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The Global Initiative for Breast Cancer Awareness in Egypt

Community Profile

Cairo – Alexandria – Luxor

Executive Summary

2010

The information contained in this Community Profile has been compiled by Course for the Cure™ participants and comes from a variety of sources. Participants have attempted to obtain the latest and most reliable data available and to accurately reflect breast cancer challenges and resources in their city at the time of the profile. This work was made possible by the generous support of the American people through the United States Agency for International Development (USAID). The contents are the responsibility of the Global Initiative in Egypt and do not necessarily reflect the views of USAID or the United States Government. USAID, Susan G. Komen for the Cure, and the Institute of International Education do not recommend, endorse or make any representations or warranties of any kind with respect to the accuracy, completeness, timeliness, quality, efficacy or non-infringement of the information contained in this document.

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Suzanne Mubarak Center for Women's Development, Luxor

The Global Initiative Steering Committee

EXECUTIVE SUMMARY

Introduction of the Global Initiative in Egypt

An estimated 25 million around the world will be diagnosed with breast cancer over the next 25 years, and up to 10 million could die without care. Although breast cancer is a global disease, reaction and approach to its diagnosis and treatment vary greatly by a country's cultural norms and economic means. Given that no single approach to breast health will prove effective around the world, local communities must implement innovative programs customized to address local needs.

With this in mind, Susan G. Komen for the Cure® launched the Global Initiative for Breast Cancer Awareness in 2007. The Institute of International Education (IIE), one of the world's most experienced global higher education and professional exchange organizations, designed and manages the Initiative through its West Coast Center in San Francisco, in collaboration with local partners in the Middle East and North Africa, Eastern Europe, and Latin America. Since the program's inception, the model has been customized for implementation in several additional countries, including Egypt most recently in 2009.

The Global Initiative for Breast Cancer Awareness in Egypt is made possible by the United States Agency for International Development (USAID), with the generous support of the American people, in partnership with the Institute of International Education (IIE) and Susan G. Komen for the Cure®.

The primary goal of the initiative is to create a dynamic global network of dedicated activists with the skills, knowledge and vision to play a strategic role in shaping their country's response to breast cancer. This is being accomplished by (1) Empowering diverse stakeholders with the training, tools and support needed to influence strategic country-specific programming and funding decisions around breast cancer; and (2) Strengthening individual and organizational capacity to launch effective education, awareness and advocacy campaigns that will increase early breast cancer detection and reduce mortality.

At the core of the program is the Course for the Cure™, a series of training modules that are based on Komen for the Cure's experience in breast cancer awareness and advocacy. The training modules, which have been customized in each country, cover five key topics: Community assessment, volunteer & organization development, awareness & education, fundraising, and advocacy. Graduates of the Course for the Cure™ are eligible to apply for community grants to address needs identified in the community profile.

An integral component of the Initiative is the collaboration of local partners in each country, including organizations working on women's rights, advocacy, public health and health education, as well as medical foundations, hospitals and universities. These partners help create national steering committees and nominate participants, who represent a wide range of breast health stakeholders, for the Course for the Cure™. In-country partners also support the locally-led collaborations that are integral to reducing breast cancer mortality through improved awareness and education.

The Global Initiative in Egypt has three lead local partner organizations. ***Breast Cancer Foundation of Egypt (BCFE) in Cairo*** promotes breast health through breast cancer awareness, education, and research and facilitates services and support to women in all social and economic strata. A registered Egyptian NGO, it was founded by Egyptians and expatriates concerned with the high incidence of breast cancer and the lack of related services in Egypt. ***Suzanne Mubarak Regional Centre for Women's Health and Development (SMC) in Alexandria*** is a training and research centre dedicated to women's health and development in Egypt and neighboring countries.

The centre was conceptualized by Mrs. Suzanne Mubarak, the first lady of Egypt, and contributes to her on-going efforts to improve the physical and social wellbeing of women in the Arab World. ***Suzanne Mubarak Center for Women's Development in Luxor*** furthers women's economic and social development through raising the standard of living for families, reducing unemployment, and preserving handicrafts. Suzanne Mubarak Center partners with government and civil society to implement comprehensive programs, while promoting heritage preservation, fair trade, and pollution reduction.

Goal of the community profile

This community profile represents an assessment of the breast health needs and resources in a given community. It also serves to inform the work of breast health organizations and activists in their fight against breast cancer. Participants in the Course for the Cure™ workshops are trained on types of data collection, identifying and prioritizing gaps, and devising strategic long-term goals and short-term objectives. As part of the workshop follow up activities, participants collaborate with Global Initiative staff in each country to apply the community profile skills they are learning. By collecting and analyzing available data on breast health, participants identify and prioritize the community's unmet needs or "gaps" in breast health. These gaps are areas where the available resources do not meet the needs of the community or specific segments of that community. These prioritized gaps form the basis for developing strategic plans for education outreach, awareness programs and advocacy efforts to improve breast health outcomes.

The Community Profile is a living document. It should be used on an on-going basis to inform strategic planning in the community around breast health and to strengthen existing programs and services. As a living document, it also needs to be updated on a regular basis as circumstances change and new information becomes available.

This Community Profile Report details the findings of Course for the Cure™ participants in Cairo, Alexandria and Luxor and identifies the priorities they have identified for these communities. The method of data collection and criteria of prioritization are explained in the methodology section.

