patients’ illness influences their lives indirectly as well. (Kleinman 1988)

I thus asked patients to tell me about their life instead. I discovered that some women’s discourses entirely evaded any reference to biomedical treatment

or their illness despite the biomedical setting in which our interviews took place. Through a biomedical lens, such discourse would appear nonsensical and unrelated to the processes of disease; however, by situating the illness experience of these women within the broader context of their life their discourses became lucid.

Breast cancer is an illness that certainly has the potential to inundate and alter a woman's life, but as is evident through other discourses this is not always the case. Discourse on illness is malleable depending on what is most at stake in the woman's life. Kleinman (1988) has a fixed notion of how illness is to present itself in a person's discourse; however, he does not recognize that the ways in which illness are discussed are subject to change depending on the context in which they are examined. Illness fits into a greater series of negotiations that can only be captured by fitting illness into life that generates what I have observed to be like "streams of consciousness"- a flowing and ebbing of ideas and life experiences that overlap in various ways with the thread of illness. (Kleinman 1988)

I will adopt the Kleinman (1988) definitions for illness and disease when interpreting the interviews I conducted. While Kleinman (1988) holds disease to be the strict biological representation of sickness, he deems illness to be the "innately human experience of symptoms and suffering... how the sick person and the members of the family or wider social network perceive, live with, and

respond to symptoms and disability” (Kleinman 1988:3). I will also utilize certain facets of Kleinman’s (1988) “illness narrative” that aid in discerning the ways “illness” as a term is directly correlated with the term “life” and how information revealed in such discourse from chronically ill patients can contain greater meaning and tie to Max Weber’s notion of a wider “web of significance” (Geertz 1973:5). I will also augment and alter other features of Kleinman’s (1988) construct of the “illness narrative” that I find to be incongruent or ineffective in the pursuit of comprehending the way “illness” acts as a filament manifested in many layers that compose the diverse scope of what is at stake in a person’s “life.”

Kleinman relates:

“Illness narratives edify us about how life problems are created, controlled, made meaningful. They also tell us about the way cultural values and social relations shape how we perceive and monitor our bodies, label and categorize bodily symptoms, interpret complaints in the particular context of our life situation...” [Kleinman 1988: xiii].

There are several issues; however, with such a construct. Firstly, the “illness narrative” (1988) assumes that people afflicted with a certain chronic ailment will or should inevitably factor “illness” into their discourse about “life,” thus limiting the span by which we can understand the natural ways these two terms intersect. I argue that the term “life,” unlike “illness,” represents a much more vast and complex category for people. Things like “illness” fit into the category of “life.” Thus, when the mind is not restricted to associate the immense category of “life” with some succinct, specific thread, it is given free range to draw on *any* thread.

It is this situation that allows us to observe what key threads are truly at the forefront of a chronically ill person's outtake on "life." This process, I contend, reveals that a person's life description is not solely inundated by their disease and neither does their illness completely define their life. Instead, a patient relates their disease to different circumstances, relations, and incidences in their life and may also use this structure to describe their disease. I will therefore refrain from calling the discourses provided by the chronically ill breast cancer patients I interviewed "illness narratives" per se, and instead I prefer to think of them as "inflected streams of consciousness."

Secondly, the Kleinman (1988) "illness narrative" construct provokes a false presumption that the manner by which these two terms, "illness" and "life," relate follows a fluid, specific, and structured pattern- ebbing and flowing in sync dependent upon intensity of the illness. This pattern does not necessarily need to be consecutive to be ordered and for it to follow Kleinman's (1988) model. Kleinman's (1988) "illness narrative" suggests that "life" imitates the thread of "illness" from the point of inception. By analyzing these conjoined oscillating patterns of "illness" and "life," Kleinman (1988) argues that we can adequately comprehend how the somatic experience is "made meaningful." It intrinsically situates "illness" as the root cause of certain "life problems" and provides a limited scope for generating and attributing meaning to those issues and how they are talked about. Since Kleinman's (1988) "illness narrative" construct excludes the way other life events affect a person, whether related or independent of

“illness” events, it is difficult to extrapolate the ways “illness” truly manifests and is “made meaningful” in a chronically ill person’s life (Figure 1; Figure 2).

How then do “illness” events interact with “life”? I argue that the true and natural relation between “illness” and “life” is actually a completely randomized phenomenon- the trajectory of “life” is unknown, and thus the points at which “illness” events will intersect with it appear to us random and unpredictable. The behavior of chronic illnesses like cancer is such that its points of its creation, control, cure, and triggers can be somewhat unpredictable, frantic, and undefined. Although there may be commonalities between the ways “life problems,” “illness events” and the general concept of “life” are discussed, no two discourses are identical. Rather, such “inflected streams of consciousness” are individualized based upon the situations, events, and experiences that occur during the course of one’s life. I imagine a series of events or waves of varying wavelengths floating along the linear continuum of life, intersecting with each other at various indiscriminant points. Life problems may branch from these various points of intersection and some are maybe more prominent in patient “streams of consciousness” than others (Figure 3).

My contention is that “illness” impacts “life” by potentially exacerbating already existing problems, but “life” can also exist separate and independent of “illness” and its affects. To generate a more complete lens for understanding the ways in which “illness” manifests in a chronically ill person’s life, it is necessary

to delineate “life” and “illness” based upon what is at stake in that person’s life.

Such an approach situates the various “life problems,” both encompassing and independent of “illness problems,” in perspective. (Figure 3)

Figure 1. *Kleinman “Illness Narrative” Model: My Understanding and Description of Klineman’s Interpretation of Illness and Life Interaction- Pattern of Life Mimics Pattern of Illness. (Parallel Arrow= Life, Circle = Point of Illness Inception with Life, Fluctuating Arrows= Coinciding Illness- Life Trajectory)*



Figure 2. *Life and Illness Model: My Explanation of “Streams of Consciousness Theory”- Life Problems are Independent of, Inversely Related, or Correlated with Illness Trajectory. (Parallel Arrow= Life, Circle= Point of Illness Inception with Life, Fluctuating Arrows = Illness Trajectory, P1= Life Trajectory Coincides with Illness Path, P2= Life Trajectory Independent of Illness Path, P3= Life Trajectory Inversely related to Illness Path)*

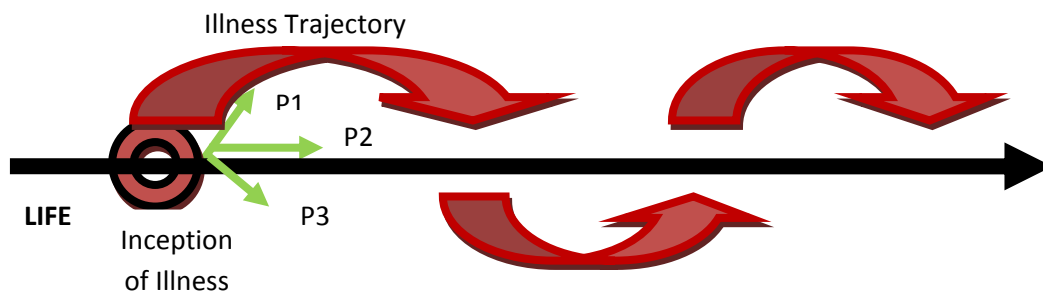
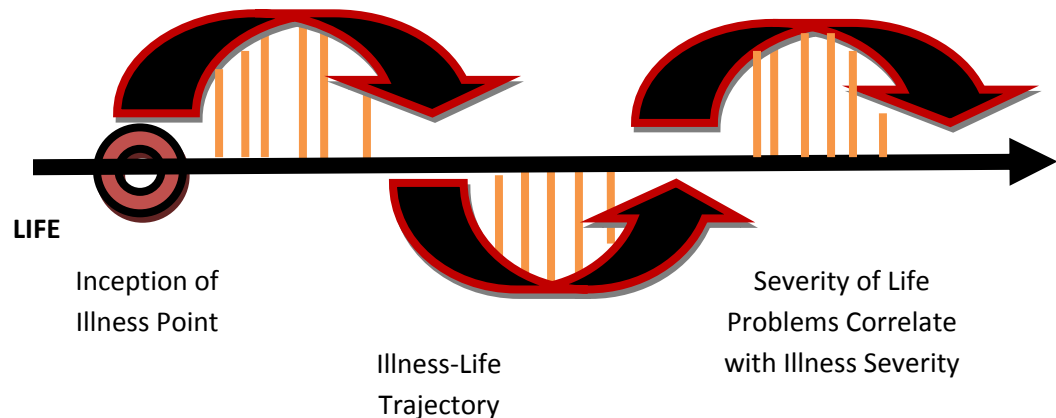


Figure 3. *Kleinman "Illness Narrative" Model: My Undersatnding of Kleinman's Description of Intensity of Life Problems- Correlation of Intensity of Life Problems Dependent Upon Intensity of Illness. (Parallel Arrow= Life, Circle= Point of Illness Inception with Life, Fluctuating Arrows = Coinciding Illness-Life Trajectory, Verticle Lines of Varying Lengths = Varying Intensities of Disease)*



Kleinman (1988) conducts an interview in Taipei with Dr. Song, a terminally ill patient with metastatic carcinoma of the pancreas. He relates, "For the next hour we talked of many things, but never about the cancer, or the treatment, or the fact, visible for all to see, that Dr. Song was severely cachectic and deathly ill." Despite their shared discourse, Kleinman still tries to pose some direct questions about treatment and illness to both Dr. Song and his family members; such questions are met with "embarrassment," and "avoidance." Kleinman states, "Dr. Song acted as if he were unaware of what was going on, though clearly he realized that he was dying" (Kleinman 1988:152). He interprets their exchange to have meaning solely relevant to death, more specifically "death in another country" as he titles the chapter, but he fails to realize that it also has

significance in relation to life. How Dr. Song chose to discuss his illness may not have been formulated in the direct aggressive terms that Kleinman chooses to use, but rather his illness represents underlying threads that manifest and are expressed in other layers that Kleinman may have missed. Kleinman describes death and sickness in death and sickness terms, while many cultures though out the world may describe death and illness in life circumstances and as a continuum of life. Thus, I contend that by excluding “illness” from a posed question about “life,” interviewees not only reveal the cultural and social factors that influence the way they relate to their body, illness, and life situations, but also it reveals the depth and overlap of filaments surrounding the single thread of “illness” that Kleinman’s (1988) “illness narrative” fails in some ways to make apparent. What is at stake and important in a person’s life thus surfaces in a new and meaningful way.

Life speeds along a track littered with precarious and arbitrarily anchored bumps and intersections. Illness is just one of these temporary disruptors that cause the ill person to constantly challenge concepts of the “body,” “illness,” and “life.” How these ideas are expressed linguistically inspires us to rethink the depth, interconnectedness, and the multiplicity of affects “illness” has on the lives of the chronically ill. Contrary to Kleinman’s (1988) conjecture, life and illness do not necessarily become linked inevitably and come to follow the same patterns. The “chaos” that “illness” creates can be temporary and although the disease may persist, the way “illness” interacts with “life” may alter.

When breast cancer patients at Fakous Cancer Center told me about their lives, “illness,” and its problems/restrictions were not always intrinsic to their “life” discourses. When these women were asked about how “illness” specifically affected their lives, a different picture was painted. It is evident that a patient’s complaints about illness are not always at the forefront of their concerns in their daily lives and their relationship to their illness may change over time and it may become independent from other events in their life. I am not disputing that in some cases the Kleinman (1988) “illness narrative” approach is useful, descriptive, and insightful; however, I contend that it cannot be taken as an absolute. Thus, my notion on “streams of consciousness” will provide added insight into how patients describe the symptoms, causes, and coping mechanisms within the scope of their lives.

LEARNING TO OBSERVE THE DOCTOR-PATIENT RELATIONSHIP:

The patient-doctor relationship is not only an integral, complex, and intermediary entity to many rural patients’ diagnostic, treatment, and recovery processes within the Egyptian healthcare system; it is also an inconsistent and discordant entity on many levels that affects how a patient will experience such phases of illness. The doctor-patient relationship has traditionally been situated within the “biomedical” model, synonymous with a perception of disease as a strictly biological/somatic unit of experience independent of social, psychological,

and behavioral elements. The medical anthropological discipline; however, has approached the observation of this relationship from several alternative angles. Engel defines a model to be “nothing more than a belief system utilized to explain natural phenomena, to make sense out of what is puzzling or disturbing” (Engel 1977:130). Hence, the development of the medical anthropological “explanatory” and “critical” models serve as two key analytical perspectives for observing the composite nature of the patient-doctor relationship and how “disease” and “illness” manifest within it. (Lazarus 1988:34-40)

The “biomedical” model adopts a rather reductionist approach that overlooks the distinction between “illness” and “disease” and other key facets that medical anthropological models would contend supplement and shape the doctor-patient relationship in meaningful ways. Thus, “explanatory” models encompass “the beliefs and expectations, norms and behavior, meanings of health and illness, and therapeutic activities and evaluation of outcomes embedded in a person’s cognitive system and general culture patterning,” (Lazarus 1988:36-37) that affect how individuals (doctor and patient) act within the medical system. “Critical” models observe how individuals within the medical system manipulate its various inherent social relations and political-economic constructs. Unlike “explanatory” models that embody the personal cognitive and symbolic illness experience, “critical models primarily focus on the “social context in which personal experience takes place” (Lazarus 1988:44). Morsy, however, asserts that the “theoretical formulations in anthropology are affected by the cultural environment

in which they are constructed and by the social identities of those who propagate them,” (Morsy 1978:137) and thus in the process of conducting my research at Fakous Cancer Center, I was forced to rethink such medical anthropological models and reinterpret them to more effectively observe the patient-doctor relationship within the context of the Egyptian healthcare system. (Hahn and Kleinman; Kleinman 1988; Lazarus 1988:37; Nelson 1977)

Kleinman defines the “ethnographic *experience*” as the following:

[It is] the felt flow of *interpersonal* communication and engagements. Those lived engagements take place in a local world. Experience is thoroughly *intersubjective*. It involves practices, negotiations, contestations among others with whom we are connected. It is a medium in which collective and subjective processes interfuse. We are born into the flow of palpable experience. Within its symbolic meanings and social interactions our senses form into a patterned sensibility, our movements meet resistance and find directions, and our subjectivity emerges, takes shape, and reflexively shapes our local world. By local world I mean the ethnographer’s village, neighborhood, networks, family, and other institutions” [Kleinman 1998:4-5].

As a participant-observer, I was obligated to manipulate and negotiate the various complex social, political, and economic webs that compose the Egyptian healthcare system in ways specific to Kleinman’s (1988) description of the “ethnographic *experience*” so as to observe the doctor-patient relationship. Discerning the patient-doctor relationship by strictly utilizing either the “explanatory” or the “critical” medical anthropological models proved insufficient and generated a rather incomplete blueprint. The “explanatory” model acts as a form of micro-analysis while the “critical” model provides a macro-analysis of

illness and the individual within a system. Applying the “explanatory” model, in isolation as Kleinman and others have done, places dominant emphasis on the patient’s narrative and biopsychosocial understanding of illness, thus greatly limiting the range of observatory data collected. The drawback of applying only the “critical” model is that it only provides insight into the ways in which individuals navigate the greater social, political, and economic spheres that overlap and help shape the medical system, but it does not delve into the underlying cognitive, personal, and individual processes of agency that influence how an individual may come to assume a specific position within that system (Lazarus 1988: 46- 49).

Thus, I came to employ a sort of malleable hybrid model that involved merging concepts of both analytical approaches to interpret both the internal cognitive and exterior social, political, and economic fabrics in which the individual’s (patient and doctor) illness experience is embedded. Similarly, anthropologist Byron Good beckons for a similar approach in his study of Harvard medical students and their relation to illness within the medical educational system. He states, “I [argue] that if we are to understand how medicine constructs its objects, we will need to join together critical studies of practice and the analysis of embodied experience” (Good 1995: 69). In light of Kleinman’s usage of “explanatory models to determine what is considered relevant clinical evidence...,” (Kleinman 1980:110) I hoped that by combining these two models into a flexible and adaptable format, that I would safeguard

against biasing my observations; a rigid theoretical structure would have meant either pre-emptively rejecting observed information or forcefully incorporating certain observed material into the strict framework.

In the process of observing the patient-doctor relationship, Kleinman states that “most anthropological research on practitioners has relied on what the practitioner *tells* the researcher about a type of illness or a particular patient’s disorder. This is not an adequate determination of functioning clinical rationality,” he claims (Kleinman 1980:109). With this argument in mind, I sought to maintain a strong awareness of my role as participant throughout the processes of traveling to Fakous, conversing with nurses and family members, attending clinical appointments and surgeries, and conducting interviews with patients and doctors. It was my function as active participant that allowed me to perform my role as observer and to extract valuable data.