Community Profile Methodology

All 93 Course for the Cure participants played a major role in the design of the questionnaire, collection of data, as well as data extraction and analysis. Through the community profile workshop, the program manager and master trainer coached and guided the participants to develop the questions they needed to answer through the community profile. The program manager and master trainer then developed the final questionnaires for both women's and community leaders' surveys. The women's survey aimed to collect information from regular women about their own knowledge and attitudes about breast cancer, as well as their perceptions of that of their peers. The community leader survey gathered insight from community leaders on a more macro-level about a variety of breast cancer related issues and barriers that they have seen in their local communities. Participants were given the questionnaires and they interviewed women and community leaders based on a convenience sampling technique.

The program manager and master trainers then analyzed and interpreted the data, and discussed the results with the participants, who identified and prioritized the gaps in breast health in their communities based on the results of the community profile.

Brief Overview of Country and Community contexts

The Arab Republic of Egypt is located in the northeast corner of the African continent. It is bordered by Libya to the west, Sudan to the south, the Red Sea to the east, and the Mediterranean

Sea to the north. Egypt is one of the oldest societies in the world, and is also one of the largest (with over 1,000,000 square kilometers of land) and most densely populated of the Arab countries, with about 78 million people. However, much of the land is desert, and only 6 percent of Egypt's area is inhabited. Recently, the Egyptian government adopted a policy of land reclamation and fostering of new settlements in the desert. Despite these efforts, the majority of Egyptians live either in the Nile Delta located in the north of the country or in the narrow Nile Valley south of Cairo.

The latest population census in Egypt was carried out in November 2006. According to the results, Egypt has a de facto population of 72.2 million. This number excludes the roughly 3.9 million Egyptians who are living abroad. By the beginning of 2008, it is estimated that the population had increased by around one and a half million to reach 74.3 million (CAPMAS 2008).

The age structure of the household population – of which 49 percent were males and 51 percent females – reflects the effects of past demographic trends in Egypt, particularly high fertility. The majority of the population (55 percent) was less than 25 years old, and 34 percent were under 15 years old. The proportion of individuals under age 15 was greater in the rural population (37 percent) than in the urban population (30 percent).

According to CAPMAS census 2006, there is gender inequality in education, where illiteracy among females is 37.26%, compared to 22.34% among males. Also the percent of women with at least some university education is 7.85%, compared to 10.8% among males. The 2008 EDHS confirms this finding. Overall, 85 percent of males in the 2008 EDHS households had ever attended school, compared with 72 percent of females. The median number of years of schooling for men was 6.7, which is almost 2 years higher than the median for women (4.9 years). Urban residents were more likely to have attended school and to have remained in school for a longer period than rural residents; the median years of schooling among rural women is 2.9 years, whereas it is 7.6 years in urban areas. In rural Upper Egypt, 57 percent of women have ever attended school, while in urban Lower Egypt, 85 percent of women have some education.

According to the CAPMAS census 2006, the labor force (those 15 years or older) represents 44.3% of the total population, but within the female population aged 15 years or older, it represents only 16% compared to a 71.5% among males of the same age group. Nevertheless, within the female labor force, unemployment is 19.18% which is close to the 9.72% of the unemployment among male labor force.

Breast health statistics

It is challenging to find breast health statistics for Egypt, as there is no national registry for breast cancer. The only reliable registry available in Egypt is the Gharbia regional registry, The Gharbia registry reported for the period 1999-2002 that the crude rate of breast cancer among females age 0-85+ is 33.5 per 100,000, and the age-standardized rate is 42.5 per 100,000, whereas the number of cases reported for the same period is 2426. (IARC's *Cancer Incidence in Five Continents, Vol. 9*)

The International Agency for Research on Cancer (IARC) is the World Health Organization's source for information about cancer. According to the IARC, breast cancer is the most frequent cancer among females and is the most frequent cancer among both sexes in Egypt.

The IARC reports more detailed data about the most frequent cancers among women in Egypt. Breast cancer had the highest incidence (ASR (W) 37.7) and the highest mortality (ASR (W) 20.1) among all cancers that afflict women in Egypt. Thus, the mortality rate is approximately 53%.

Brief Overview of Cairo Community Profile Findings

With a population of 6.8 million spread over 453 square kilometers (175 sq mi), Cairo is by far the largest city in Egypt. With an additional ten million inhabitants just outside the city, Cairo resides at the center of the largest metropolitan area in Africa and the eleventh-largest urban area in the world.

Most of the breast health programs and services in Egypt are based in Cairo, including the National Cancer Institute, Cairo University (Kasr Al Aini), Ain Shams University Hospitals, the Breast Cancer Foundation Egypt, as well as the Ministry of Health's National Program for Women Health and the Women's Health Outreach Program.

Demographics:

According to the Egyptian Central Agency of Public Mobilization and Statistics' (CAPMAS) 2006 population and housing census, the total population of Cairo is 6,758,581, which is almost 9.3% of the total population of Egypt. There is almost equal distribution of gender in Cairo where the male population represents 50.8% of total Cairo population, and females represent 49.2%. Cairo contains 3,325,383 females, of whom 23.6% are over the age 15, 15.6% are aged 15-45 years and 8% are aged 46-60 years.

Among the women in Cairo aged 10 years and above (83.35% of total female population), 23.18% are illiterate, 9.05% can only read and write, 45.56% have had below intermediate or intermediate education, and 22.19% have had above intermediate, university or higher education.