To delineate the meaning of “doctor” or “healer” and the meaning of “patient” in this system, I not only observed the doctor’s and the patient’s social interactions with each other, with staff, family members, neighbors, friends, and with myself, but I also obtained their own individual accounts of the doctor-patient relationship, illness/life experience, and medical system embedded within the institutional, political, and socio-economic fabrics. I interviewed patients and doctors about certain aspects of the illness experience in each other’s presence and privately. I also requested that the doctor pose a few specific generic

questions to the patient pertaining to the patient's illness and general life experience at the end of the appointment and then I observed how he would recall and interpret her responses back to me. I was simultaneously able to monitor the patient's facial, behavioral, and verbal responses as the doctor reiterated her statements to me and throughout their clinical interaction. I found this exercise, in combination with private individual interviews, to reveal much about the underlying conceptions doctor's and patient's have of one another and how such conceptions affect the ways in which bioethical issues are addressed. (Lazarus 1988)

THE "IGNORANCE GAP":

Understanding the various disparities that govern how the doctor and patient talk about illness is a crucial starting point for analyzing such questions. What the body "means" to the individual when expressed verbally has the capability to extend, interrelate, and become representative of what it "means" to entire societies. Historian Kuriyama (2002) elaborates upon this phenomenon in his book *The Expressiveness of the Body*. He discerns that the Greek and Chinese linguistic descriptions of simply touching the wrist, inspired different linguistic descriptions- the Greeks collectively called that feeling "the pulse" while the Chinese deemed it "the mo." The Greeks were able to unite and share a single comprehension of the body as discerned from individual experiences observing,

feeling, and touching it. The same affect was observed amongst the Chinese; however, when these two different societies tried to understand each other's renditions of the body, there was a great disconnect. (Kuriyama 2002)

It became an obsession in Greek society to find the exact linguistic constructs that represented experiences of the body. The Greeks labored extensively over how to describe their feelings and observations of "the pulse," and to make the "meaning" of those words as factual or "truthful" to the body as possible. Galen was one of the most renowned Greeks to have written extensively, possibly utilizing every adjective in the Greek language, in attempts to make the "factual" body comprehensible linguistically. "The pulse" was even translated into musical notes as it was claimed to be a more representative medium for generating meaning of the "true" nature or essence of the body. Such efforts exerted by individuals and societies ultimately created complexly spun webs of "meaning" to illustrate the body. (Kuriyama 2002)

Kuriyama's observations of the Greek and Chinese linguistic renderings of the body and illness penetrate and provide valuable insight into those varied discourses amongst patients and doctors within Egyptian society as well. There appear to be at least two distinct interacting socio-cultural systems of Egyptian society encompassing the doctor and patient- one is the local Egyptian understandings of illness and the other is the biomedical comprehension of illness. (Kuriyama 2002)

Understanding how these different discourses and understandings of the body clash is entrenched in Foucault's (2003) theory in his piece titled "Society Must Be Defended", in which he discusses issues of power and how power is channeled and manipulated through biopolitics. Although he discussed these ideas in relation to war, it is also plausible to apply them to power dynamics in biomedical healthcare realms. He states:

"What does this new technology of power, this biopolitics, this biopower that is beginning to establish itself, involve? I told you very briefly a moment ago; a set of processes such as the ratio of births to deaths, the rate of reproduction, the fertility of a population, and so on. It is these processes- the birth rate, the mortality rate, longevity, and so on- together with a whole series of related economic and political problems..." [Foucault 2003:243].

He contends that such cultural, belief, and socio-demographic issues contain a network of interlocking symbols that work together to reinforce the particular ways that social relations function. Power relations, attitudes, and identities are all projections of a specific form of discourse. Thus, the rural Egyptian peasant when typically classified as the "ignorant peasant" by doctors is a projection of a number of symbols within the biomedical realm working to shape their discourses on illness and to reinforce a set of specific social relations and disparities within the doctor-patient relationship. This in turn generates the "ignorance gap."

CHAPTER 1

MAPPING BIOMEDICAL TREATMENT FOR RURAL BREAST CANCER PATIENTS



I was met at the gated entranceway to the Fakous Cancer Center by a tall, bushy-mustached doctor with kind eyes. “Welcome *ya Doctora*. Please, this way,” he motioned toward a narrow doorway at the end of a dusty path that ran around the periphery of the 1,000 square-meter facility. We meandered past a group of patients relaxing on a series of wooden benches in the shade of a well groomed garden. They stared, transfixed on an exotic peacock, housed within an enormous metal cage in front of them. The bird awkwardly jabbed its small head in the dirt floor picking up various seeds and straws of wheat. Dr. Zuber drew close to the cage and the bird gawked at him. “This,” he explained, “was created to bring a sense of peace and serenity for patients to enjoy. It is therapeutic for them.” He paused thoughtfully and then grinningly admitted, “We used to have several of these birds in the beginning. Well, we would leave the facility in the evening and return the next morning to find one missing! We wondered at this mystery for some time. Finally we discovered our guards were taking the birds at night to have a cookout and eat them. Only this one escaped the barbeque pit!” he remarked sarcastically. He chuckled and escorted me inside.



Image 1. Fakous Cancer Center.

The interior was dimly lit and a cool relief from the sweltering heat outside. Most of the large panel lights were switched off and only sunlight trickled in from several windows. Dr. Zuber explained, “This facility offers many services to patients.” It has surgery, radiotherapy, radio-diagnosis, chemotherapy, urology, pediatric oncology, histopathology, clinical pathology laboratory, rehabilitation and pain clinics, and data registry units. There are also internal medicine, anesthesia, and ICU wards. We entered the patient waiting room. It was a large open space crammed full with patients seated on the series of benches or on the floor. Oversized folders lay concealed on their laps or tucked carefully beneath their arms. “Those,” Dr. Zuber pointed out, “are x-rays and other scans. Patients have brought them to be assessed by doctors as a first step in their diagnosis and treatment processes.” (Landskroener, M. 2008)

He explained to me that patient cancer stages were defined based on three categories: tumor size (T), spread of cancerous cells with proximity to the lymph nodes (N), and malignancy (M). A T1 tumor was two centimeters or less in diameter and a T2 tumor was between two and five centimeters in length. Tumors in these two phases were considered 'early' stage cancer and potentially curable. A T3 tumor was greater than five centimeters across and was considered more 'advanced' but still treatable with an aggressive regimen. T4 tumors varied in size but all extended into the chest wall or skin. T4 stage tumors were deemed 'advanced' stage cancer and virtually incurable. Chest x-rays were one of the most common mediums for tumor assessment and treatment monitoring in Egypt. Chest x-rays were not always reliable though, since smaller tumors and various complications like clotting may go unnoticed in such images. If treatment was effective then there would be a decrease in tumor size evident when x-rays were revised in follow-up visits. (American Cancer Society 2009)

Dr. Zuber described the more technical aspects of the x-ray scan. "When the machine is off, no radiation is emitted," he explained. The machine at Fakous accelerated beams of electrons at 75 kev, however, ideally the highest voltages used in diagnostic x-ray tubes should reach 140 kev. The half-life of the radiation energy utilized by the machine depleted. Exposure times then needed to be increase to assure efficiency. "Our machine needs to be calibrated. Unfortunately, to change the source costs US \$1 million," he stated. Most patients at Fakous were typically referred to other nearby facilities and even as far

as NCI in Cairo to obtain x-ray scans.

Dr. Zuber led me down a short corridor. He squeezed into a small room, maneuvering amongst the clutter of file cabinets and large processing machines, finally positioning himself squarely in front of the Fakous Cancer Center's digitizer. "Like the x-ray, this device is also important for diagnosis and mapping treatment regimens. It is able to construct a rough contour of a patient's breast and chest cavity generating an image similar to that produced by a CAT scan." He laboriously manipulated the computer mouse drawing a series of circles on a grid. "As you can see, operating this machine involves a great deal of dexterity to trace a drawing or scan of the patient breast image onto a computer that will then allow physicians to directly narrow down the necessary region for target treatment." He switched off the monitor and complained, "A CAT scan could produce the same images with greater accuracy and ease, but unfortunately a CAT scan machine costs US \$2 million - money our hospital does not have the funds to buy one."

"Now I will show you how exactly we use these scans to treat cancer." We entered a doctor's office where a patient was reclined on an examination table. An x-ray was pinned to a light box on the wall. Armed with only a felt tip marker and a twelve-inch ruler in hand, the doctor painstaking set to work. He eyeballed the exposed area of the patient and then the scan, back and forth, measuring and marking the approximated area for treatment. With a felt pen he boxed the treatment area defining the region and dosage of radiotherapy for the

patient to receive. He estimated a blue dot onto the patient's skin that radiologists would use to align the patient with the radiotherapy machine. Dr. Zuber explained, "Since we don't have a CT simulator,¹⁷ we are forced to do it manually by approximation from other scans."

After being mapped for target treatment, patients would then proceed to the center's cobalt machine for radiation dosages. Dr. Zuber took me to a tiny obscure hallway where an elderly technician was seated behind a desk staring at a television screen that projected an image of a patient in the neighboring room. The patient was lying on a table. A strange arm protruding from a gigantic machine hovered above the target region of her body. The man started the timer and sluggishly turned a set of dials adjusting the radiation intensity. "This is how we operate the cobalt machine," Dr. Zuber stated. "The cobalt machine is relatively reliable and easy to maintain compared to the radiation therapy machine, but the cobalt machine is still unable to administer the high power radiation capable of linear accelerators in radiotherapy machines. Therefore, patients need to receive longer exposures to radiation. This is especially a problem if the tumor size is large or has a rapid growth rate. If the tumor keeps growing, despite radiation exposure then there will be an increase in side effects."

The timer pinged and Dr. Zuber entered the dimly lit room. He removed the boluses or rice sacks on top of the patient's chest that were used to increase

¹⁷ CAT Scan Simulator is a machine that generates a 3-D image of the patient's internal anatomy and with extreme precision measures the location for treatment

the density and reduce radiation exposure along the border of the superficial region. He explained to me how the machine operated. The radiation produced by a linear accelerator radiation machine could be controlled and switched on and off, but the radioactive source material in a cobalt machine was always on. “The advantage to the cobalt machine is that it is more efficient in treating obese patients. It emits up to one million kv of photon energy that can penetrate greater densities,” he stated. “Patients typically will experience radiation therapy¹⁸ every five days at a time over two or three months depending on the severity and type of cancer.”

Sometimes patients in advanced stages of the disease undergoing radiation therapy and surgical procedures would also undergo chemotherapy. If a doctor chose to prescribe chemo for a patient in an advanced stage cancer, it typically would indicate that there was a possibility that the cancer could be controlled or even cured. “Trained nurses and those in training typically administer chemo dosages intravenously to patients in a closed off area upstairs,” Dr. Zuber explained. Patients who did not stay over at the hospital were prescribed chemo drugs in pill form to take home. Treatment cycles consisted of chemotherapy dosages administered five days a week over the course of three to six months followed by a break period for recovery.

¹⁸ Radiation therapy, a form of targeted treatment designed to specifically kill cancer cells could also destroy the nuclear DNA of any cell that proliferated quickly. Radiation could also indirectly kill the cytoplasm of normally dividing non-cancerous cells if the target treatment field was not correctly assessed causing more severe complications for the patient. (American Cancer Society 2009)

Chemotherapy drugs were extremely potent and aggressive. Much like radiotherapy, they killed any cell, cancerous or not, that was proliferating at an abnormal rate. When healthy cells were damaged by these drugs, various side effects could result. When normal cells in the bone marrow were killed, patients experienced extreme fatigue, susceptibility to bruising, bleeding, and infection. When cells that composed hair follicles died, the patient's hair fell out. Cells destroyed or compromised in the stomach and intestines caused patients to feel severe nausea, vomiting, and diarrhea. "It is important that chemotherapy is delivered in its correct dosages and within the designated timeframe in order to work most optimally in eradicating the cancer without risking tumor re-growth or other complications" stated Dr. Zuber. (American Cancer Society 2009)

Some women at Fakous Cancer Center were given hormone therapy instead of chemo or radiation therapy if their tumors test positive for estrogen and progesterone hormones. "For doctors to prescribe hormone therapy here at Fakous, doctors take into consideration whether the woman is pre- or post-menopausal- if she is pre-menopausal then she is at higher risk for developing an estrogen or progesterone-positive breast cancer," explained Dr. Zuber. Hormone therapy for breast cancer involved regular dosages of pills that suppress estrogen production in the ovaries and block its effect. Women's treatment regimens involved years of hormone therapy. These drugs could induce early menopause. Most women experienced complications that included fatigue, hot flashes, and even blood clots. "They do not need to be hospitalized though, like most patients

undergoing chemo, radiation therapy, and surgical procedures” stated Dr. Zuber. (American Cancer Society 2009)

We pushed through the double doors. A long stretch of hallway lined a series of in-patient rooms. We entered one. The room was stuffy and cramped. Twelve patients, men, women, and children, lay in two rows. There were no dividing curtains to give patients privacy. IV drips hung from metal poles next to their beds and family members and friends tried hard to avoid bumping into them. Dr. Zuber introduced me to a little boy sitting quietly alone at the edge of his bed. “Like the other patients in this room, this boy has just received chemo treatment for third stage cancer lymphoma,” stated Dr. Zuber. An old man lying in bed with a severely distended and swollen belly solicited Dr. Zuber to his bedside. Dr. Zuber tapped his belly and listened with his stethoscope. He instructed a nurse to give him an enema.

As the nurse entered, Dr. Zuber quickly shuffled me out and into a room across the hall. It was dark and there were only a few beds inside. One bed at the far end of the room was occupied. “This woman has just had a mastectomy and is just waking up now from anesthesia,” Dr. Zuber told me. “She will stay here a few days, as do most of the patients who undergo surgery, and soon after she will begin radiation therapy.” Often the waiting period necessary for recovery was not conducive to the measures necessary for eradicating the cancer. Doctors recommended that radiation therapy was started soon after the surgical procedure

to avoid the chances of tumor re-growth or cancer cell generation elsewhere in the body. Complications from mastectomies included infection, soreness, severe pain and restricted arm movement. Lymphedema¹⁹ was also very common. (American Cancer Society 1999; BCFE 2009)

“Let me now show you our surgical ward.” He led me through a set of padlocked double doors. He picked up a pair of plastic bags lying on the ground next to the door and placed them over his shoes. I followed suit. A nurse in the surgeon lounge equipped me with a surgical gown and mask. “There is a sink in the lounge used to ‘scrub-in’ but you do not need to since you won’t be touching the body,” she told me. I followed Dr. Zuber down the hall. Sand and dirt from the tiled floor collected on the bottom of my encased shoes as I shuffle behind him and into a large room cluttered with all sorts of glaring lamps, shiny devices and sharp metal objects. A team of surgeons were hunched over the body of an older woman.

An anesthesiologist, Dr. Jabari, pulled me aside to explain the series of procedures they performed for breast cancer patients here at Fakous. “We do everything from biopsies to radical mastectomies here,” he stated. “Biopsies are basically the removal of a sample tissue that is examined under a microscope to determine if the lump is benign or malignant before other kinds of treatment are prescribed.” He made a fast slicing movement through the air with his hand. “If

¹⁹ Lymphedema is a severe swelling in the limbs due a blockage in the lymphatic system that result in localized fluid retention. (American Cancer Society 2009)

the tumor is big though and if we find it is malignant, we will go ahead and cut it out one time. It is not useful to the patient that we conclude the biopsy and then schedule the mastectomy for another date. The cancer will just progress.” Even some women in early stages of breast cancer were recommended by their doctors to undergo simple or total mastectomies at Fakous. The logic was that the radical procedures would eliminate the chances of cancerous cells being left behind during surgery and therefore also avoiding the painstaking processes of subsequent radiotherapy and chemotherapy treatments. If doctors believed the cancer was curable and could be treated effectively with chemical therapies, then the patient would undergo a conservative surgery involving just the removal of the tumor and immediately surrounding tissue. (American Cancer Society, 2009; BCFE 2009)

I inquired about the process of reconstructive surgeries²⁰. Another surgeon standing over the woman’s open body explained, “These patients do not want reconstructive surgery. They are not so concerned with their image. They are simple people. They think it is not natural and that it will cause the cancer to come back.” “Yes, they prefer just to leave it as it is,” stated another surgeon. It was extremely rare that any patient at Fakous received such procedures since they were deemed unnecessary and “simply for aesthetic purposes” by physicians and

²⁰ Women who have undergone mastectomies can undergo reconstructive surgery that rebuilds the breast to match the same size and shape as it was before. Breast prostheses are another option for mastectomy patients.

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by some patients as well. Such surgeries also would require added resources, time, and money.

The surgeons concluded the operation by sewing up the woman's chest and rubbing iodine over the wound. Dr. Jafari accompanied me to the lounge to clean up. He confided, "We do not have consults with patients before or after surgery- the first time we see our cases is on the operating table at Fakous. The patient is prepped by our nurse staff. At Fakous Cancer Center we perform around 10 surgeries a day- I begin around noon and work till 2 a.m. This woman we just finished will be taken by a nurse to the recovery room and that is probably the last we will see of her. Then it is on to the next case."

A nurse helped me remove my surgical gown. She was a woman in her late 40's from a town in the Sharkiah district. "I have three daughters," she told me. "I was not trained as a nurse, but I have become experienced in this work. I work here because I want to help these women. Dr. Jabari, passing by overheard our conversation and inserted, "She wants to be an example to her daughters of how to be strong. She is here to help with all the surgeries and she is not afraid." He nodded respectfully to the older woman. A surgeon called her from the operating room to take the patient to the recovery room. Dr. Zuber escorted me out of the surgical ward. We removed the plastic bags from our shoes placing them near the entrance way to be reused by incomers, and exited through the double doors.

Treating cancer is not like treating any other ailment. Cancer has no kryptonite- it remains yet an obscure disease even within the biomedical realm. Fakous Cancer Center is representative of the biomedical realm in which doctors and patients struggle commonly against breast cancer. Although the goal is mutual, the avenues by which doctors and patients approach and combat cancer are skewed.

CHAPTER 2

“STREAMS OF CONSCIOUSNESS” ON LIFE AND ILLNESS

Discourses from Rural Egyptian Women with Breast Cancer



Rural Egyptian women of the Delta Region had a unique discourse on illness that was situated within specific “belief”²¹ and “socio-cultural” systems that allowed them to approach breast cancer from different angles than that of the biomedical. When they contacted biomedical facilities like Fakous Cancer Center, their perceptions of illness were expanded, but not inundated by the experience. These women continued to reference their illness experiences within a certain overlapping subtext of symbols,²² relationship networks, and mentalities. (Good 1995; Geertz 1973; Levi-Strauss 1963)

The peasant women who lived and worked the fields of the Delta Region were amongst Egypt’s poorest. About 70% of the *falaheen* (peasant) women were illiterate and only about 10% had attained a university level education. Over one-third had raised at least five children in their households. 50% of patients treated for breast cancer were between ages 36 and 50; however, some were as young as 15 years old. Simple statistics, such as these, have been used to explain or define these women, but it is evident that the women who frequent Fakous Cancer Center relay their experiences of life and illness in a much deeper frame of

²¹ “...a prominent paradigm in the medical behavioral sciences is organized around the comparative study of beliefs about disease...” (Good 1995:66). Similarly, patient illness discourses are arranged around a certain set of interacting beliefs about disease. “Given the semantics of the term, that is the *meaning* “belief” had taken on by the late nineteenth century and continues to have in the twentieth century, the analysis of culture as belief thus both reflected and helped reproduce an underlying epistemology and a prevailing structure of power relations.” (Good 1995: 21)

²²“If we add that these structures are not only the same for everyone and for all areas to which the function applies, but that the are few in number, we shall understand why the world of symbolism is infinitely varied in content, but always limited in its laws.” (Levi-Strauss 1963:203) Levi-Strauss’ analysis of the interaction between Shaman and birthing woman shed light also on the interactions of symbols between doctor and rural patient.

complexities. (Fakous Cancer Center 2007; Fuad 1999; Mitchell 1990; Saber 2006)

In examining the following passages, it is necessary to bear in mind that these illness discourses are to be comprehended not through a “biomedical” lens, but rather through a “life” lens. Contrary to what is revealed through Kleinman’s (1988) “illness narrative” approach, patients did not always define their life and illness discourses in direct reference to illness or its treatment. Also, illness was not always an instantaneous cause for chaos in a patient’s life. Symptoms could go ignored as could disease for extended periods of time during which patients carried on with their lives “normally” before seeking treatment or aid. A patient’s illness experience could thus be alluded to through a series of other recollections about life in which sickness is not a main theme, but rather a supporting character. Certainly for some, the debilitating properties of illness influenced what was most at stake in their lives thereby appropriating a central space in their discourse. However, it is important to remember that how a patient speaks about illness represents a strand in an overlapping patchwork of patterns of experiences. Understanding patient “streams of consciousness” on life and illness is thus an exercise in recognizing the broader frameworks and critical roles at play in creating patient illness discourse in the context of life. It is an approach dedicated to acknowledging a holistic view of the way illness and treatment interact with what is most meaningful in the lives of these women with breast cancer. (Das 2006; Dodd et al. 1985; Kleinman 1988)

When I asked women at Fakous Cancer Center to “tell me about your life,” they would impulsively respond either inquisitively or jokingly. But then they would pause and ponder this heavy question. The notion that much can be revealed about the contextual and sub-contextual framing of “illness” without imposing a direct correlation between “illness” and “life” is evidenced in the following monologue from a woman in her mid-50’s undergoing chemo for metastatic breast cancer in her liver:

“My husband left me with six children and he died and a Christian man converted to Islam to marry me and raise my children with me because I had no one else. He is sleeping outside (*meaning he is not living in her home*). I swear he is a Christian and converted 15 years ago. He does not love me or anything but he just saw the little kids and... He had pity on them because the neighborhood where we are, no one helps the other. He is, no offense, a shoemaker²³ and he went and he converted and married me in order to raise the kids. He got Nahed, Hamdi, and Hanna married. And we still have Zeinab with us in her first year of industrial studies... And our conditions ‘are the zero’ or conditions are minimal. Thanks God I always say... Well the life goes on and I got used to that and we are content with whatever we have *elhamdulillah* (thank God). This is my life, *ya setti* (oh madam).”

Although this woman made no direct reference to the term “illness” in her response, the prominent and eminent complexities and layers in her life shined through. Primary threads could be extracted concerning family, community, poverty, and religion that assumed different molds when I posed to her a secondary question that directly correlated “illness” and “life.” She did not directly blame her illness for hindering her ability to care for six children. Instead, she faulted the death of her husband and her community that failed to

²³ Although her husband’s occupation is a shoemaker, she says no offense because in Arabic it references to shoes also carry a negative linguistic connotation as shoes are considered something dirty and can be used to offend as an insult.

lend a helping hand. Although her current husband relinquished his former faith and converted to Islam in order to marry her, she did not attribute such an act to love. She did not hold her illness explicitly accountable, but rather explicated his intentions; he had pity on her children and this she claimed was his motive to care, not for her, but for her children. She mentioned their desperate financial situation, but evoked God as responsible for providing for her, thus allowing her to become accustomed to and content with her life. This woman was fighting a disease that had resulted in the loss of her left breast, lymphodema, and it had since advanced into her liver. She was undergoing chemotherapy and ultimately her disease may not be cured. However, these were not the things that impulsively sprung into her mind when someone, like myself, asked her about “life.” What she held to be immediately at stake in her life in the context of this dialogue was the wellbeing of her children and the ability to maintain a viable lifestyle with the help and provision of her current husband and God. Nonetheless, these main themes were still invariably related to her illness experience.

Although this woman did not directly mention or relate her illness to her life and what was at stake in it, I did not consider her “stream of consciousness” to be an act of denial, as Kleinman (1988) seemed to assume of Dr. Song’s, whom as a terminally ill cancer patient “evaded” discussing his disease or treatment in direct terms with Kleinman (1988). Instead, the way she saw her illness manifesting in her life carried undercurrents that she did not associate implicitly

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with her financial struggle or method of caring for her children on a day-to-day basis. This suggested that “illness” had affected her life, but she affirmed that it had only intersected; it did not run parallel to the entire continuum of her life - as she stated, “life goes on.”

When I decided to enact Kleinman’s (1988) “illness narrative” construct by directly asking her the question, “how has your illness affected your life?” she interestingly did not address any of the key themes related to illness that she correlated with “life.” Her thoughts took a drastically different path and became solely focused on the specifics of the somatic and medical experiences she had in her life. Primary threads surfaced pertaining to the physical and bodily description of her illness, her interactions with doctors, and her treatment regimen. Again, her “stream of consciousness” did not follow any specific pattern and frequently she would get carried off on “tangents” that were incited by various trigger words or ideas flowing through her mind. She spoke briefly about her previous occupation baking bread, which then triggered her to speak about her current inability to raise her arm over her head. The topic radically altered when soon after she described her reasons for coming to Fakous and the other doctors she had seen in the past. She talked about the cost of travel to these different facilities and then about the quality and types of treatment she had received. Her train of thought drastically changed again, addressing the process by which her disease was diagnosed and then she backtracked recounting her interactions with the

doctors in the various facilities she visited. (Das 2006; Dodd et al. 1985; Kleinman 1988)

The variability in this woman's discourse depending on the question asked reveals drastically different descriptions of her experience with her illness and the extent to which it is made meaningful within the context of her life. Kleinman's (1988) "illness narrative" construct is too narrow to explicate this phenomenon as it only refers to life in the immediate context of illness. In this instance, by applying a broader scope, we learn how illness has afflicted her family and her relationships with them, while in Kleinman's (1988) model, we only gain a direct picture of how her biomedical, somatic and bodily experiences have impacted her. It is clear that illness is further reaching than just the immediate bodily effects usually associated. Kleinman's (1988) approach predisposes the listener to ignore or compromise the true extent to which these women's illnesses afflict their lives. A broader scope must be applied to fully appreciate the various aspects of illness that may be debilitating to what is most meaningful in their lives. It also provides a more practical and comprehensive understanding of the ways in which various factors in a patient's life impact timing, methods, and duration of diagnoses, treatment, and pathways to care that are selected. (Das 2006; Dodd et al. 1985; Kleinman 1988)

A- SYMBOLS: “SYMPTOMS” AND “CAUSES”

Kleinman states:

“The meanings of symptoms are standardized “truths” in a local cultural system, inasmuch as the groups’ categories are projected onto the world, then called natural because they are found there... As a result it is more sensible to speak of local systems of knowledge and relationships that inform how we regard symptoms...” [Kleinman 1988:10,15].

According to Kleinman’s (1988) observation, it is indeed sensible to assess patients’ understandings of their disease according to their society’s accepted views and protocols as opposed to only by those imposed by medical “doctrine.” Patients’ somatic experiences of life with breast cancer were entrenched in a complex causal nexus. Contrary to Kleinman’s (1988) understanding of the correlation between chronic illness and life, the first recognition of symptoms or onset of illness did not always cause a woman’s life to take a turn for the worse. Both illness and life operated on separate scales that intersected at various phases of illness impacting differently the lives of patients. This model may explain why some patients would seek certain modes of treatment at different phases of illness and only upon noticing certain varying “signs.” The phases of illness were not necessarily predictors of life events as the following passages will demonstrate.

“The ill body is certainly not mute- it speaks eloquently in pains and symptoms- but it is inarticulate,” as Buber notes (Frank 1995:2). Medical anthropologist, Gay Becker states, “When their health is suddenly disrupted,

people are thrown into chaos. Illness challenges one's knowledge of one's body. It defies orderliness," (Becker 1977:37). For some women, chaos struck upon entering biomedical facilities and negotiating its forms of treatment. A 40 year-old woman with metastatic breast cancer related:

"I got ill. Even this time when he (the physician) saw the *mesh ad-dhuri* (CAT scan), he found it had spread until the skull bone. They forbid me from moving because even my ankle...when I step on my leg... I get tortured a lot when the anesthesia effect goes away. I mean my situation is hard. I keep screaming (from pain)... I'm living now on drugs (anesthesia/pain killers) that allow me to talk, but when the effect goes away I just stay quiet... so I'm coming to take the sessions because they say that the pain can calm a little..."

Another patient exclaimed, "This scar is hurting me. (*She rubs where she had the mastectomy*) The scar itself is hurting me. Like when I'm sitting, it is like there is a fire! A fire!"

Often patients struggled to define this chaos through descriptions of their somatic experience. The chaos that illness had brought upon this woman was emphasized in her struggle to articulate it, drawing on metaphors and specifying the location of her pain rather than utilizing biomedical terms to describe her sensations. A Lebanese woman, Evelyne Accad, who had written about her experience with breast cancer, mirrored such experiences of rural Egyptian women fighting this disease in the biomedical realm. "From now on, I belonged to all my sisters who have been mutilated, subjected to a mastectomy, hysterectomy, cliteridectomy, i.e., all the ectomies," Acad states (Malti-Douglas 2001:72).

The symptomatic recognition of the onset of disease, disability, or distress that patients tended to correlate with "illness" did not always immediately strike

panic into their lives, but eventually it had some effect. When illness disrupts a person's life, the bodily sensations it provokes become key points of reference for observed change. It is the bodily physical, emotional, and sensory restrictions and alterations that illness generates that can cast a sick person to a whirlwind of ostensible anarchy and disarray. "Biomedical breast cancer symptoms," however, were not always attributed to the disease in the villages. Variations in the nature of these "signs" mandated the exigency with which patients would seek medical attention. A woman in her 40's recalled that the day her daughter discovered "the thing in her breast" the neighbors and her daughter were swearing at her and shouting at her the Egyptian saying "your day is black," indicating this discovery was a bad omen or sign. It was this prediction of "bad fortune" expressed through a linguistic idiom that this woman used to describe the chaos inspired at the sight of her physical abnormality. (Becker 1977; Frank 1995; Morsy 1993)

Another woman in her 50's diagnosed with metastatic breast cancer in her bone marrow related:

"I was living my life normally. There was no problem. I mean having a normal life and working at home. Then I found that *biti'i* (thing or piece) that I have by surprise. I was working in the house and then I went to have a shower. I found my breast enlarged and I went to the doctor. The doctor said "You had this a while ago..." but I didn't notice. It never hurt me at all and that was surprising. And after I went for Umrah (pilgrimage) in 2006 and I had it removed in 2007 when I went to the doctor and he told me that you need to remove it immediately and they removed all of it. That's the story. Currently, I have it in my leg and I am coming right now to have sessions. Its normal."

This patient described a tumorous lump as a “thing.” Other interviewed patients described physical changes as “bruises” “little grains” and “small residues” on their breasts, legs, and chest. Many patients like this woman spoke about discovering masses or irregularities in their breasts by surprise while showering or bathing; however, the initial shock did not always influence patients to immediately seek the medical attention of a doctor. In fact, only 5% of abnormal changes in the breast were actually discovered by a doctor, 7.7% using a self-breast examination. 86.7% of irregularities were discovered by chance. This particular woman dismissed the “thing” since it was not painful until she found her breast becoming “enlarged,” at which point she sought medical help. She viewed the symptoms she experienced and the presence of the disease in her leg as something “normal.” (Dodd et al. 1985; Down Staging Project. 2007; Mol 2002; Morsy 1993; Morsy 1980)

Another woman described her symptoms as the result of breastfeeding her baby. She stated:

“I was pregnant and my daughter was breastfeeding one month and a half and after she hated it. She breastfed from one breast but refused to drink from the other. I come to give it to her but she just refuses it and she is just a child of two months and a half and after it froze and (became) big and horrible, horribly red. Then I told my husband and he told me “let’s go to the doctor.”

This patient indicated that her first symptom was her baby refusing to breastfeed. 44% of women from villages in the Sharkiah district breastfed between six months to a year and a minimal 0.55% breastfed less than three months. 28%

would breastfeed up to two years and only 5% would breastfeed for a longer period of time. This woman described her breast as having become “frozen” “big” and “horribly red” after noticing her baby’s refusal to breastfeed. Although she acknowledged her baby’s change in behavior, it was not until the physical and observable changes in her breast appeared that she was inspired her to consult her husband. In fact, 47% of women from Sharkiah villages believed that such symptoms did not merit even an important complaint. This augmented the explanation of why it was not until the onset of late stage symptoms that actually “looked” serious that women then took the step to consult others for advice. Contrary to the prevalent stereotype of the domineering and restrictive patriarch in peasant societies in Egypt, statistics show that only a minimal 2.2% of women were actually prevented from seeking treatment by their husbands. The couple conferred that she should see a doctor. (Dodd et al. 1985; Down Staging Project. 2007; Lindsey et al. 1985; Messias 1997; Morsy 1993; Morsy 1980; Morsy 1978)

Most patients attributed such alterations not only to breastfeeding, but also to certain eating habits, “beating” or scrubbing the chest while bathing, stress, an accumulation of breast milk as well as various “superstitious beliefs.” Certain superstitions in the society claimed that such irregularities were related to the breast milk. It was not uncommon for women experiencing such symptoms to be accused of “breastfeeding from the horn of the devil,” as the Egyptian superstition said. Another young woman in her 30’s told me that she discovered a lump in her breast accidentally while bathing. Upon such a discovery, she decided to consult

a female neighbor. The neighbor told her that “stress caused the “Chinese tumor.” Stress was considered a common cause of breast cancer and many other illnesses in rural villages in Egypt. Patients also attributed the “evil eye” and “bad omens” to the onset of symptoms as well. One woman motioned to her missing breast and stated, “When my brother died, bad luck followed me and caused bad things to happen.” (Levi-Strauss 1963; Lindsey et al. 1985; Salem et al 2003; Morsy 1978; Morsy 1993; Morsy 1980;)

B- NEGOTIATING “CULTURAL” SYSTEMS AND SEEKING TREATMENT

Upon noticing such symptoms, family members, close female friends, and women in villages typically became immediate sources for consults and information. It was common for women exhibiting symptoms at various stages of the disease to consult these sources before resorting to doctors and hospitals. Several patients stated that they had already established informational units amongst close family and friends in their villages and thus they preferred not to share their experiences with others (strangers) if they were not required to do so. (Lindsey et al. 1985; Messias 1997; Morsy 1978; Morsy 1980; Morsy 1993)

However, various social stigmas and misinformation about breast cancer within these rural communities had the potential to influence patient choices in seeking treatment and outside aid. One woman with breast cancer stated, “I just don’t want people to look at me differently and I don’t want anyone to experience

my illness.” A patient’s mother stated, “My community says that it (breast cancer) is a dangerous disease... I do not know anything much about cancer though. People tell my daughter not to lift anything by her arm since it will affect the tumor.” Psychotrampa was also deemed a cause for cancer. One woman said it was hereditary, while another shared that her family members thought that her disease was contagious and so her relatives went to get checked at the hospital. Breast cancer was typically seen as an illness that could affect anyone. After seeking advice from their familial networks concerning their medical complaints, Fakous Cancer Center statistics show that 68% of women would then visit a general practitioner in their village while 32% would see a doctor at a cancer center. Before resorting to the biomedical realm however, some patients and their families recommended seeking the aid of traditional healers. (Dodd et al. 1985; Down Staging Project. 2007; Lindsey et al. 1985; Morsy 1980)

Traditional healers would typically prescribe honey to ‘remedy’ such symptoms. Patient symptoms were often not linked to breast cancer. But traditional healers who were aware of the association between such symptoms and the disease or if symptoms appeared too serious for natural remedies to treat, they would then refer patients to seek help from a doctor. The remedies prescribed by natural healers were generally less harsh and more conducive to the needs and lifestyles of these women. They were not required to commute back and forth to receive medications that would make them egregiously ill over extended periods of time as was inherent in seeking treatment from biomedical facilities.