Women represent 25% of the total labor force in Cairo. According to the 2006 census, 471,769 women were employed, which represents 84.8% of total female labor force, and the unemployment rate among the female labor force was 15.2%.

Women Survey Findings:

A sample of 387 women was interviewed. The whole sample was almost equally divided between the two age groups that were targeted (47.3% were 20-39 years old and 46.8% were 40-60 years old; the rest did not mention their age). Age had no significant correlation with almost any of the results. Most of the sample (63.8%) has a secondary or higher education. More than half of the sample did not have any health insurance coverage (51.7% of total sample).

Knowledge of symptoms was low among the sample; only 20.2% of the sample knew 100% of the possible symptoms of breast cancer (BC). Most of women were unaware of the symptoms except the appearance of breast lump. The very few women who were fully aware of BC symptoms have shown no special character (age group – socioeconomic class – educational level), which clearly reflects a severe gap in knowledge among women of different categories. Furthermore, this could also reflect that BC basics have not been communicated systematically by media, health service providers or community social organizations (CSO). Education level and family monthly income had a significant effect on the knowledge of symptoms: the lower the education level, the worse the knowledge, and the lower the family monthly income, the worse the knowledge. It is also worth noting that knowledge of symptoms had no significant relationship with practicing early detection of BC, whether it is breast self exam (BSE), clinical breast exam (CBE) or screening mammography.

When women were asked about the risk factors, the knowledge gap was even worse, as only 2.3% of the total sample got 100% of BC risk factors right. The most common supposed risk factors identified by women, in order of frequency, were: (1) BC is common in women than men; (2) Smoking; (3) BC risk increases with age; (4) Women over 35 years old are more liable to get BC; (5) Post-Menopausal Hormone Replacement Therapy (PMHRT); (6) Family History of BC; (7) Women who never breast fed. Air and food pollution, hormones, marriage of a relative, God's will, family history and using contraceptive pills were all reported by women in the interviews to be additional factors that predispose one to BC. This obvious mix of predisposing factors declares without doubt that women simply do not know, and calls for an immediate awareness raising actions. Again, knowledge of BC risk factors had no significant relationship with practicing early detection of BC, whether BSE, CBE or screening mammogram.

Knowledge of early detection of BC was much better than knowledge of symptoms and risk factors. 68.7% of the sample knew and believed that early detection would lead to better treatment results.

But the familiarity with CBE was very low (27.6% of sample) compared to BSE (56.1%) and Mammography (46.3%). In a country where mammography is not available to most of the population for screening purposes, this is an issue, since CBE may be a more accessible and thus effective, alternative method for early detection of BC.

The prevalence of wrong beliefs occurs among all women, with no special consideration to age, socioeconomic class or educational level. The most common community beliefs, as reported by interviewed women, were: BC affects the woman's femininity; lactation will definitely prevent BC; BC will definitely lead to death; the daughter of a BC patient/survivor will not be asked for marriage; and mammography can lead to BC since the woman is exposed to radiation. They have also mentioned other beliefs such as: BC is infectious, surgical removal of the tumor leads to spreading of the tumor everywhere, and BC is humiliating disease.

There is quite a gap between knowledge of BC early detection practices and the actual practicing of them. Although 56.1% of the sample has heard of BSE, only 55% of them actually do BSE, of whom only 37.8% perform it every month and the rest at a more distant spacing. Among the 107 women who have heard of CBE (27.6% of total sample), only 49.5% of them (53 women – 13.7% of total sample) had ever gone for a CBE, and less than half of them had it within the last year whereas the rest had it 2 years ago or more. Practicing mammography as an early detection method was much more common than CBE. Among the 179 women who have heard about mammography (36.3% of total sample), 134 women (31.1% of total sample) had a mammography before. But the frequency of doing a mammography was low, as only 23.1% of those who ever had a mammogram (31 women) had it within the last year, whereas the rest (103 women) had it more than a year ago.

Interviewed women reported that the most common two reasons for not doing BSE were denial of their susceptibility (they do not think they could have a problem in their breasts) and fear (they are afraid to discover that they have BC). These reasons are closely linked to knowledge for if women understand BC better and that it can be treated if discovered early, these factors will decrease massively.

Interviewed women stated several reasons why they think women in their community do not perform CBE & Mammogram. These reasons could be divided into two groups:

A. Knowledge/beliefs – related reasons, mainly:

- Ignorance: they did not know they should do CBE or screening mammography, or they did not know that these were important
- Fear: they were afraid that they would discover cancer
- Denial: even if they had cancer, they would not want to know

B. Service-related reasons, mainly:

- They do not know where screening services are provided
- There is no female doctor/nurse to do the examination for them
- There is no privacy where the service is provided

The sampled women were then asked about why they believe women in the community who are diagnosed with BC sometimes do not continue their BC treatment. As expected, cost plays an important factor in not continuing the treatment. But it is obvious that this is not the only major factor, as there are other factors that were mentioned by a big percentage of the interviewed sample, mainly: (1) Not believing that the treatment will work; (2) Ignorance of where the service is being provided; (3) Fear that people would find out she has BC and the effect of this stigma on her family and her life. These factors are equally important to cost especially in that they could affect the woman's decision to discontinue treatment even when has the financial capability to do, thus eliminating the cost factor. It is also worth noting that family income, education level and beliefs have no significant relationship to interviewed women's opinion on why women in their community do not continue BC treatment.