Traditional healers would simply send them home with remedies that were easy to administer and would result in relatively fewer side-effects than those of biomedical facilities. (Ibrahim 2003; Saad et al. 2005)

Despite the religious and historical contexts of this ancient remedy within rural societies in Egypt, most of the women I interviewed at Fakous Cancer Center were actually quite wary of the powers honey actually possessed to remedy breast cancer. Others feared falling prey to charlatans and paying exorbitant prices for their treatments. The treatments offered by traditional healers were also uncompensated by the government, unlike many of the treatments offered by the biomedical realm. One woman in her mid-30's with stage IV breast cancer traveled from her village to Fakous Cancer Center after initially resorting to traditional healers. She recalled:

“I heard about herbals- that they may help. I called my cousin in Cairo to ask about their effectiveness but he said that it is just a rumor that they help. He told me that they will only give you some honey and an herbal that I do not recall the name of and some others. That is it. I do not believe they have an effect because when we called them (traditional healers) they told my husband to deposit 1070 EGP (US \$107) as just part of the total fee. They told him to just send my papers and my analysis. That's it! They did not even ask to see or examine me! So I did not try. I am just sticking to the chemo and the radiation.”

Another woman in her 40's with stage IV breast cancer at Fakous Cancer Center stated:

“I went to go see a traditional healer after a year of having this thing in my breast. It was not painful but it was becoming very enlarged and changing color. The healer told me to apply honey on it every day. I took a jar of honey home and I followed his advice, but it was not helping. The thing was just getting bigger, so I

went back to him. I told him it is not working. He told me that he could not help me and that it was too serious for him to treat. He told me to come here to Fakous for treatment.”

Usually the secondary approach to treatment involved seeking help from general practitioners in the villages and traveling to biomedical facilities in the region. Only 8.8% of patients admitted that fear from diagnosis was the perpetrator in delaying medical assistance, and 21% of those diagnosed stated that they wanted treatment but were afraid and lacked complete confidence that it would help them. On the contrary, over 66.7% sought treatment immediately at Fakous Cancer Center when advised to do so by their general practitioner in the village. The general attitudes of 68% of diagnosed women were conducive towards treatment and they were confident that it would help them recover. However, if patients were prescribed drugs that were ineffective then only about half would return again to the general practitioners or medical facilities for help. (Dodd et al. 1985; Fakous Cancer Center 2007)

For some patients the experience of going through the various treatment processes in biomedical facilities posed a series of consecutive hurdles. They blamed the biomedical approach for preventing them from fully returning to their normal routines- caring for their families, children, and maintaining their roles in society. Fakous Cancer Center statistics indicated that 20% of women complained about the high cost of seeking treatment at their facility, 15% complained about having no time, 6% complained about the distance. (Down Staging Project. 2007; Morsy 1993)

Although illness had disrupted their lives, it was the biomedical approach that some patients thought had kept them entrenched in “chaos” especially when treatments failed. One woman who was wheelchair bound stated:

“Inside me I feel tired and sick. I was fine before these three doses. I could clean and do everything, but when I take the dose of chemo it influenced my legs. It suffered or inflicted me such that I can never walk. There is a big pain in my legs honestly. It doesn’t go away all night.”

Another woman stated:

“Look. My children are not having me around all the time now. They are *mahroum* (deprived). When I go and come back my middle child cries about me. And you know that the situation is not easy. The eldest daughter remains crying about me too, but the youngest one is with their *settihoum* (“lady” or caretaker). She is always with them and my mother-in-law- she is the one who cleans, showers them, and does everything for them...so they do not know me. They only know their lady and their aunts. My husband and my family are taking it easy and giving me my rest. Before I could do my work and now they don’t tell me to do anything. There is no problem, but I am feeling sick inside. ”

These women reference the ways in which their illness has impacted the dynamics of the family. For this woman, as with many of the patients I interviewed, home-life and community-life were central elements to their streams of consciousness on “life” and “illness.” Roles have been reversed- the family must now take care of them by relieving them of their duties. The second woman indicates feelings of being replaced by the female friend and extended family members that have usurped her position as caregiver and provider for her children. What is most at stake in this woman’s life is her relationship with her family and her illness has challenged that bond. Although such chaotic events have changed her life, she still states “there is no problem.” She isolates there

being an issue in her home with the issue of her illness. Many women went for years carrying out their daily duties and living their lives without giving heed to the growing mass in their breast, but once they did address their symptoms through biomedical care, all that had changed. (Lindsey et al. 1985; Messias et al. 1997; Morsy 1978; Morsy 1993; Morsy 1980; Salem et al. 2003)

C- “BELIEF” SYSTEMS: COPING AND CURES

I never directly posed the question, “Why do we suffer?” to the women I interviewed, but somehow this question seemed intrinsic to their discourses. Because breast cancer and its “symptoms” were commonly perceived as universally and ultimately caused by God and fate, just as death was something from God and fate, the coping methods patients employed tend to stem from religious and certain cultural ideologies. Kleinman argues, “For the chronically ill, details are all. To cope with chronic illness means to routinely scan minute bodily processes. Attention is vigilantly focused, sometimes hour by hour, to the specifics of circumstances and events that could be potential sources of worsening,” (Kleinman 1988:47). (Husain 2003; Ibrahim 2003; Saad et al. 2005)

Contrary to Kleinman’s (1988) statement, the women I interviewed were not obsessed with chronicling the different aspects of their illness and symptoms. They did not scrutinize the different bodily effects of their illness as it progressed, but tended more toward an attitude of acceptance or denial than one of self-pity

and obsession. Only specific somatic and illness experiences that directly influenced what was most meaningful in their lives were harped upon in their discourses. The woman who admitted to being overcome with sadness upon realizing that her breast had been removed immediately after asked for God's forgiveness. The woman who eluded to the afflictions her illness caused through the financial hardships faced by her family, concluded with the declaration that all provisions are from God. I asked another patient bound to a wheelchair left to care for two children, who it was that helped her. She responded by stating that God is the Helper, Thank God.

The "why me?" question was never blatantly exposed in discourses about "life" and "illness." Patients often evoked colloquial and religious phrases and their faith in God when lamenting their situation. Patients would adopt a literary form of expressing discontent and then excusing the ailment. Their usage of such phrases did not necessarily mean they were religious individuals, but rather these common religious phrases had been adopted to fit a cultural context specifically in referring to discourses on illness. "Thank God- *Elhamdullillah*," "God willing- *Incha'Allah*," "God forgive me- *Rabbi Aghfirli*," "God cure me- *Allahu Shafani*" "God knows all-*Allah howa A'alim*," were such idioms evoked by both Muslim and Christian women with breast cancer (Figure 6). (Husain 2003; Ibrahim 2003; Saad et al. 2005)

A central theme in Islamic theology is the notion that one's life is written or foretold. Because of this belief, illness was viewed as just a part of the continuum of one's life. Because this life was considered just a stepping stone to the afterlife, any sort of illness in this life was seen as penance for the afterlife. Such notions were also implemented in governing one's outlook on other life problems as well as those related to illness. One breast cancer patient stated:

"I was working. I was baking bread for people and selling vegetables in the market and now there is nothing. I cannot work anymore... no, and I cannot even raise my hand over my shoulder. Well, it is only God who is taking care of us and all the money we are making goes directly to the hospital and I hope it will come to something (solution). What can we do? We are content. Thank God."

Patients, like this woman, tended to adopt a sort of acceptance of their illness and other issues since they contended that it was God's will that they were afflicted with it in the first place. Thus, religious ideology played a crucial and central role in patients' perceptions and management of illness and how illness was discussed and manifested in their lives. (Husain 2003; Ibrahim 2003; Saad et al. 2005)

Religious references within the discourse of illness also influenced patterns of treatment and even methods for seeking help. As God is viewed as the ultimate healer, some patients would delay seeking biomedical treatment. Instead they would make pilgrimage to Mecca, or visit various religious shrines and leaders to help them deal with their illness. There were countless supplications or *dua'a* that addressed particular ailments. The drinking of the holy water *zamzam* from Saudi Arabia was also considered not only a spiritual purifying act but also a

physical one. Drinking *zamzam* water was believed to cure and restore the balance in the body, mind, and soul. (Husain 2003; Ibrahim 2003; Saad et al. 2005)

This phenomenon is clearly illustrated in Malti-Douglas' account of a Moroccan woman Leila Lahlou who was afflicted with breast cancer and spent a number of years negotiating biomedical treatment in Morocco, France, and Belgium. She recalls in her autobiography Do Not Forget God (*Fala Tansa Allah*), her plight with biomedical care. She discovered an irregularity in her breast while taking a bath and endured chemotherapy treatment, but it was not until her 'umrah pilgrimage to Mecca and her maintenance of an aesthetic diet on egg, bread and *zamzam* water that she was cured of her ailment. Although her belief systems entrenched in specific Islamic ideology may have directly correlated aesthetic acts to remedying her breast cancer, she soon after passed away from intestinal cancer (Malti-Douglas 2001:69-73). It is evident from the parallels drawn between these discourses on illness, the significant role religious beliefs and symbols may play in helping a woman make sense of, cope, and even cure her illness. Thus this ideology has an impact on patient experiences and interactions in the biomedical realm. (Dodd et al. 1985; Husain 2003; Ibrahim 2003; Morsy 1993; Morsy 1978; Morsy 1980; Saad et al. 2005; Salem et al. 2003)

By analyzing the "streams of consciousness" Egyptian woman shared with me pertaining to "life" and "illness" using aspects of the Kleinman's (1988)

“illness narrative” construction and other modes, the complexities at the heart of rural Egyptian women’s recollections of what living with breast cancer meant to them became apparent. What it means to be ill or to suffer takes on new meaning depending on how a question is phrased to a chronically ill patient. Awareness of this phenomenon can permit light to be shed on new ways to understand what is truly at stake in their lives and thus impacting their negotiation of symptoms and treatment for this illness. (Dodd et al. 1985; Morsy 1993; Morsy 1978; Morsy 1980)

Treating breast cancer is a costly endeavor not just for hospitals and physicians, but also for patients, their families, and communities. The process requires time, commitment, motivation, money, transportation, and support for patients to successfully complete treatment regimens in the biomedical facilities. The biomedical treatment of breast cancer is equated to having poison pumped through the body. There is no guarantee of a cure after patients undergo such difficult treatments. Thus, it is not unordinary if patients take the road of complacency, refusing treatment and choosing to die naturally.

Rural Egyptian women carry these elements of discourse on illness with them to the biomedical realm. Thus, viewing patient discourse on illness solely from a biomedical perspective in the doctor-patient relationship does not always elucidate their reasons for failing to complete treatment regimens and late diagnoses. However, when patient discourse is situated within this broader

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context of their life, their approaches, conceptions, and methods of coping become clearer. (Lindsey et al. 1985; Malti-Douglas 2001; Messias 1997; Mol 2002; Morsy 1978; Morsy 1993; Morsy 1988; Morsy 1980; Salem et al. 2003)

CHAPTER 3

“THE IGNORANCE GAP”

Differing Illness Discourses in the Doctor Patient Relationship



The doctor's office was a small, plain room at the end of a hot and narrow corridor. It was nearly noon and Fakous Cancer Center was bustling. The line to see the doctor was growing steadily and I maneuver my way through its din of distressed patients and their loquacious family members, neighbors, and friends. The door to the office was closed so I knocked. Instantly, it flung open and I was welcomed in by Noura, the secretary, and her broad arms and shining smile. "*Ya doctora! Izeyek?*" she exclaimed embracing me. Dr. Zuber stood up in front of his cluttered desk and shook my hand. I gave my *salam* to the middle-aged woman reclined on the examination table. Noura removed a tower of patient files stacked on a metal chair and motioned for me to sit. I situated myself unobtrusively at a corner of the desk so Dr. Zuber and the patient were at a distance to either side of me. Dr. Zuber thumbed through the woman's file, extracted a chest x-ray from a large folder, and squinted at it. The woman was silent and waiting, as was I. Dr. Zuber tapped his fingers on his pursed lips. "The breast mass has increased. The chemo is not working," he finally exclaimed and pulled on a white latex glove. As Dr. Zuber initiated the exchange, he assumed his role as healer and the woman became patient. I was thus solicited to engage my role as participant-observer.

The patient was a sturdy woman with a short frame and prominent facial features. She opened her blouse revealing a swollen, hard mass jutting from her breast. The doctor poked and prodded the foreign mass also feeling the auxiliary nodal area under the arm to sense the span of the spreading cancer. There were

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no words exchanged as he worked diligently measuring the mass with a ruler, comparing his observations with the patient's chest x-ray pinned against a light box on the wall. With a black marker he mapped the target region for radiation therapy by drawing on the woman's chest a box around the afflicted region and an X marks-the-spot on the tumor. "You can come off the table now," were Dr. Zuber's first words to the patient as he slipped out from behind the white-clothed divider allowing her to dress in private. He removed a legal pad with a Fakous Cancer Center header from a desk drawer and scribbled on it her next treatment course. The woman took a seat in front of his desk. He ripped the paper from the pad and handed it to her. "Give this to the doctor who will give you your chemo and radiotherapy sessions," he instructed. The patient nodded her head, thanked him, and exited the office.

Dr. Zuber showed me her x-ray; a large white area emerged from the black chest cavity. "This patient has TIII stage breast cancer," he explained pointing out the tumor. "She skipped four months of chemo! She was supposed to remain on it for a year and now the tumor has advanced.... All I can do here is to treat these patients, to write the prescriptions when I see something wrong." "What if you explain to her that she must stay on the treatment?" I asked. He shrugged. "The problem is that in some communities you can tell patients the *truth* and there is no adverse patient reaction, but in this community they just see something corrupting their lifestyle but they don't understand the medical entirety of the

problem. If I tell them the *truth* they will become afraid and they will not come back.”

When patient discourses on illness and life encountered the biomedical realm and interacted within doctor-patient relationship a schism occurred that I have called the “ignorance gap.” This “ignorance gap” was fueled not only by socio-demographic differences between doctor and patient but also by the ways in which language was employed to define and discuss the body. This should provoke us to rethink what is “truthful” or “factual” about the body and illness. The human body is a dynamic and complex entity in and of itself. Although we all share a common physical blueprint and are sensitized to the corporeal and metaphysical properties of our own bodies and of those around us, this universal bearing is shattered when “the body” is verbalized. Naturally, language acts as a visceral and overarching medium in this process; however, our relation to and our perception of words are as varied as the personalities held within our composite shells. A doctor does not explain to a patient her illness as he does not believe she will understand. A patient remains silent about her battle with cancer in her daily life since she believes the doctor will simply think her “ignorant.” This in turn reinforces a specific power dynamic within the doctor-patient relationship. (Farmer 1999; Foucault 2003; Gawande 2002; Kleinman 1980; Kleinman 1988; Kuriyama 2002; Lindsey et al. 1985; Morsy 1993; Morsy 1978; Morsy 1980; Salem et al. 2003)

Doctor and patient were situated within a set of dichotomies. Differences in education, socio-economic status, geographic residence/origin, gender, and personal frame-of-reference with regard to the disease influenced the doctor-patient relationship within Egyptian healthcare system. Most doctors at Fakous Cancer Center were male and work pro-bono. Their average income was around US \$100 a month that they obtained from their private practices, which was almost triple the salary of the peasant population they service. Most doctors lived and studied in Cairo or other major cities at some time in their lives, while most peasants never left their villages or even visited a metropolitan area. Doctors were highly regarded and respected in Egyptian society, while peasants were generally looked down upon. The Arabic word for peasant *falaheen* even assumed a derogatory connotation in colloquial usage synonymous with ignorance or stupidity. Thus, the “ignorance gap” was reinforced by this stereotype of the peasant as “ignorant” *jahil* and the doctor as the *a’ali* or possessor of knowledge within the doctor-patient relationship. (Farmer 1999; Focault 2003; Goldman 1980; Kleinman 1980; Malti-Douglas 2001; Mitchell 1990; Morsy 1993; Morsy 1978; Morsy 1980; Salem et al. 2003)

Although both doctor and patient shared the Arabic language, differences in linguistic terminologies used to describe “illness” complicated the fabrics of communication and comprehension. Even what was termed “empirical language” by biomedicine was in some way biased. Byron Good declared:

“... I am more convinced than ever that the language of medicine is hardly a simple mirror of the empirical world. It is a rich *cultural language*, linked to a highly specialized version of reality and system of social relations, and when employed in medical care, it joins deep moral concerns with its more obvious technical functions” [Good 1995:5].

The ways in which language was employed and manipulated by various social, economical, personal, and cultural factors within the biomedical realm and Egyptian society became apparent. Doctors’ illness discourses were influenced by gender disparities; a majority of doctors were male treating mostly female patients for a disease widely deemed a “woman’s disease.” Most doctors working at Fakous Cancer Center resided in Cairo or other metropolitan areas commuting a few days a week to Fakous. Other doctors have moved to Fakous with their families. Some proudly declared that they were from the rural themselves tracing their familial lineage and therefore claimed they possessed a special insight and connection to the land and the people they treated. Others maintained a rather removed association with the cancer center and patients, strictly coming to treat or operate on patients and then returning back to the city where they felt they “belonged.” (Focault 2003; Kuriyama 2002; Malti-Douglas 2001; Mitchell 1990; Morsy 1993; Morsy 1978; Morsy 1980; Salem et al. 2003)

Socio-economic status varied depending on a variety of factors- some doctors were paid more than others depending on medical specialty, employment/practice status, and work hours. All doctors; however, were wealthier than the rural patients they treated. All doctors had received a formal education, but not

all the patients they treat had. The personal experience doctors had with breast cancer within their own familial and friendship networks also affected the ways they interact with patients and spoke about the disease. (Farmer 1999; Foucault 2003; Goldman 1980; Kleinman 1980; Kuriyama 2002; Malti-Douglas 2001; Mitchell 1990; Morsy 1993; Morsy 1978; Morsy 1980; Salem et al. 2003)

The biomedical term *saratan* (cancer) was used by doctors to describe the disease of their patients. In a biomedical context, disease was described as a physical experience centered on a set of comprehensive questions: who, what, when, how, and why. The National Cancer Institute identified cancer as:

“A term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems. There are several main types of cancer. Carcinoma is a cancer that begins in the skin or in tissues that line or cover internal organs. Sarcoma is a cancer that begins in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue. Leukemia is a cancer that starts in blood-forming tissue such as the bone marrow, and causes large numbers of abnormal blood cells to be produced and enter the blood. Lymphoma and multiple myeloma and cancers that begin in the cells of the immune system. Central nervous system cancers are cancers that begin in the tissues of the brain and spinal cord- also called malignancy. Breast cancer is a cancer that forms in tissues of the breast, usually the ducts (tubes that carry milk to the nipple) and lobules (glands that make milk). It occurs in both men and women, although male breast cancer is rare” [American Cancer Society 2009].

This definition illuminated the kind of language employed by doctors. It was centered on describing the microscopic, the unseen internal functions, and the external physicality of the body. Doctors not only described this disease in English medical jargon to patients but they also translated and utilized its Arabic

medical terminology as well. Doctors referred to cancer by the synonymous Arabic translation *saratan* (cancer) or *saratan athady* (breast cancer). They also use the words “tumor” and “cell mass” to describe the lumps on their patients’ breasts. It is important to recall that few patients referred to the mass in these terms. This particular difference in language usage to describe the body and illness opened up a chasm of opportunities for misunderstandings and misinterpretations between patients and doctors. (Blackhall et al. 2001; Focault 2003; Goldman 1980; Kleinman 1980; Malti-Douglas 2001; Mitchell 1990; Morsy 1993; Morsy 1978; Morsy 1980; Salem et al. 2003)

The issue of “education” was a key variable controlling how doctors would interact with patients and describe the illness to them. It was common for doctors to emphasize disparities in educational backgrounds either blatantly through their references to patients as “ignorant” or as “*falaheen*,” (peasants) or more subtly in their choice and use of specific jargon when explaining the disease to patients. (Blackhall et al. 2001; Focault 2003; Goldman 1980; Kleinman 1980; Malti-Douglas 2001; Mitchell 1990; Morsy 1993; Morsy 1978; Morsy 1980; Salem et al. 2003)

One day while I was working at Fakous Cancer Center, I had observed a doctor’s interactions with two patients that had consecutively scheduled appointments. The first patient to enter the office was an elderly woman in her sixties being assessed for treatment or surgical candidacy by a team of doctors.

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She was a widow residing with her two sons in a rural area near Fakous. She received no formal schooling; she dressed modestly in a black *djellaba* and hijab. This woman first noticed a mass in her left breast a year ago, but she was afraid to seek help because there were only men around her in her home and neighborhood. She finally had her son take her to Fakous Cancer Center, but her breast cancer was already in its terminal stage. She came to visit Dr. Yahya. Dr. Yahya was seated at his desk with two consulting surgeons to either side of him.

The patient was seated across from them, her head down and she was nervously wringing her hands. I noticed her eyes were welling with tears and she was anxious. The doctors carried on discussing her case. Dr. Yahya was visibly irritated. He rubbed his eyes and groaned. Instead of turning to converse with the patient or explain to her the situation, he turned to me to air his frustration exclaiming that due to ignorance this patient had come in this late stage. Dr. Yahya rocked in his chair and then pointed to the patient and instructed her to lie down on the examination table. She obediently tried to hop up on the table and lay down. She lifted her *djellaba* revealing a stiff bluish and crimson globular mass on her breast just as a bulbous flaming fungus protrudes from a withering tree. None of the doctors offered any comfort or aid to the patient during this process- they continue discussing which treatment course to choose for her. She waited silently, patiently. A few minutes later they approached the examination table. I watched the three male doctors hover over her body pushing and prodding her swelled and deformed breast. The doctors discussed the size of the

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mass and whether it was indeed operable. The patient listened, visibly uncomfortable on the table. After another five minutes or so, the doctors concretized their plan of action. They withdrew from the table leaving her still laying there exposed.

Dr. Yahya told me to go examine the patient. He handed me a latex glove. I greeted the patient and requested permission to examine her. She smiled and responded, “yes, of course *doctora*.” I feel her auxillary nodes and they are like a pulsating rock. Dr. Yahya instructed me to touch the mass. I politely refrain as I was afraid to hurt her. The patient asked him what caused this. Much to my surprise, he ignored her question and turned away rather despondently. I ask him what he would tell her. “They believe this comes from God, so we must change the way we explain it to them so it does not shock them.” He did not proceed to provide her with any explanation. He walked away from the examination table and returned to his seat.

I helped the woman sit up and slide off the table. She asked me, “Doctor, it is bad?” I too was suddenly stuck in the same position Dr. Yahya was in just moments before. I hesitated and I did not know what to tell her so I tried instead to console her. “A little... it’s a little bad, but with God’s help it will be cured. Just take care and stay on the regimen,” I told her. I was not pleased with my answer and perhaps Dr Yahya’s silence was justified. But when I told the patient that, the wetness in her eyes and the distress on her face dissipated and she let out

a sigh. I lead her back to her seat and Dr. Yahya informed the woman of the new course of action. He explained to her that the size of the mass would need to be decreased using chemotherapy. If it shrunk successfully then the mass could then be removed surgically and she would not have to undergo a radical mastectomy. The patient thanked us and left the office.

The experience this woman had starkly differed from that of the patient who entered next to see Dr. Yahya. This woman was much younger, in her mid-forties and was accompanied by her husband. She was school teacher in a nearby town located in a rural area near Fakous. Dr. Yahya openly greeted the couple and as they took their seats he cracked a few jokes with the husband. The atmosphere was suddenly much lighter and more informal. She clearly had more leverage over the situation than the elderly woman. I sensed the dynamic has shifted. The surgeons consulting on the previous case left and Dr. Yahya got straight to business. He directly conversed with the woman and her husband about her health situation. He explained to her that she had an active internal problem with the tumor in her breast.

The woman's husband excused himself to speak with someone outside the office for a moment. The woman jumped at the opportunity to address some issues privately with the doctor that she did not want to ask in front of her husband, afraid to worry him. She directly asked Dr. Yahya what caused her illness and what the state of her illness would be. Although this woman's

inquiries were identical to those of the elderly woman who was in the office before her, Dr. Yahya's reaction was not. Dr. Yahya openly and honestly addressed her concerns by providing a detailed biological and medical explanation for her illness. He even illustrated a diagram on his notepad to more accurately convey to her what he believes to be happening inside her body. The woman nodded her head and smiled in appreciation for his efforts, but she still donned a confused expression. I was skeptical that she understood much more than the previous patient would have, as even I did not fully comprehend all his medical jargon. Before she had a chance to inquire further into the matter, her husband returned. Discussion turned toward her treatment. Dr. Yahya asked the patient if she needed anything else before dismissing her. They exchanged pleasantries, her and her husband thanked him and exited the room.

Dr. Yahya drew back in his chair. Noticing my confusion he stated, "This patient is a teacher, so she is more educated and can comprehend the biological explanations... The role of the doctor is to act as both a psychologist and to treat physical problems. He must listen to the patient..."

Doctors' illness discourses not only varied in accordance with the education level of the patient they were dealing with, but also the specific vocabulary and nuances they employed changed depending on the effect they believed their words would have on a patient- either pushing that patient to pursue or abandon treatment and her faith in the biomedical system. Levi-Strauss (1963)

elaborated on the ways in which “meaning” becomes interrelated with the body through its ability to physically heal it or affect it. Levi-Strauss (1963) spoke of a song used by shamans in South America to help a woman in childbirth. He related:

“Once the sick woman understands, however, she does more than resign herself; she gets well. But no such thing happens to our sick when the causes of their diseases have been explained to them in terms of secretions, germs, or viruses. We shall perhaps be accused of paradox if we answer that the reason lies in the fact that microbes exist and monsters do not. And yet, the relationship between germ and disease is external to the mind of the patient for it is a cause-and effect relationship; whereas the relationship between monster and disease is internal to his mind whether conscious or unconscious...” [Levi-Strauss 1963:197].

Although many people are able to identify with the “meaning” of the body through empirical, medical, and other sorts of lexicon, such language does not possess the ability to manipulate the psychological state in such a way that it induces a physical bodily response. Does the “meaning” a language creates then become more “factual” based on its ability to cure the body and return it to its original and universal state? According to Moerman (2002), such an argument could indeed be true. For bodies and “meaning” to be interrelated, not only must its listeners agree with the language used, but it must also elicit what he terms a “meaning response” for it to be “true” of the body. Similar to Levi-Strauss’ observations between the Shaman and pregnant woman, Moerman (2002) used the idea of the “placebo effect” to illustrate how specific names of medications or

placebos and the ways they are dispensed can create “meaning” for the body and cause it to become well again. (Becker 1977; Kuriyama 2002; Moerman 2002)

Similarly, doctors at Fakous Cancer Center and the National Cancer Institute in Cairo employed euphemisms to help generate analogous “meaning responses” in patients to the “placebo effect” or to Levi-Strauss’ (1963) shaman account. When delivering a cancer diagnosis to patients, doctors at the National Cancer Institute in Cairo and Fakous Cancer Center had devised strategies, “various euphemisms,” and in some instances even offered positive prognoses, despite absence of medical authenticity. “The term *saratan* (cancer) was rarely used when disclosing [such a] diagnosis to patients. Most doctors preferred using the words: swelling, tumor, active cells, bad cells, malignant cells and/or fibrosis instead.” In cases where patients were in the terminal stage, “nearly all doctors professed that they would never disclose” to the patient such information and some admitted to not always disclosing diagnoses directly to patients but rather to close family members first. It was almost unanimously accepted by medical officials that “the socioeconomic background and level of education affected disclosure” methods. Doctors implemented such approaches to instill trust and hope in their patients, to spare them the anxiety of hearing such a diagnosis, or simply because they did not want to invest the time in explaining to an uneducated rural woman the technicalities of her illness and were afraid of intimidating her from accepting any form of treatment. (Blackhall et al. 2001; Dodd 1985; El-Jesri 2006; El-Noshokaty 2002; Freedman 1993; Kabbani 2006)

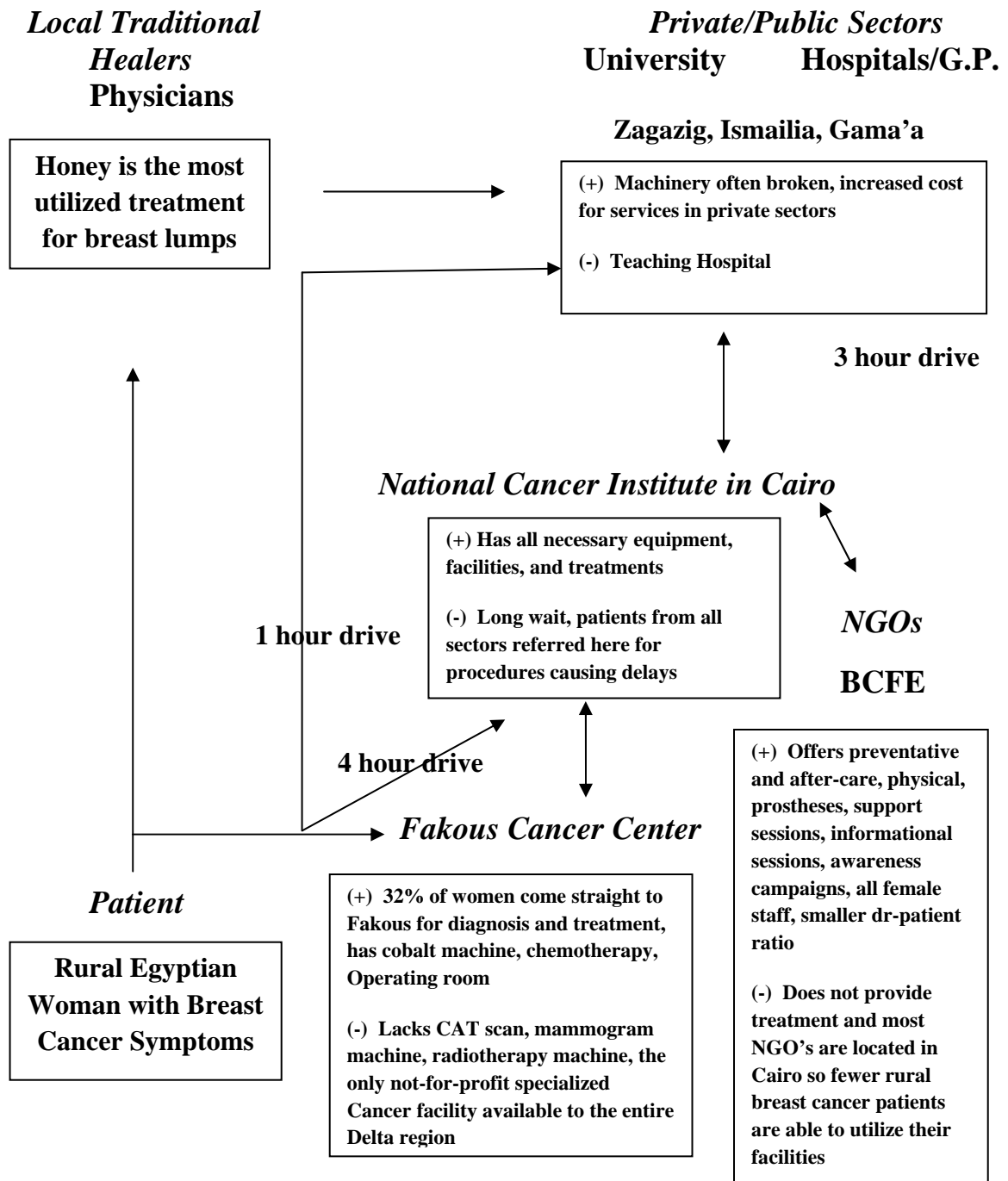
“Working at a National Cancer Center, Dr. Abdul saw many cancer victims, and he was often angered and saddened by the amount of ignorance and fear he faces, especially when it comes to breast cancer.” He related, “I don't think any woman, no matter what the level of her education, even if she were totally illiterate, would find a piece of stone in her breast and not go and seek medical help. But the sad thing is, many Egyptian women just believe that if they ignore it, it will go away. She does not want to face the reality that the surgeon may tell her 'You will lose your breast'” (El-Jasri 2008). Another doctor added, “The breast is part of the sexual identity of the woman. She fears losing it, and she cannot imagine what she would look like if she does” (El-Jasri 2008). This notion was often expressed by physicians working at Fakous Cancer Institute as well. (Blackhall et al. 2001; Dodd 1985; El-Jesri 2006; El-Noshokaty 2002; Fakous Cancer Center 2007; Freedman 1993; Kabbani 2006)

When rural women resorted to medical aid within the biomedical realm, there were four types of facilities they usually came in contact with to complete treatment regimens. Patients traveled between Fakous Cancer Center, university hospitals in Zagazig and Gama'a, the National Cancer Institute in Cairo, and various private practices scattered throughout the Delta Region in places like Gama'a, Ismailia, and Sidnawi.