Finally, to be able to outreach to the community, it is important to know what channels they trust as a major source of health information. When the interviewed women were asked about their trusted sources of information, several sources were mentioned, the most frequent of which were the doctor, media (mainly television), health education sessions (which is again delivered by doctors), and other patients or survivors.

Community Leaders' Interview Findings:

A sample of 83 community leaders (CL) has been interviewed for the sake of exploring the level of knowledge, attitudes and practices the community has in regard to the Breast Health issues. Most of the interviewed CL (83%) acknowledge that breast cancer is a huge problem in their community, affecting mainly women ages 20-49 years.

Community leaders have identified a number of causes that hinder women from utilizing breast health services. Poverty has ranked as the first cause that hinders better access to available breast health services (69 CL), while being afraid to have BC is the second cause (68 CL), and the economic factor rises again in the third cause of being unable to afford the cost of the health service (63 CL). Fear of results of investigations and fear to lose the breast both have the same power as the third cause, followed by lack of awareness (62 CL), low level of general education (61 CL), prevalence of wrong information and beliefs (57 CL), and shyness and embarrassment (46 CL). We should not underestimate factors related to lack of knowledge/awareness and prevalence of wrong information and beliefs because the sum of these three factors exceeds the sum of the two economic factors.

Most of the CL (77% of total sample) reported that women are not practicing and utilizing early detection techniques (BSE – CBE – mammogram screening). They attributed this to 3 main causes: lack of awareness, fears and economic factors. They mentioned that the main motives which encourage women to practice and utilize early detection techniques include: hearing about BC in the media, from BC survivors, or doctors; and feeling something wrong in the breast.

BC is always surrounded by a cloud of rumors and wrong beliefs everywhere in the world, and each community has propagated its own beliefs to the extent that people are resistant to change them and behave accordingly. In this regard the Community leaders have ranked the beliefs that prevail in Cairo in order of frequency mentioned by interviewed women: BC affects a woman's feminine characteristics, BC definitely lead to death, breastfeeding prevents BC, the daughter of mothers with BC will not be asked for marriage, post- menopausal hormonal therapy enhances BC risk, and finally that mammogram screening tests cause BC as the lady is exposed regularly to the radiation X-ray.

CL reported that *awareness services* are not sufficient and in some places are completely absent, and they believe that media and civil society sectors are not playing their role in raising the community awareness towards breast cancer related issues. They also believe that the health educators are lacking the required skills to perform their roles effectively. *Screening services* have also many gaps: 16 CL see that in some places, such services are not available at all, a few CL explained the poor quality of available early detection services by the lack of competency of the staff in charge, whereas 11 CL see that poor people cannot afford the price of these services and the governmental free of charge services are either insufficient or unknown to the people. *Treatment services* show 3 main gaps, as identified by the CL. The first is insufficiency as most of the CL identify only the National Cancer Institute as the main curative player; the second is the high price of such services in the private sector (which is aggravated by the insufficiency of the governmental free services); and the third is that people do not know where to get the service. *Support services* are either non-existent or insufficient, as reported by 14 CL. The unskilled teams that lead the very few existing support groups are making the gap of insufficiency even worse.

When asked about men's attitudes towards breast cancer, most CL agreed that men often support their wives when diagnosed with BC, and they attributed that to the morals and community culture

as well as to the influence of sons and daughters, friends and relatives. Nevertheless, the type and duration of support were a matter of question. Support - as interpreted by the CL - ranged from acceptance of God's will, providing all financial support required, encouraging her to continue the treatment, and psychological support.

Identified and prioritized gaps:

After seeing the results of both women's survey and CL interview with CFTC participants from Cairo, participants identified and prioritized six gaps, as follows:

1. Various media and awareness outlets (visual mass media, doctors, survivors, NGOs) do not play enough role in providing sufficient correct information about BC and BH
2. Lack of awareness about BC symptoms and risk factors among women 20-60 years old in Cairo, especially within those with low income and education level
3. Weak practice of early detection of BC (especially CBE) and women do not perform it regularly
4. Spread of wrong beliefs about BH and BC, which negatively affects women's practice of early detection of BC
5. Not enough treatment services for those with low incomes (treatment is expensive and not enough free services)
6. Weak support possibilities at both the quantitative and qualitative level, and incompetent teams providing the already-limited support groups

Brief Overview of Alexandria Community Profile Findings

Alexandria, with a population of 4.1 million, is the second-largest city in Egypt, and is the country's largest seaport, serving approximately 80% of Egypt's imports and exports. Alexandria is also an important tourist resort. Alexandria extends about 32 km (20 mi) along the coast of the Mediterranean Sea in north-central Egypt. It is home to the *Bibliotheca Alexandrina* (the new library). It is an important industrial center because of its natural gas and oil pipelines from Suez, another city in Egypt.

There are several MOH breast health programs and services based in Alexandria. The most prominent is the Alexandria University hospitals, as well as several military hospitals. The Suzanne Mubarak Regional Center for Women's Health and Development in Alex (SMC) also plays a prominent role in providing breast health services in Alexandria. Also there are a few NGOs that provide some awareness services and support groups like Ayadi Al Mostakbal NGO, but they do this on a narrow scale. In addition, the National Program for Women Health and the Women's Health Outreach Program have been providing their services at Alexandria.

Demographics:

According to Egypt's CAPMAS 2006 population and housing census, the total population of Alexandria is 4,123,869, which is almost 5.7% of the total population of Egypt. There is almost equal distribution of gender in Alexandria, where the male population represents 51% of total Alexandria population, and females represent 49%. Alexandria contains 2,017,519 women, 21.6% of them over the age of 15, 15.2% aged 15-45 years, and 6.4% aged 46-60 years.

Among the women in Alexandria aged 10 years and above (83% of total women population), 23.48% are illiterate, 11.23% can read and write, 48.58% have had intermediate education or below, and 16.71% have had intermediate or above education (secondary, tertiary, or post-graduate).

Women represent almost 20% of the total labor force in Alexandria. According to 2006 census, 206,275 women were employed, which represents 81% of total female labor force, whereas the unemployment rate of female labor force is 18.99%.

Women Survey Findings:

A sample of 527 women was interviewed. The whole sample was almost equally divided between the two age groups that were targeted: 50.7% of the sample (267 women) was within the age group 20-39 years old, whereas 49.3% (260 women) was within the age group 40-60 years old. Age had no significant correlation with any of the results of the survey. More than half of the sample (53.3%) has a secondary or higher education, 30.7% had basic or elementary education, whereas only 15.7% were illiterate. More than half of the sample did not have any health insurance coverage (53% of total sample).

Knowledge of symptoms was very low among the sample: only 18.6% of the total sample (98 women) got 100% of the symptoms right and 17.1% (90 women) got 50% of symptoms right. Interviewed women also commented about symptoms of BC they know; almost half of the 245 agreed on mass in the breast, while changes in color, shape or pain in the breast was only mentioned by 102 women. Less than one third of the interviewed women (161) said that they do not know any symptom of breast cancer. Education level and family monthly income had a significant effect on the knowledge of symptoms, where the lower the education level, the lower the knowledge, and the lower the family monthly income, the lower the knowledge. Knowledge of BC symptoms had no significant relation with practicing BSE, but it had a significant relationship with practicing CBE and mammography as screening tools.

Knowledge of risk factors was even lower than knowledge of symptoms. Only 1.7% of the total sample got 100% of the risk factors right, and 9.7% got 50% of risk factors right. Most common risk factors identified were: (1) BC is more common in women than men; (2) Women over 35 years old are more at risk; (3) Smoking increases risk. 73 women think that administration of medications or medications containing hormones such as oral contraceptive pills are predisposing factors to BC. Other small group of women linked BC to marriage, delayed pregnancy, those who did not breastfeed their babies or who do not have children. Diabetes Mellitus (DM), obesity or low immunity were mentioned – albeit less frequently – as BC risk factors. Exposure to x-ray and stress were mentioned by less than 20 women. Poverty, unhealthy food and psychological status were also mentioned among the predisposing factors.

Knowledge of early detection of BC was much better than knowledge of symptoms and risk factors. But even though 66.8% of the women know about early detection, their knowledge of the screening methods was not equally high, especially CBE (25.4% of total sample).

Women agreed that wrong beliefs are prevalent among women of all ages, socioeconomic classes and educational levels. It's worth noting though that misleading beliefs were most common among women with higher education. The most common community beliefs, as reported by interviewed women, were: (1) BC affects the woman's femininity; (2) lactation will definitely prevent BC; (3) BC will definitely lead to death; (4) daughters of a BC patient/survivor will not be asked for marriage; and (5) mammography can lead to BC since the woman is exposed to radiation. These are the same wrong beliefs that were reported prevalently in Cairo community.

There is quite a gap between knowledge of BC early detection practices and the actual practicing of them, though this gap is less than in Cairo. Although 49.1% of the sample has heard of BSE, but out of those who have heard of BSE, only 60% of them actually practice it, of which only 47.1% of them perform it every month and the rest at a more distant spacing. Among the 134 women who has heard of CBE (25.4% of total sample), only 44 women (32.8% - 8.3% of total sample) had ever gone for a CBE, and about half of them had it within the last year whereas the rest had it 2 years ago or more. Practicing of mammography as an early detection method was much better than CBE. Among the 181 women who has heard of mammography (34.3% of total sample), 164 women (31.1% of total sample) had a mammogram before. But the frequency of doing mammography was not that good, as only 35.4% of those who ever had a mammogram (58 women) had it within the last year, whereas the rest (14 women) had it more than a year ago.

Similar to Cairo sample, the most common 2 reasons for not doing BSE were denial of their susceptibility (they do not think they could have a problem in their breasts) and fear (they are afraid to discover that they have BC). Also, a considerable percent (32.4%) just do not know how to do it. All these reasons are attributed to lack of awareness and knowledge.

Again, the reasons for not doing CBE and Mammography are very similar to not doing BSE: ignorance, fear and denial. Additional factors are related to the service provided: no female doctor, no privacy, and finally not knowing where to go for the service.

The sampled women reported several reasons causing other women in their community who are diagnosed with BC to sometimes not continue their BC treatment. As expected, cost plays an important factor in not continuing the treatment (86.5% of the sample reported that treatment is too expensive). But similar to Cairo sample results, that it is not the only major factor, as there are other factors that were mentioned by significant percentages of the interviewed sample, mainly: (1) not believing that the treatment will work (60.9% of interviewed women); (2) fear that people would find out she has BC and the effect of this stigma on her family and her life (56.7% of interviewed women); (3) ignorance of where the service is being provided (51.4% of interviewed women); (4) factors related to transportation whether the treatment services are too far, or there is no available transportation (39.7% of interviewed women).