A physician at Fakous Cancer Center commented on what he believed to be the function of a doctor. He stated, “The role of a doctor is to treat and to help

these people who are in a place where they otherwise would have no help...” Fakous Cancer Center is indeed the only not-for-profit facility available to communities in the rural delta region of Egypt. Other private and public healthcare facilities are expensive, lack necessary machines and treatments. NCI in Cairo, a governmental hospital, was the only facility where patients from all over Egypt could receive every type of treatment, but the facility was extremely overburdened. NGO’s were the only sources for after-care, prostheses, and therapy. The exigency at which doctors tended to treat patients was usually not situated in perspective with the needs and wants of the patient. The doctor-patient relationship was built upon a biomedical foundation that did not consider trust or open communication between physician and patient to be a vital tool in accomplishing successful treatment regimens and early stage diagnoses. The setup of the Egyptian healthcare system was thus a double-edged sword; physicians hoped to cure their patients but they also did not have the resources to do so competently, while patients hoped to get better but became lost in the labyrinth of patient care. Ultimately these factors were contributing to failed breast cancer treatment regimens that far outnumbered the cases cured. (Blackhall et al. 2001; Dodd 1985; El-Jesri 2006; El-Noshokaty 2002; Freedman 1993; Kabbani 2006)

Diagram 1. *Pathways of Care Sought by Rural Egyptian Women with Breast Cancer in the Egyptian Healthcare System.*



Transportation, finances, and unavailable machinery and medications were key factors that contributed to the shuttling around of patients between these facilities. Patients often fell through the cracks in the process thus contributing to failed treatment regimens and late stage diagnoses. One woman who was diagnosed with metastatic breast cancer at age 37 recalled:

“They told me they needed to remove my leg and then do radiation to it. In Sidnawi the machinery is broken, so I went to Dr. Imad in Gama’a. He told me that a session is EGP 150 (US \$15) and I have to take ten sessions that I need to take every day. I can’t pay EGP 150 every day.”

Another woman with stage IV breast cancer commuting from Awrein to Fakous Cancer Center stated:

“The university hospital in Gama’a is closer but I came to Fakous because the machinery is broken there. I did not try to go to NCI in Cairo because it is too far. The first treatments did not have any result, but I will continue my treatment course here and God willing I will be fine.”

A woman in her 40’s who did fair the four hour journey to NCI reported:

“I had breast cancer for five years and diabetes for six months. Originally I had gone to NCI but it was too crowded. There were sometimes up to two month waits just for radiotherapy. Instead I went to Osman Khalil Scan Center for my treatments. I am currently on hormonal treatments and being treated here at Fakous.”

Yet another woman with metastatic breast cancer complained:

“The cost to go from here to Cairo is EGP 6.50, let’s say EGP 7 going and EGP 7 returning. We must factor in the time too- four hours commute each way. I tried going and I took six doses one month ago and 1 dose in the past. Since January I took six doses and after Dr. Rashid at NCI transferred me to another facility and then I had 25 sessions and I still do not know how many are left.”

Upon asking a woman what she thought was the key issue preventing her treatment, she declared:

“Money! Money will do everything. It is needed to have information about the illness and treatments. There is also no machine that runs without money. It is money that gets the treatments and machinery. For example, if I had EGP 150 (US \$15) I would take sessions with Dr. Imad in Zagazig and I would not come here to Fakous. Zagazig is closer and now I am taking three means of transportation just to get here. I have been here since nine in the morning and I still did not enter to see the doctor. EGP 150 is a large sum of money when it is totaled- EGP 1500 for ten sessions. I had my breast removed in Sidnat for free. They gave me the x-ray and the chemo for free in Zagazig because I had the government financial aid.”

Patients paid about US \$4 a day in commuting between all these facilities. They took taxis, buses, donkey carts, and some would even hitchhike to reach their destinations. There was no direct transportation offered by these facilities to bring patients back and forth safely and easily. These facilities were not conveniently situated- to reach them patients traveled in the heat on sand-covered roads that pass through stretches of desert and farmland on a regular basis to fulfill their treatment regimens. Patients were referred to NCI from all over the country and thus the wait to get a simple x-ray or to see a doctor could not be obtained for up to six months. There was a lack of communication between these facilities so patients would often make the trip to one facility only to discover that their machine was not working and so then they made the journey to yet another facility in hopes of receiving the needed procedure. It was pure guesswork for patients as to whether they would actually get treated after exerting the effort to come to these hospitals. All these issues were tied to finances. These facilities could not afford the staff or machines necessary to care for patients effectively and efficiently. Their tight budget limited the scope of services that could be

offered to patients; the socio-demographics and financial constraints of patients also limit the frequency with which they can blindly rely on this sector of the healthcare system. (Fakous Cancer Center 2007; Morsy 1980; Morsy 1993; Omar et al. 2003)

Logistical factors did not contribute to failed or successful treatment courses alone. A patient's pyramid of needs was viewed solely in perspective to the disease by doctors, explaining why they saw it necessary to treat with such exigency. Patients, on the other hand, put their health in perspective with the demands of their personal lives explicating why they may have been more relaxed or reluctant to follow treatment regimens. According to a Fakous study conducted in 2007, statistics showed that fear and ignorance could not account for the reasons behind a majority of failed treatment regimens. Apparently the top three reasons women delayed seeking medical attention were that it was not an important complaint (47.5%), high cost (19.9%), and no time (15.5%). One Egyptian breast cancer survivor stated, "Egyptian women can endure almost anything, and they don't come forward unless they feel really terrible. Such ideals were commonly held among women between the ages 35-65, most of whom are married with children" (El-Noshokaty 2002). (Fakous Cancer Center 2007).

Allocated within the patient's pyramid of needs was also the contention between doctors and patients concerning quality of life versus quantity of life. Most doctors would do almost anything in their power to save and prolong a life even if that meant the patient would face a compromised or debilitated future.

Such decisions were made all the time. Many patients scheduled for biopsies were wheeled out of the O.R. with mastectomies, doctors put young women on hormone therapy that could result in infertility, and elderly patients were constrained to hospital beds treated with chemo and radiation that could kill the cancer but certainly compromised their immune system leaving them vulnerable to infection and death. Most doctors would argue that such measures are necessary to cure the body of the immediate ailment. However, such decisions have a strong impact on a patient's overall well-being, life, and choices to comply and complete treatment regimens.

A case that exemplifies this issue quite prominently concerned a woman in her late 40's who came for an appointment with Dr. Zuber. She concealed a plastic bag that connected to a thin tube in the bell-shaped sleeve of her *jellaba* as she lay on the examination table. She was suffering with metastatic breast cancer in her bladder. She had her bladder surgically removed a few months ago and a plastic bag was implanted in its place. Dr. Zuber asked her how she was feeling. She told us that the problem is not the cancer- the problem is the bag for the urine. She inquired if Dr. Zuber could provide any solution to the bag because it was not conducive to her lifestyle. She avoided going out in public spaces because she was afraid an accident would occur and dirty her clothing. Dr. Zuber paused and told to just be patient. The bag is the best solution and the situation will improve. The woman emphasized that she could not live like this, but Dr. Zuber was unyielding. He told her there was nothing he could do. The disheartened patient

slid off the table and thanked Dr. Zuber. The doctor turned to me. He too was distressed but for a different reason than that of the patient. He explained to me that the problem is that in some communities the truth should be concealed from the patients because they react poorly to such information. They become despondent and hopeless. This is one of those communities- patients just see something corrupting their immediate lifestyle, but they do not understand the broader and long-term implications such treatments can have in prolonging their lives.

Another young woman in her 30's underwent a radical mastectomy at Fakous Cancer Center and was suffering complications that included lymphedema. She consulted with Dr. Zuber about the recent discovery of metastatic breast cancer cells in her bone marrow. Dr. Zuber discussed hormone therapy, but she was adamantly against it. She exclaimed, "I am still young to experience menopause. I am living alone (an orphan) and I plan to get married and have children." She pleaded with him for an alternative. From a medical standpoint the hormone therapy was the most suitable option to rid her cancer; it was not the most appropriate choice in relation to her future goals and hopes to have children and raise a family. There was a fine line between choosing to prescribe these harsh drugs to prolonging life despite their side effects, and choosing to administer a less effective drug to preserve the life aspirations of the patient.

A woman in her 40's came to BCFE for a prosthesis- fitting. She was a rural woman, but she had family in Cairo that referred her to this NGO. She shyly revealed to me the fake prosthesis she had sewn herself from a piece of cloth stuffed with cotton like a small pillow. Doctors at Fakous Cancer Center contended that rural women were unconcerned with vanity and had no desire to undergo reconstructive surgery, but this woman's desperate efforts to become whole again seriously countered such notions.

Another issue reinforcing failed or successful treatment regimens concerned trust. It was important that patients maintained a certain level of comprehension pertaining to the significant changes their bodies were experiencing. Sometimes accidents happened, mistakes were made, and when these patients turned to their doctors for an explanation they usually did not receive a valid answer. This often inspired emotions like anger, alarm, frustration, and hopelessness in patients. Doctors contended that concealing the truth from patients would give them reassurance and suppress their fear. This may be true in some specific incidences, however, again the bigger picture must be considered. When a patient and doctor confide in one another, a strong bond should be formed. Health is always fluctuating, medical mistakes are always made, but when the trust and confidence between patient and doctor is established, it gives the patient the firm foundation to combat these issues. When doctors withhold information from patients, patients cannot broach their concerns

openly with their doctors and resort to making treatment decisions on their own and not within the confidence of the doctor-patient relationship.

A woman in her 60's came to Fakous Cancer Center wincing in pain and cradling her right hand wrapped in gauze. Her daughter helped her onto the examination table. Dr. Zuber quickly unbound the patient's hand. She cringed and yelped as the gauze sharply tore free the dead flesh. The pungent stench of necrosis, gangrene, and puss-filled infection choked the tiny office. To my surprise Dr. Zuber handed her back the dirty gauze instead of throwing it away. The patient held her exposed oozy, flaking hand upright as Dr. Zuber examined it. The woman was being treated for stage IV breast cancer. She had a mastectomy performed a few months ago and she was undergoing radiation therapy. She recently started chemotherapy administered intravenously here at Fakous Cancer Center. She came a few days ago for her dosage. One of the nurses in training accidentally ruptured the vein causing the drugs to leak out and spread throughout her hand. Anthracyclines are a class of drugs used in chemotherapy that interfere with enzymes necessary in DNA replication. These drugs destroy any cell it contacts. Dr. Zuber emphasized to the patient that this was a very rare occurrence- he sees maybe one case in an entire year like this, but he did not actually tell her the reason behind her sick hand. He sympathized with the pain she was experiencing, but he insisted that the only solution would be for her to undergo surgery for a hand graft. The patient inquired about the state of her hand and if it would recover, to which Dr. Zuber replied in the affirmative.

Dr. Zuber abruptly left the room to tend to some other matter leaving me alone with the patient and her daughter. We took the opportunity to chat a bit about Egypt and how they found themselves at Fakous. The daughter informed me that they live two hours away from the Fakous in a rural part of Sharkiah district. "It is the most beautiful part of rural Egypt. The flowers there are the smell of *Misir* (Egypt)," she asserted. I did not ask about her mother's hand, but it was she who confided that they were frustrated with the treatment and did not understand what was happening. Usually they see a doctor at the medical university near their village, but they were referred to Fakous Cancer Center for treatment. She explained to me that her mother began chemo treatment here; then suddenly the hand began to get very bad and they became very worried. They returned again today to see a doctor because the hand was not improving. She requested an explanation from me as to why her mother's hand was ill. I told her that a complication occurred during treatment that usually does not occur. Surgery would remove the dead tissue. The gangrene and puss continued to erupt from her hand. The mother began picking at the pustules. I told her not to touch it because it can worsen and cause further infection. I told them to try to keep the hand clean and wrap it in new bandages. They thanked me for my advice.

About 15 minutes later, Dr. Zuber rushed back into the room. He said there was nothing more he could do but to send them to surgery. He was about to dismiss them when the daughter mentioned another problem in her mother's legs. Dr. Zuber lifted her *jellaba* just enough to reveal the severely swollen limbs. He

told them not to worry and that it will resolve itself. The two women thanked him and went to schedule the surgery- the old woman still clutching her dead hand and her daughter carrying the dirty bandage.

Dr. Zuber sighed and massaged his eyes. “The patient does not understand what is happening to her hand, but she will panic if I tell her she may lose her hand. There is nothing more I can do for her besides to send her to surgery. The woman’s legs are swollen because she was receiving frontal and posterior radiotherapy treatments and the auxiliary fluids drained through the lymphatics from the frontal and posterior tissues causing lymphedema- swelling in her legs.” The doctor-patient interaction was void of such clarifications; however, it was evident that the patient and her daughter did want a more concrete explanation for the anomalous affliction and more importantly they demonstrated that they could handle the truth. When patients tended to get sicker and weaker due to these cancer treatments, they thought that they were not working and quickly abandon them. An open dialogue maintained between doctor and patient could easily help and encourage patients to stay on their treatment regimens because they would not be guessing as to what was happening to their bodies.

Another key stone in the patient’s pyramid of needs pertained to the varying importance patients and doctors placed on preserving life. Doctors considered it their primary role to prevent death, but some patients found it more agreeable just to let life take its natural course. Often the pressure physicians

exerted on patients to treat the physical malady compromised patient options and forced them into a treatment regimen that they may not have agree with. Some patients simply came for a diagnosis and then wish to return home, live out the rest of their days with their loved ones, and then die. Once doctors made a diagnosis, however, there was a sense of obligation to cure the patient.

A woman in her mid-30's came for her appointment with Dr. Zuber accompanied by her husband. She had an aggressive metastatic breast cancer tumor- chronic lymphocytic leukemia. This patient was hormone positive and thus the prognosis was good. She could either be treated successfully with chemo or hormone therapy. The patient told Dr. Zuber that she was afraid and asked him if she would get better. Dr. Zuber told her that the treatment would help and the tumor is responding to treatment. Indeed the tumor was receding. The patient acknowledged this point, but she confided that she did not wish to undergo these harsh treatments that would make her ill. She just wished to have an explanation for this change in her body and she would like to return home. Dr. Zuber discussed the options with her husband. He prepped the woman for radiation therapy anyways, but when they left the office we were unsure if they would actually comply with the treatment regimen the doctor had given them.

The "biomedical" rendering of the bodily and illness experiences had become tantamount to "*truth*" for physicians. Those who could not comprehend the biomedical language were deemed "ignorant" and this idea of "ignorance" supported certain methods by which doctors conveyed illness and treatment to

their patients. Ultimately, “meaning” became intertwined with the body in ways specific to the thickness and relativity of its linguistic description and to its ability to manipulate and heal. Doctor’s illness discourses were greatly situated within the biomedical and the upper echelons of Egyptian society. How they understood and explained the body and illness to their rural patients generated different psychological and physical reactions to the disease. Although this disconnect existed between doctor and patient illness discourses, this did not mean that there was not “truth” underlying both conceptions of breast cancer. The question becomes, what impact do these two kinds of “truth” within doctor and patient discourses of illness have on moral decisions and what impact does that ultimately have on failed treatment regimens and late stage diagnoses? (Goldman `980; Kuriyama 2001; Marshall 1992; Morsy 1988; Morsy 1978; Muller 1994; Scheper-Huges 1992; Wilce 1995)

CHAPTER 4

CONNECTING THE HEALERR AND THE ILL

Ethical Issues Embedded in the Doctor-Patient Relationship



An Egyptian peasant woman in her mid-50's recounts her experience battling breast cancer. The following excerpt is from an interview I conducted with her as part of my case study a few months after she underwent surgery at a rural cancer facility in the Egyptian Delta Region. She recalls:

“It never crossed my mind, and I never knew about this illness. I went to the hospital to Dr. Malaki and I told him that I have something on my breast and I am unsure of what it is. He touched it and immediately wrote on a paper that I needed to enter the hospital. He said, ‘This thing needs to be removed right now.’ I replied, ‘Which operation are you talking about? This thing doesn’t even hurt me!’ He laughed and exclaimed, ‘Its just you, the *falaheen* (countryside people). You don’t understand or know anything!’ I told him that no one knows about that (breast cancer) in the house so I should go back home... Then my daughter took me to Zagazig to see Dr. Faysal and he said that I need to have the operation. They held me and would not let me leave. Of course I knew that they would not take my breast and they will just take the thing inside it... But then on the day of the operation, my girls were crying and I didn’t know why. I asked them, ‘Why are you crying as I am not the first or the last to have an operation?’ I said this because I had operations before and they never cried. They did not want to tell me... When the doctor was changing my clothes (after the operation) and I looked to my breast, I became so sad and wondered why I got this sickness... God forgive me.”