Finally, when asking the interviewed women who practiced BSE who taught them how to perform it, the most frequent response was health education sessions, television and doctors. This goes hand in hand with the most common sources of information that were identified by the interviewed women in Cairo.

Community Leaders' Interview Findings:

As community leaders are aware about the behaviors, traditions and the major health problems in their community, interviews with 82 community leaders were conducted in order to paint a fuller picture about the breast cancer in the community.

The majority of the interviewed community leaders (73, 89% of total) agreed that the problem of breast cancer is considered to be a big and difficult problem in their community. A small number of them consider it as an acute problem in some areas only (6, 7.3% of total).

Three-fourths of the interviewed Community Leaders reported that the main reasons hindering women from getting BH services (screening as well as diagnosis and treatment) were poverty; followed by fear of the disease itself; lack of awareness about breast cancer programs; inability to pay for the services; fear of the results of the examination; fear of losing their breast(s); and unavailability of female providers. At the same time, causes related to the service itself and its provision were less mentioned such as: location of places of service provision, the volume of the services provided, shortage of number of providers, inaccessibility of the place by public transportation or transportation being too expensive. A small number of them agreed that women do not get the service because of lack of knowledge about the disease, wrong beliefs and shyness.

Regarding the early detection methods and women who practice it, the majority of the community leaders (67 out of 82, 82%) mentioned that none of the women do BSE, while around 60 of them (73%) said that none of women above 40 in their community had either clinical examination or mammogram. When asked about the reasons for this lack of early detection practice, most of them related it to lack of awareness about the importance of time and quick action in the management of the disease, fear from getting diseased, and unavailability of places providing early detection services. Meanwhile, poverty and high expenses of services were less mentioned by the community leaders (3 out of 82 leaders, or 4%, for each). It is noteworthy that CL believe that feeling a mass in the breast, hearing breast health messages in the mass media, meeting a BC survivor or having a physician's recommendation are the commonest encouraging factors to pursue screening or diagnostics related to breast cancer

Wrong beliefs and rumors related to breast cancer are widely spreading in the community. Community leaders ranked these beliefs as follows: breast cancer affects feminine character of women, breastfeeding protects women from getting breast cancer, hormone replacement therapy increases the incidence of BC, BC leads to death, daughters of BC women will not get married, exposure to mammogram increases risk of BC as women are exposed to radiation, women above 50 will not be affected, and finally BSE is impolite for girls.

Regarding their opinion about breast cancer services in their community, the majority of community leaders (50%) reported that all BC services (awareness, early detection, curative and supportive services) are of poor quality, and only 12% feel that the quality is good. Almost two thirds of the leaders agreed that the support groups for BC are not present in their community. In order to improve these services they recommended raising awareness through the media and the health governorate, increasing the number of places of service provision and the collaboration between the NGOs, business men and health authority to support or cover the costly treatment. Also they recommended starting support groups in their communities.

Finally, the majority of the interviewed leaders (50 out of 82, 61%) accepted the idea of having their mothers, sisters and wives visiting the physicians yearly to assess their breast health. However, only 31 of them think that men will agree to allow their female relatives to have any type of breast investigations or examination. Also, a similar number agreed that men will support their wives if they are affected by breast cancer (28 leaders, 34%), although “support” was not further defined by this group of CL. In general, community leaders attributed the causes that men do not support their wives when having BC to culture, lack of awareness about the disease and the influence of family and relatives.

Identified and prioritized gaps

After seeing the results of both the women survey and CL interviews, CFTC participants from Alexandria identified and prioritized the gaps as follows:

1. Lack of awareness and knowledge gap about symptoms, risk factors and early detection of BC among women in Alexandria.
2. Prevalence of wrong beliefs about BH and early detection among women in Alexandria, especially those among the higher education and higher income group.
3. Lack of knowledge about BH services and where they are available, especially free-of-charge BH services.
4. Lack of support groups in Alexandria
5. Gap in the sources of BH information, especially from doctors and media, although they are identified as the major sources of health information among women in Alexandria.

Brief Overview of Luxor Community Profile Findings

As the site of the Ancient Egyptian city of Thebes, Luxor has frequently been characterized as the "world's greatest open air museum," as the ruins of the temple complexes at Karnak and Luxor stand within the modern city. Immediately opposite, across the River Nile, lie the monuments, temples and tombs on the West Bank Necropolis, which include the Valley of the Kings and Valley of the Queens. Thousands of international tourists arrive annually to visit these monuments, contributing a large part towards the economy for the modern city.

The economy of Luxor, like that of many other Egyptian cities, is heavily dependent upon tourism. Large numbers of people also work in agriculture, particularly sugarcane. The city is notably poorer than Cairo and poverty is widespread in Luxor. To make up for shortfalls of income, many cultivate their own food. Goat's cheese, pigeons, subsidized bread and home-grown tomatoes are commonplace among the majority of its residents.

In 2009, The Supreme Council of Luxor City was declared a governorate and Esna and Armant districts were added to it.