Many rural Egyptian women have navigated two distinct “socio-cultural” systems- the “biomedical” and “local” conceptions of illness illustrated in their health seeking patterns. As exemplified by this woman’s account, when individuals from rural communities contacted the “biomedical” sector their “local” conceptions of illness carried over into the doctor-patient relationship and created complex fissures in the dominion of medical ethics. The doctor-patient relationship became an integral thread engaging and mediating a series of

interactions between the incoming individual and the existing biomedical system. The negotiation between “local” and “biomedical” conceptions of illness within the doctor-patient relationship have thus impacted the quality and nature of patient care with regard to ethical issues of “truth-telling,” disclosure, informed consent, patient autonomy, patients’ rights to refuse treatment, and (non)-compliance. (Blackhall et al. 2001; Emanuel & Emanuel 1992; Farah & Heberlein 2007; Goldman 1980; Keating & Cambrosio 2003; Morsy 1980; Lazarus 1988; Marshal 1992; Steinbrock 2009)

“Anthropologists traditionally have investigated the normative behavior and moral codes of cultures they have studied...” (Muller 1994:449) and have aimed to discern the ways in which biological and cultural aspects affect how people connect and interact within a set of complex bonds; medical anthropologists view the medical realm as an extension of such networks. The medical anthropological study of bioethics serves as a means of relating the observed doctor-patient relationship to overlapping “socio-cultural” systems. (Joralemon 2006; Rapp 2000)

Disparities between doctor and patient are at the backbone of variant discourses in the doctor-patient relationship leading to a series of bioethical concerns. “Although patients and physicians draw on similar concepts of moral order, they apply these constructs in distinct ways” (Hunt 1998:298). Particular religious, bio-medical, foreign, and dialectal vocabulary evoked in both doctor

and patient dialogues about “illness” are apparent throughout the interviews I conducted. Similarly, Hunt observes that in the relationship doctors hold with breast cancer patients in southern Mexico, “...physicians’ explanations are necessarily framed in terms of object, their causal stories employ generalized presumptions about how categories of persons behave (e.g., women, the lower class). In contrast, patients’ explanations are framed in terms of subject; they are based on the specific details of their personal history” (Hunt 1998: 298). It is the significance that each of these variables poses with regard to the conceptualization and causal explanations of “illness” that has, in turn, affected the practical interactions between patient and doctor. Overall, doctors label the ubiquitous presence of non-biological terms in the patient’s “illness” discourse as “ignorance.” This notion of “ignorance” (*jahil*) is often juxtaposed by ideals of “education, knowledge, non-traditional, urban, and Western.” Doctors employ such discrepancies and differences in “clinical realities” to justify their perceptions on bioethical issues of truth-telling, disclosure, informed consent and patient autonomy. Doctors hold patients’ “ignorance” of “illness” responsible for patient non-compliance and the prevalence of breast cancer in rural areas like Fakous. (Blackhall et al. 2001; El-Noshokaty 2002; Steinbrock 2009)

The medical anthropological explanatory and critical models serve as a basis for the discipline’s approach to bioethical issues within the doctor-patient relationship and are augmented by certain concepts constructed by bioethicists. “An important line of thinking in the academic field of bioethics argues that the

ultimate moral precepts from which specific ethical rules are derived are ‘applicable to all people, at all times and places, equally’ (Joralemon 2006: 110). Divergent threads within the bioethics discipline only assert that some moral rules should be context-specific and culturally relative. The medical anthropological approach to bioethics; however, contends, “The primary assumption that should guide a comparative medical ethics is that moral decision making is contextual... Moral dilemmas and the means to resolve them cannot be separated from the institutional, political, economic, social, and cultural contexts in which they are embedded” (Joralemon 2006:111). Medical anthropologists, thus, have employed the four step approach that involves determining: “the contextual nature of bioethical dilemmas; the cultural embeddedness of moral systems; the culturally pluralistic character of many bioethical problems; and the examination of the field of bioethics as a cultural phenomenon” (Muller 1994: 448). Although a growing number of bioethicists are becoming more sensitive to this approach of studying the moral elements in the patient-doctor relationship, what sets the medical anthropological approach apart is the ethnographic component. (Emanuel & Emanuel 1992; Keating & Cambrosio 2003; Muller 1994)

The explanatory and critical models when integrated into this four step approach reveal much about the power dynamics observed between patients and doctors that result from dichotomies both within the cognitive and socio-economic, and political realms shaping the “illness” experience in the medical sphere. Morsy argues that when considering the dynamic between power and sex

roles, “the debate should no longer be in terms of whether women exercise power and choice or not...” (Morsy 1978:138). Instead, “power, defined as the ‘control one party exercises over the environment of another’, is available to both parties in any social relationship” (Morsy 1978:138). The power struggle is an entity that “both enables and constrains” (Lazarus 1988:45). What factor(s) then dictates which actor within the patient-doctor relationship will dominate such implicit negotiations?

“The doctor-patient relationship is asymmetrical, and power therefore becomes domination. This domination rests on the structural asymmetry of resources: who in the situation controls medical knowledge and technology. Unequal access to these resources necessarily implies a relationship in which one actor is more autonomous and the other more dependent” [Lazarus 1988: 45].

Explanatory models help extract the root sources of such unequal distribution of intellectual resources and how it impacts the patient-doctor relationship. “Patient-doctor interactions are transactions between explanatory models, transactions often involving major discrepancies in cognitive content as well as therapeutic values, expectations, and goals” (Lazarus 1988: 37). It is the critical models, though, that situate such disparities within a greater picture to show how they are established and reinforced by socio-economic and political structures in the system. “...the practitioner’s therapeutic imperative to act and his compelling need to rationalize his actions” (Kleinman 1980:110), feeds off of such differences that create the patient’s “illness” account. Thus, when doctors are broached by ethical dilemmas concerning “truth telling” and medical care for

the “ignorant” or “under-educated” patient, they tend to enlist the bioethical “paternalistic model”:

“The physician-patient interaction ensures that patients receive the interventions that best promote their health and well-being. To this end, physicians use their skills to determine the patient’s medical condition and his or her stage in the disease process and to identify the medical tests and treatments most likely to restore the patient’s health or ameliorate pain. Hence the physician can discern what is in the patient’s best interest with limited patient participation. Ultimately, it is assumed that the patient will be thankful for decisions made by the physician even if he or she would not agree to them at the time” [Emanuel and Emanuel 1992: 2221].

Since no official or legal form of informed consent exists in the Egyptian health care system, doctors are given full leverage over such decisions. As bioethicist Goldman remarks:

“Paternalistic measures may be invoked when either the individual in question, or any rational person with adequate knowledge of the situation, would choose a certain course of conduct, and yet this course is not taken by the individual solely because of ignorance, carelessness, fear, depression, or other uncontroversially irrational motives” [Goldman 1980: 63].

Because peasant women do not express their “illness” in bio-medical terms and most lack a formal or “western” style education, doctors do not feel they are well equipped to make “medical” decisions on their own. Issues of “knowledge” and the “body” factor into how patient autonomy and doctor’s paternalism manifest within their relationship. In an interview with one physician at Fakous Cancer Center, he stated that “the role of the doctor is to act as both a psychologist and to treat physical problems. He must listen to the patient...” This, however, does not always extend to providing patients explanations or convincing patients to follow recommended treatment regimens. In a recorded

account of a Moroccan woman battling breast cancer, her doctor refers to her compliance to follow his prescribed medical treatment as “her promise to submit herself” to the plan. He states that her concern “over her physical appearance and fear of hair loss prevented her from following the prescribed medical treatment, thus helping the cancer to spread throughout her body.” Malti-Douglas observes that “the voice of the physician is at once superior, strong, and protective” (Malti-Douglas 2001: 84-87). Thus, the way doctors interact with rural “uneducated” patients starkly differs from their interactions with rural “educated” patients. A doctor often will examine an “ignorant” patient and tell her the prescribed treatment plan. Although she may ask questions, the interaction is short, clear cut, and mostly one-way. A doctor’s interaction with an “educated” rural patient; however, is often longer and augmented with two-way exchanges, questions and answers, and small talk. (Blackhall et al. 2001; Morsy 1980; Pincus 1993)

Most doctors within the Egyptian healthcare system do not feel that this dichotomous interaction with patients is contributing to or even creating patient “ignorance” and prevalence of breast cancer in rural communities. They justify the paternalistic approach by claiming that even if they dedicated the entire appointment towards explaining the “medical” situation to an “ignorant” patient, she still would not comprehend. Instead, she will become fearful and angry. She will not want to seek further treatment and this will harm her in the end. Most doctors feel a sense of hopelessness in the face of patient “ignorance.” They do not know how to make a patient “understand” her illness. Freedman suggests that the

cancer patient's knowledge of diagnosis and prognosis should be seen as existing along a continuum; however most doctors see it as a static all-or-nothing concept (Freedman 1993: 572-576).

Doctors thus consider it their duty to protect the patient from further suffering and anxiety. To do this most effectively, "concealment of diagnosis/prognosis" and incomplete patient disclosure are common tactics. Due to cultural practices and stigma surrounding breast cancer in Egypt, close family members will often receive such information instead of the patient. It is also ordinary for information to exclude patients' circles entirely and remain solely within the professional realm in which adequate decisions can be made in an efficient and timely manner. As in the case of the 50-year old woman I introduced at the beginning of this essay, doctors attribute her reluctance to comply with their advice to undergo surgery as soon as possible to be "ignorance." The doctors knew that if she delayed surgery, her tumor would grow and her cancer would advance, ultimately compromising her life. Thus, they felt obligated to operate and remove the physical malady. When a patient comes to a doctor with an ailment, the doctor assumes it to be his utmost duty to preserve the physical being of the patient. (Freedman 1993; Malti-Douglas 2001; Morsy 1988).

Although doctors consider the paternalistic approach to be most advantageous for treating patients with breast cancer, patients on the other hand

do not always agree. The 50-year old peasant woman who underwent surgery assumed that her breast would not be removed and was deeply upset and saddened when she discovered it had been. She resisted surgery and the fact that doctors barred her into having the surgery violated her autonomy and right to refuse treatment. Her daughters had been informed that she would undergo a mastectomy, but she was not told. Although doctors would argue that she had refused treatment solely on the premise of “not having heard of breast cancer before,” doctors also did not help her become anymore equipped to make an informed decision for herself. Thus the only information she could draw on was from her community and family. (Blakchall & Frank 2001; Goldman 1980; Lazarus 1980; Lindsey et al 1985)

Freedman acknowledges that in the U.S. doctors face ethical issues with regard to patient care and respecting cultural and traditional believes/practices of patients and their families. In Egypt, however, doctors encounter the reverse problem. Cultural and traditional practices with regard to illness that doctors comply to place the family at the forefront for receiving and handling all issues concerning a relative’s health. This often overbears the patient’s own autonomy and personal wishes with regard to her health. Many patients who underwent mastectomies expressed that they wished doctors had told them directly that they would lose their breasts and had given them the time to come to terms with this information. Surgeons do not have consultations with patients before or after operations. The first time they see the patient is on the operating table. One

patient described the treatment process as, “like being in a labyrinth.” Patients are left to always guess what is around the corner in this system. Many patients stated that had they known about this “illness” (breast cancer) they would have sought treatment earlier and more strictly adhered to regimens. (Freedman 1993, Morsy 1980)

Another prime issue with implementing the paternalistic approach is that doctors do not attempt to gain an understanding of what is at stake in a patient’s life. Patients’ physical well-being is assumed to be their utmost priority and concern. Although patients may go to a doctor to address a physical ailment, patients express that sometimes treating the physical malady at the exigency of doctor is not always conducive to their immediate needs or concerns. The stance rural patients took on issues of truth-telling resembled the findings of the Blackhall et al. study (2001). Most patients I interviewed stated that since this illness is something from God, just as death is from God, they should have the right to make peace with their illness and choose when and whether to treat it. Some patients wished to arrange their financial, personal, and familial affairs before receiving treatment. Other older patients wished to simply let the disease take its course and spend their final days in their communities rather than in a hospital bed. (Blackhall et al. 2001; Goldman 1980)

In light of the medical anthropological modular approaches to observing the doctor-patient relationship and its overlap with the bioethical discipline, much

can be discerned about the ethical nature of the patient-doctor relationship and the question as to its role in perpetrating late diagnoses and failed treatment plans amongst Egyptian peasant women. Breast cancer in rural areas, thus far has been tackled with emphasis on the individual rather than community. In comparison with other medical anthropological studies focusing on patient-doctor interactions, failure to maintain an open dialogue with all patients proves a detriment to the leverage doctors have in the community. Although doctors may feel they are saving patients from further anguish by hiding information from them, patients inevitably encounter suffering in this process and many even come to blame the treatment for their pain and problems. They compare their health before and after receiving treatments like chemotherapy and see an adverse affect. “The evaluation of a new technique as a standard therapy must derive, therefore, from an understanding of the social setting in which treatment takes place” as well as the personal and more complex intersecting spheres that help shape doctor-patient “illness” discourse (Muller 1994: 454) to more effectively generate appropriate modes of intervention to promote a greater moral premise for the doctor-patient relationship and decrease breast cancer rates in rural Egyptian regions. (Blackhall et al. 2001; Ellinor & Gerard 1998; Frank 1995; Morsy 1980; Morsy 1993; Shapiro 2005)

CHAPTER 5

BRIDGING THE GAPS

Targeting Prevention, Treatment, and Curative Approaches for Breast Cancer in Rural Communities



The World Health Organization holds cancer responsible for approximately 7.9 million deaths worldwide each year. More than 72% of these deaths occur in second and third world countries. According to the National Cancer Institute in Cairo, breast cancer accounts for one-third of all cancers in Egyptian women effecting approximately 18,000 women each year. Egypt's healthcare system represents a unique conglomerate of hospitals, NGO's, private, public, and not-for-profit biomedical facilities.

These medical facilities coordinated and supplemented care for patients. Central to all care, though, was the doctor-patient relationship, which once deconstructed held a primary key to late stage diagnoses, incomplete treatment regimens, and rising mortality rates. Although I utilized an anthropological basis for discerning the dynamic in the doctor-patient relationship, it was necessary to couple such observations with epidemiological, biological, and governmental overarching frameworks to practically decrease late stage diagnoses and failed treatment regimens amongst peasant women in the rural Egyptian Delta. (Abu-Zeid & Dann 1985; American Cancer Society 2009; Amr 1999 Omar et al. 2003)

**A- EPIDEMIOLOGICAL APPROACH: SURVEILLANCE AND CANCER
REGISTRIES**

The epidemiological approaches to disease management and surveillance are crucial assets to the compilation of data that will lend further insight into determining what services are necessary and efficient for managing breast cancer rates. The CDC defines surveillance as “the ongoing systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice closely integrated with the timely dissemination of these data to those who need to know” (Gordis 2009: 54).

There is currently a shortage of data on breast cancer in the Egyptian Delta Region and thus governmental and independent interventions are instituted somewhat blindly. Fakous Cancer Center is virtually the only facility collecting data and actively conducting surveys specifically in the Sharkiah governorate. The 2007 Fakous Downstaging Project was one of the last surveys conducted in the area. Health officials and volunteers implemented the “shoe-leather” epidemiological practice of going door to door collecting data from patients and residents in surrounding villages in exchange for honey. Cancer surveillance involves the collection of information from death certificates, physician reports, surveys, and questionnaires that aim to answer questions about which specific people in the area are most at risk for breast cancer, the spread of the disease at the time of diagnosis, and treatment methods and adherence. This data can be

collected through surveys, or physicians can report their findings to a national or regional data registry. (Abu-Zeid & Dann 1985; Amr 1999; Fakous Cancer Center 2007; Gordis 2009; Landskroener 2008; Omar et al. 2003)

Presently there is only one National Cancer Institute in the country that houses a majority of amassed information on breast cancer. There are only a few national data registries that exist in Egypt. The Gharbiah Population-based Cancer Registry (CPCR) is located amongst 316 villages in the middle of the Nile Delta about 60 km from Zagazig in the urban-rural governorate of Gharbiah. This registry was launched in the 1980's and was the first population-based cancer registry in Egypt.

Its main objectives are to define the breadth of the cancer issue and the pattern of cancer incidence rates. This data allows scientists to examine how breast cancer changes over time and if there has been alterations in breast cancer diagnoses and distribution. This information can then be utilized in statistical analysis that can help researchers, professionals, health planners, and policy-makers implement more effective cancer prevention plans, control and manage the disease in a more cost effective manner, and determine the effectiveness and quality of existing prevention and control programs. Although it is affiliated with the Ministry of Health and Populations of Egypt and is headed by investigators at the National Cancer Institute, Cairo University, funding remains a key issue in maintaining this establishment. (Abu-Zeid & Dann 1985; Al-Bawaba 2008; Amr

1999; Fakous Cancer Center 2007; Friis & Sellers 2009; Omar et al. 2003; Wingo et al 2005)

Although breast cancer can be a genetically inherited, 91.7% of cases in Fakous Cancer Center do not know their medical family history. The implementation of the first population cancer registry in the Nile Delta Region is in its early phases. This initiative will advance “the quality and reliability of mortality statistics [which] may be a crucial step in supplementing the registry information and verifying cancer survival studies” (Soliman et al. 1999: 353). This may ultimately provide a more adequate method of understanding “familial clustering of cancers in Egypt.” (Abu-Zeid & Dann 1985; Al-Bawaba 2008; Amr 1999; Fakous Cancer Center 2007; Friis & Sellers 2009; Omar et al. 2003; Soliman et al. 1999; Wingo et al 2005)

“This is especially important because in rural Egypt extended families reside in the same village, and several generations usually live in the same village and even the same household. This plan will help identify relatives who have died from related cancers, especially if older mortality records can be examined. Because the disease is estimated to occur in children from 35% of marriages, future studies should investigate whether the inheritance of hereditary cancers and the likelihood of familial clustering with cancer afflictions are increased in Egypt” [Soliman et al. 1999: 353].