Breast health services in Luxor are very poor. They are mainly curative services provided by the MOH hospitals, and screening services are scarce. There are only two mammography machines in the governorate – at Luxor International Hospital and Gournah Hospital - but both of them are under-utilized.

Awareness services are absent in Luxor, and breast cancer is not on the agenda of almost any NGO or CDAs in the various districts of Luxor

Demographics:

It is very challenging to get demographic data about Luxor Governorate, since most available demographic data were collected prior to its formation. Thus all available data were about Luxor city and its districts, not including the Esna and Armant districts that were added later on in 2009.

According to the Egyptian CAPMAS population and housing census of 2006, the total population of Luxor is 457,286, which is almost 0.628% of the total population of Egypt. There is almost equal distribution of gender in Luxor where the male population represents 51% of total Luxor population, and females represent 49%. Luxor contains 223,605 women, 17.8% of them over the age 15, 11.7% aged 15-45 years, and 6.1% aged 46-60 years.

Among the women in Luxor aged 10 years and above (80.5% of total female population), 35.81% are illiterate, 10.42% can read and write, 46.14% have had below intermediate or intermediate education, and 7.62% have had above intermediate, university or above education.

Women represent almost 21.8% of the total labor force in Luxor. According to 2006 census, 22,757 women were employed, which represents 72.84% of total female labor force, whereas the unemployment rate of female labor force is 27.16%.

Women Survey Findings:

A sample of 404 women was interviewed. The whole sample was almost equally divided between the two age groups that were targeted (44.3% 20-39 yr old and 49.5% 40-60 yr old, the rest did not mention their age). Age had no significant correlation with any of the results except with some beliefs. The sample was almost equally distributed between the three identified education levels: 30% were illiterate, 36.4% had primary or elementary education, and 29.7% had secondary or higher education.

Knowledge of symptoms was very low among the sample: only 20% of the total sample (81 women) got 100% of the symptoms right and 19.3% (78 women) got 50% of symptoms right. The majority of the interviewed women mentioned breast mass, changes in the shape of the breast nipple, and discharge as the common symptoms to suggest breast cancer. Less commonly mentioned symptoms included pain in the breast and axillary mass. Education level and family monthly income had a significant effect on the knowledge of symptoms, where the lower the education level, the less the knowledge, and the lower the family monthly income the less the knowledge. Knowledge of BC symptoms had no significant relation with practicing BSE, CBE and mammogram

Knowledge of risk factors was even lower than knowledge of symptoms: only 2.2% of the total sample got 100% of the risk factors right and 10.6% got 50% of risk factors right. Females in general were identified as more susceptible to breast cancer by the interviewed women: especially those who are married, above the age of 40, or never breastfed. It is noteworthy that interviewed women considered breast cancer to be a genetic disease, and a smaller group of them mentioned breastfeeding, pollution, smoking, hormone replacement therapy, high fat diet and lack of personal hygiene as causes of breast cancer. Education level and family monthly income had a significant effect on the knowledge of BC risk factors, where the lower the education level, the worse the knowledge, and the lower the family monthly income the worse the knowledge. Knowledge of BC

risk factors had no significant relation with practicing both BSE and CBE, but it had significant relation with practicing mammogram as screening tool.

Knowledge of early detection of BC was much better than knowledge of symptoms and risk factors. But even though 39.6% of the women know about early detection and 37.1% think it is important, their familiarity with the screening methods was very low, especially CBE (11.1% of sample) and mammogram (10.4% of sample).

The women interviewed agreed that wrong beliefs about BC are prevalent among all women in their community. The most common community beliefs, as reported by interviewed women, were; (1) BC affects the woman's femininity; (2) lactation will definitely prevent BC; (3) BC will definitely lead to death; (4) a daughter of a BC patient/survivor will not be asked for marriage; and (5) mammography can lead to BC since the woman is exposed to radiation. These are the same wrong beliefs that were reported to be prevalent in both Cairo and Alexandria communities.

There is quite a gap between knowledge of BC early detection practices and the actual practicing of them. Although 25.5% of the sample knows BSE, but only 55.3% of them actually do BSE. However, the frequency of doing BSE among those who do it is quite good when compared to Cairo and Alexandria samples - 50.9% of Luxor women perform BSE every month after the end of menstruation. The women who practice BSE mentioned that the social workers (Ra2edat Refiat) and primary health care doctors were the ones who taught them how to do BSE. Among the 45 women who know CBE (11.1% of total sample), only 11 women (24.4% of them – 2.7% of total sample) had ever gone for a CBE, and more than half of them had it within the last year whereas the rest had it 2 years ago or more. Practicing mammography as an early detection method was less frequent than CBE, as only 10.4% of the total sample knows mammography, and only 31% of them (13 women – 3.2% of total sample) had a mammography before.

The most common two reasons for not doing BSE were denial of their susceptibility (they do not think they could have a problem in their breasts) and ignorance of either its importance or how to perform BSE.

Interviewed women stated several reasons behind women in their community not performing CBE or mammogram. These reasons could be divided into two groups:

A. Knowledge/beliefs – related reasons, mainly:

- Ignorance - they did not know they should do CBE or mammography, or they did not know that they were important
- Fear – they are afraid they would discover cancer
- Denial - even if they had cancer, they would not want to know

B. Service-related reasons, mainly:

- There is no female medical practitioner to do the examination for them
- There is no privacy where the service is provided

The sampled women reported several reasons causing women who are diagnosed with BC to sometimes not continue their BC treatment (unfortunately, no records are available to document how frequently this happens). As expected, cost plays an important factor in not continuing the treatment (81.4% of the sample reported that treatment is too expensive). But unexpectedly, there were other major factors that were similar to those of the other two communities, though in a different order: (1) ignorance of where the service is being provided; (2) fear that people would find out she has BC and the effect of this stigma on her family and her life; (3) factors related to transportation whether the treatment services are too far, or there are no available transportation; (4) not believing that the treatment will work.