**B- BIOLOGICAL AND DIDACTIC APPROACHES: DISEASE
AWARENESS, COMPREHENSION, AND CAMPAIGNS**

A biomedical approach is central to the fight against breast cancer. Developing more conducive and effective treatments and gaining an increased comprehension of the disease are core themes in cancer research today. Nanotechnology is one of the newest and most promising innovations in the field today. The National Cancer Institute in Cairo has joined the international race to advance this technology. The government and the institute have pumped increased funding into its research departments to launch new pioneering studies and further existing research. Laboratories at NCI are being remodeled and updated. Young students hover over centrifuges and microscopes, and professors and doctors host seminars and conferences in this expansive facility. Fakous Cancer Center hosts interns who conduct independent research in an equipped laboratory setting as well. This investment in biomedical research has given Egypt an upper hand amongst most second and third world nations in combating breast cancer. It has become an international leader in the fight against breast cancer due to its efforts to train, educate, and provide the support its scientists need to participate in the global exchange of new ideas to cure this disease. (Abu-Zeid & Dann 1985; Landskroener 2008; Omar et al. 2003)

Specific logistical and cultural barriers are fueling delayed diagnoses and failed treatment courses. The didactic approach has encompassed the formation

of community out-reach programs to promote early detection and information about breast cancer. Healthcare workers, NGO's and independent and governmental healthcare facilities have all launched such initiatives, some more effective than others. (Abu-Zeid & Dann 1985; Ahmed & Potter 2006; Al-Bawaba 2008; BCFE 2009; Dodd et al. 1985; Friis & Sellers 2009; Powell & Seddon 1997)

Although Fakous Cancer Center has concentrated efforts on awareness campaigns targeting peasant women, 86.7% of patients at the facility still discovered abnormalities in their breast by chance, only 7.7% found a lump by performing a self-breast examination, and a miniscule 5.5% of irregularities were discovered by a doctor. Patients at Fakous stated that they received most of their information about breast cancer from T.V, radio, and posters (95.6%). A minuscule 4.4% said they received their knowledge about the disease from a symposium and none surprisingly stated that they were educated by health visitors. Still, 62.4% of women in the community professed to never seeing any posters or awareness about breast cancer, a whopping 89.4% never received any explanation about the early symptoms of breast cancer, and over 80% never learned how to perform a self-breast exam. Women who did learn to perform one most likely learned from their general practitioner (47.2%). 19.4% were advised by a friend, and 16.7% were taught by a health visitor or at a symposium about Breast Cancer.

Despite Fakous Cancer Center's initiatives to control escalating breast cancer levels in the Delta Region by spreading awareness, it appears that home visits by health visitors, as they are currently implemented, have not been effective and a very large percentage of women in Fakous villages are still unaware of the importance of early detection. (Fakous Cancer Center 2007; Friis & Sellers 2009; Omar et al. 2003)

Fakous Cancer Center has also offered informational classes to patients in the past. Sessions were held at the facility about twice a week to educate women about their illness and to provide information on how they could prevent close female relatives and friends from enduring their same experience. Classes were taught by several physicians at the facility using powerpoint presentations and diagrams as aids. Staff soon discovered that few patients were willing to attend. Classes were stopped and were never resumed. In interviews with patients, I inquired about this issue. Patients affirmed that they would not attend such sessions because it was too difficult to travel to the facility to attend them and they could not spare the time away from their families and home duties. I asked patients what strategy they suggest we adopt in spreading awareness that would be more conducive to their schedule and needs. A majority of women stated that they would prefer it if educators or physicians could make home visits. (Fakous Cancer Center 2007; Omar et al. 2003)

Home visits were performed by hospital personnel before; however, they were proven ineffective. “Such outreach projects focused on creating awareness about breast cancer through public and professional education. Fakous Cancer Center trained 45 ‘pioneer’ social workers to conduct home visits. The initiative has reached 10,000 women in the area” (Landskroener 2008). Since these rural patients are still open to the idea of home visits, perhaps this medium needs to adopt a new strategy. When healthcare workers would make the journey to the villages, they would only deal with the patient and with women. I suggest that if home visits are to be made, that older children, husbands, and family members are trained and partake in the informational sessions. If women feel the burden is not entirely on their shoulders to face this disease and they have their families to rely on, home visits may then be more effective in generating a support system that is not separate from their immediate environment. (Fakous Cancer Center 2007; Friis & Sellers 2009; Landskroener 2008; Omar et al. 2003)

If outreach programs focused on training a few individuals in the community that women and family members could consult, such as midwives or local teachers, such efforts may decrease the chances that women in these communities receive misinformation and delay diagnosis or treatment. According to a 2007 Fakous Cancer Center survey, about 90% of patients do not have qualms about sharing their illness experience with others. Thus, breast cancer survivors would probably qualify as ideal individuals to train in these communities. People could resort to these capable individuals who can be easily

accessed, instead of guessing at their malady, traveling far distances to healthcare facilities, receiving incorrect advice from neighbors and family members, or resorting to traditional healers who contribute in delayed diagnosis. Traditional healers could also function as individuals trained by the hospital to recognize breast cancer. For every patient that these trained individuals refer to the hospital for treatment, they could receive a payment from the hospital. This could in turn help rectify the current trend in late diagnosis. (Abu-Zeid & Dann 1985; Al-Bawaba 2008; Dodd et al 1985; Fakous Cancer Center 2007; Veen 2003)

Targeting patients and women for awareness campaigns and inviting only women to informational classes makes logical sense since they are the ones immediately affected by this illness, however, such strategies also perpetuate the notion that breast cancer is strictly a “women's issue. Breast cancer is an illness that may afflict women physically, but the illness affects familial, marital, and social relationships as well. Rural communities in the Delta Region are rather isolated from informative hotspots- metropolises, scholastic institutions, and medical facilities. Thus, any vector that has access to such areas should be enabled to transmit information. Efforts, thus, should take on a more communal and grassroots approach. Women battling breast cancer at Fakous Cancer Center have expressed their desire that more support groups be made available to families and couples. According to Dr. Shaalan, an oncological surgeon and professor, “There are no support groups, there is no psychological approach to the patient and his family. People here believe it is a death sentence. But women can

be cured and go on with their lives” (El-Noshokaty 2002). Such sessions would help patients and their community better cope with this illness. Incorporating more people in rural communities in the fight against this illness rather than repudiating them can only help to further decrease late stage diagnoses and failed treatment regimens amongst rural communities. (Abu-Zeid & Dann 1985; Al-Bawaba 2008; Dodd et al. 1985; Fakous Cancer Center 2007; Lindsey et al. 1985; Veen 2003)

C- CHANGING A MENTALITY

In a conversation with one surgeon about Egyptian rural communities he asked me, “What do you believe ‘poor’ means?” I answered, “Poor means an inadequate infrastructure and lack of basic amenities.” “No!” he huffed. “Poor is a mentality.” Some medical officials contend that rural women with breast cancer are not doing their part to fight against the disease. Their poverty and lack of formal education are considered representative of a ‘mentality of ignorance.’ They assume that these women are “not doing productive work” in their villages anyways and by ignoring their own health, delaying diagnoses and treatment they are actually doing a disservice to their families and community. The realistic issues and obligations of these women have not been accepted into the biomedical perception of breast cancer. Physician misconceptions of their rural patients have been carelessly neglected in the planning of treatment regimens, awareness

campaigns, and other outreach efforts to decrease the incidence of breast cancer in rural areas. (Abu-Zeid & Dann 1985; Ellinor & Gerard 1998; Fakous Cancer Center 2007; Friis & Sellers 2009; Goldman 1980; Kabbani 2006; Pincus 1996; Yoder 1997)

“Fakous Cancer Center offers a number of training workshops and has designed a curriculum for physician training in the identification and treatment of Leukemia, Lymphoma, Solid Tumors, and BMT. In February 2007, Fakous Cancer Center sponsored its first professional training program addressing 45 primary health care physicians on the importance on early detection,” (Landskroener 2008). These sessions provide physicians with guidelines to deal with palliative treatment and pain management, blood products, oncological emergencies, epidemiological surveillance and family histories, statistical analyses, and supportive care. The training workshops focus on health management in non-governmental organizations, quality control in health services, management of health prospects, institutional evaluation and capacity building, result-based management and information systems, as well as, customized quality management. (Fakous Cancer Center 2007; Landskroener 2008)

Training programs should not only focus on the medical treatment of patients; they should be revamped to incorporate instructions for doctors on how to educate their patients in an appropriate manner as well. Efforts should be

concentrated in bridging the ‘ignorance gap’ that schisms the patient-doctor relationship. Most doctors are highly pressured with limited time to spend with each patient due to understaffing of medical personnel and overcrowding of patients. This also affects the quality of education that doctors are able to provide their patients with. The Fakous district is still combating physician shortages and unequal distribution. It has one of the highest ratios of 12 physicians per 10,000 citizens according to the 2003 UNDP & INPC issued by Al-Sharkiah Governorate. The number of doctors employed at Fakous Cancer Center is 45, alongside 32 nurses and 17 technicians. A few physicians and surgeons from Cairo volunteer to commute a few times per week to Fakous using a shuttle bus that departs from NCI in Cairo. (Al-Bawaba 2008; Ellinor & Gerard 1998; Fakous Cancer Center 2007; Freedman 1993; Friis & Sellers 2009; Goldman 1980; Landskroener 2008)

Since doctors are clearly overwhelmed in the current situation and most hospitals do not have the financial capability to hire more doctors, perhaps a team of health workers or trained individuals could be situated in the hospital with the specific duty of answering patients’ questions and concerns before or after appointments. Patients and their families linger in the waiting room for hours on end with nothing to do. This would be an opportune time for health workers to sit with patients and their families and address their concerns and to even filter cases that can easily be taken care of without seeing a physician. Cases of lymphedema are one of the most common reasons patients visit the doctor. Physical therapy is

the only resolution for this issue and often doctors simply diagnose the issue but do not provide patients with any exercises to reduce the swelling. Physical therapy sessions could also easily be held in the waiting room setting led by a trained individual. (Fakous Cancer Center 2007; UNDP & INPC 2003; Landskroener 2008)

D- **AMENDING THE HEALTHCARE SYSTEM**

The current set-up of the Egyptian healthcare system requires several key amendments. The National Cancer Institute in Cairo presently is the only governmental facility that is able to provide patients with all necessary services and thus this facility is significantly overwhelmed. There are a number of peripheral private, public, not-for-profit, and NGO facilities that are only able to offer limited services to patients. Egypt has founded and expanded a number of specialized cancer hospitals in the capital and neighboring cities in hopes of dissipating some of the pressure put on NCI. (Abu-Zeid & Dann 1985; BCFE 2009; Fakous Cancer Center 2007; Landskroener 2008)

Instead of relieving the stress exerted on NCI, many of these facilities are actually adding to the pressure. Patients are transferred from one facility to another in order to fulfill treatment plans. There is no coordination or communication between all these different facilities and thus patients fall through

these cracks in the system. There needs to be some common mode of transportation between all these facilities supplied by either the government or the facilities themselves to shuttle patients back and forth. There also should be a common electronic database system of all patient files that all facilities can access and that facilities update if certain machinery is unavailable. If physicians need to make referrals, they could be entered directly into the database and appointments could be scheduled effectively since the timetables of all facilities would be established. This way doctors would be able to keep their patients up-to-date on sessions and patients do not have to waste extra time and money traveling unproductively between facilities. (Abu-Zeid & Dann 1985; Ahmed & Potter 2006; BCFE 2009; Fakous Cancer Center 2007; Landskroener 2008)

The Egyptian government has declared the fight against breast cancer to be a national health priority. The Egyptian Ministry of Health has aimed to increase legislation, national data collection, quality control, and monitoring and assessment of the National Women's Health Program (NWHP). The National Breast Cancer Screening Program is part of NWHP and was launched in 2007 under the auspices of Egypt's first lady Susanne Mubarak. The program aims to increase early detection of breast cancer using mobile vans to transfer static mammography units in general hospitals to women specifically in underserved areas of Egypt and provide them with free mammogram screenings. Susanne Mubarak has also partnered with the renowned U.S. non-profit Susan G. Komen Cancer Foundation to hold a series of awareness campaigns in Alexandria and

Cairo. In 2009, giant spot lights painted the extraordinary Giza pyramids pink in honor of those who are struggling with Breast Cancer and Egypt's battle against the disease. Hundreds of thousands of people from Egypt and the international community gathered to hear the stories of survivors, to learn about prevention and care, and to participate in the walk for breast cancer. Despite all the new governmental programs and strives being made, not many of these changes seem to be reaching rural areas of Egypt. (Abu-Zeid & Dann 1985; BCFE 2009; Omar et al. 2003)

No national regulations have yet been placed on healthcare costs, governmental insurance and other types of aid. Physicians who own private practices are able to determine their own fees for any procedure they perform. The few understaffed and underfunded facilities in rural areas like Fakous Cancer Center are thus focusing efforts on providing cancer patients with subsidized or free care since a majority cannot afford the fees of private practices. When cancer devastates a family and leaves orphaned children, Fakous Cancer Center steps in to help provide for them; more than 1,200 orphans of cancer fatalities have been assisted thus far. In 2006, FCC embraced the UICC's World Cancer Campaign initiative, "My Child Matters," working to detect, diagnose, and treat children with cancer among the population of eight villages and slum areas in central Fakous." Women with breast cancer receive compensation for treatment costs from the government, NGO, and private charitable sources as well. For the most part, men women and children with cancer are able to acquire free laboratory tests

and medications at Fakous Cancer Center. (Fakous Cancer Center 2007; Landskroener 2008; Omar et al. 2003)

Efforts of not-for-profit facilities like Fakous Cancer Center have been relatively successful in providing reduced rates and free care to its patients, however, the subsequent obstacles created in maintaining this goal have compromised the quality of care patients receive. Doctors who work pro-bono and extremely long hours cannot be expected to fulfill all the medical and educational demands of patients, or to feel invested in their work environment one-hundred percent of the time.

Non-profit facilities and NGO's that offer free services tend to adopt the attitude that they are offering a free service to these people, they possess a better understanding of their situation, and thus they need not consult or debate with them about how to better address their condition at hand. This outlook is inevitable, however, it can be changed by adopting the appropriate measures that will alleviate current pressure exerted on doctors, patients, facilities, and the healthcare system overall.

Rural communities do not simply need compensation, they need empowerment. Grassroots, non-profit and NGO institutions need to provide rural communities with the tools they need to battle this disease. The current approach of implementing foreign and marginal facilities on the periphery of rural communities and remaining hopeful that awareness efforts and calls for treatment

will penetrate the society are futile. Efforts need to originate at the core of communities. Families need to possess the knowledge and ability to access and provide care to one another instead of depending on or reaching out to external medical establishments. This is how awareness will spread and incidence rates will decrease. (Ahmed & Potter 2006; Al-Bawaba 2008; BCFE 2009; Ellinor & Gerard 1998; Harro 2000; Kilby 1993; Powell & Seddon 1997)

Unlike most of the pandemics of today, breast cancer is not an infectious disease. It is not pathogenic or contagious and thus it cannot be eradicated through quarantine or an influx of medicines and vaccines as typically observed during infectious disease outbreaks. Cancer, medically known as a malignant neoplasm, is categorized as its own class of disease. It is a non-infectious, chronic disease, like diabetes or asthma, and is thus treated using other tactics. Research infers that breast cancer may still be transferable person-to-person- not through physical contact, but through certain genes can be passed down that increase susceptibility to breast cancer. Contact with specific contaminants and sources in the environment may also promote cancer development. (Amr 1999; Friis & Sellers 2009; Omar et al. 2003)

Altering someone's biological composition and environment prove broad, difficult, and even impossible tasks in many respects, and hence, eradicating cancer has taken on a more "targeted" treatment approach; by this, I mean that only specific individuals who present symptoms in a healthcare facility will be

treated. There is an invisible grid within the system filtering out who will receive medical treatment and in which healthcare facilities. Although breast cancer is one of the most common causes of death worldwide and the most common form of cancer in Egyptian women, the way in which Egyptian women experience the healthcare system in terms of defining who will receive treatment is strongly determined by the same socio-demographic factors and pyramid of needs that influence which women are diagnosed and informed about their illness by physicians. (Abu-Zeid & Dann 1985; Amr 1999; Fakous Cancer Center 2007; Magrath & Litvak 1993; Pincus 1996; Scheper0Hughes 1992; Yoder 1997)

CONCLUSION

Anthropological approaches are crucial to discerning the humanistic patterns of disease and when coupled with epidemiological, biomedical, and didactic approaches to disease distribution in populations, more effective and efficient prevention programs and treatment techniques can be employed. My fieldwork and subsequent case study sought to utilize and unite the ideas of these various disciplines in the goal of discerning the cause of soaring breast cancer rates in the rural Delta Region of Egypt. I have attempted to exploit my findings in a more practical sense and relate them to the current Egyptian healthcare model and situation. In accordance with such results, I thus have aimed to generate and suggest a few feasible adjustments that could be implemented in current

interventional models to amplified efficacy in decreasing breast cancer rates. This case study examining rural breast cancer patients and their negotiations within the doctor-patient relationship and the healthcare system serve as a contribution to other developing nations like Egypt battling similar issues. (Harro 2000; Magrath & Litvak 1993; Omar et al. 2003)

It is evident that socio-demographic factors distinguish the rural patient from the doctor in Egyptian society. When these attributes are examined within the biomedical realm, their effects cut deeper shaping the illness experience of patients and illness discourse of doctors. There is not one face to disease or illness as patient and doctor discourses reveal. There is no perspective that is blatantly incorrect, but there also is no collaboration or connection between these different views. The tension between the patient and doctor philosophies must be abandoned and the “ignorance gap” must be overcome if the ethical dilemmas faced by physicians and patients are going to be treated in a manner conducive to eradicating failed treatment regimens and late stage diagnoses in rural areas. (Abu-Zeid & Dann 1985; Dodd et al. 1985; Ellinor & Gerard 1998; Fakous Cancer Center 2007; Yoder 1997)

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