Finally, when the interviewed women were asked about their trusted sources of information, several sources were mentioned, the most prominent of which were the doctor, media (mainly television), health education sessions (which is again delivered by doctors), social workers (Ra2edat Refiat), NGOs and other patients or survivors.

Community Leaders' Interview Findings:

Upper Egypt communities have special character in terms of customs, traditions and family relationships. The community leaders in these communities are characterized by being very influential, understanding of community habits, and having great impact on social problems. So, CL are invaluable sources of information as well as of support in tackling a problem such as BC in this community. Interviews with 57 community leaders were conducted. Most of them believe that BC is a huge issue in their community and that women ages 40-49 years are the most in need for breast health services.

More than half of the community leaders attributed the reasons why women do not benefit from breast health services to the following problems: lack of awareness about breast health services, low level of education and illiteracy, fear of the investigation results, fear of losing their breasts and inability to afford the cost of the service. Being very conservative, community shyness, rumors and unavailability of female providers were also among the common problems that hinder women from getting BH services. Less commonly mentioned problems were inadequacy of the services regarding: the number of the providers and the volume of service in comparison to the number of beneficiaries. Also, inaccessibility of the place of service provision and lack of transportation methods and finally refusal of the spouse to go for BH services, which was mentioned by less than 30 community leaders.

Again lack of awareness, illiteracy, shyness, fear and wrong habits were the main reasons hindering women from practicing early detection methods for breast cancer (BSE, CBE and mammogram). On the other hand, most of the community leaders considered feeling a mass in the breast, being asked by physician, hearing about BC in the press and media, or talking to a survivor as the main encouraging factors for women to do recommended breast cancer screening, which usually take place in either governmental hospital or private clinic.

In this closed community, more than half of the interviewed leaders agreed that common beliefs related to breast cancer in their community were: breastfeeding definitely protects from breast cancer, breast cancer definitely leads to death, BC affects femininity, and daughters of women diagnosed with BC will not be asked for marriage. Envy projected onto a woman by others, exposure to radiation and impoliteness of teaching girls BSE were mentioned by fewer than 20 leaders, but these still are considered very important beliefs in such a conservative community.

In an attempt to analyze the situation of breast services in the community, leaders were asked about the gaps and weakness related to awareness, screening, treatment and support services in their community. They identified the BH gaps in their community as follows:

- Gaps in awareness services:
 - o Inadequate number of BH awareness seminars (50 CL – 87.7%)
 - o BC is not on the agenda of the NGOs (50CL – 87.7%)
 - o Media and doctors do not give BC enough focus (2 CL – 3.5%)
 - o Fear of talking about BC (because of taboos and/or fear of being “jinxed” by one’s words) (1 CL – 1.75%)
- Gaps in screening services:
 - o Not available (25 CL – 43.8%)
 - o Not enough service places (14 CL – 24.56%)
 - o Lack of specialized doctors (6 CL – 10.52%)
 - o Lack of awareness about importance of screening (i.e. lack of demand) (5 CL – 8.77%)
- Gaps in treatment services:
 - o Not available at all or inadequate (31 CL – 54.38%)
 - o Expensive (7 CL – 12.28%)
 - o Treatment services are far and transportation issues (lack of transportation, prohibitively expensive) (5 CL – 8.77%)

- Gaps in support services:
 - o Inadequate or absent due to lack of awareness about BC (38 CL – 66.66%)

Identified and prioritized gaps

After the Program Manager shared the results of both women survey and CL interview, CFTC participants from Luxor identified and prioritized the gaps as follows:

1. Lack of awareness about the importance of early detection of BC and the methods of screening (BSE, CBE and mammography)
2. Weak awareness services and information offered by doctors and social workers
3. Local NGOs do not play an active role in BC awareness
4. Low awareness of women in Luxor, especially about the symptoms and risk factors of BC
5. Local media is not giving enough focus to BC nor to increasing the awareness of the public about breast health and early detection of BC
6. Gap in community beliefs: widespread incorrect beliefs about BC among women in Luxor, thus decreasing their intention to practice BC screening methods.
7. Gap in the quantity and quality of services for both screening and treatment.
8. Lack of support group in Luxor.

Conclusion and Strategic Goals

This community profile has covered several communities in Egypt: Alexandria in the North, Cairo in the middle, and Luxor in the South. Each of these three communities represents a sample of the demographics of Egypt with its unique characteristics: frontier governorate, the capital and Upper Egypt. Thus it is possible to say that the community profile has covered almost all of Egypt.

It is very interesting that in spite of the different characteristics of each of the 3 communities, the findings of the community profile were very similar in all of them. There was a knowledge gap in all three communities regarding symptoms and risk factors of breast cancer, as well as early detection and screening practices. There was also quite a gap between knowledge and practice of early detection, though the size of the gap was different in each of the 3 communities. It is obvious that even if women know about early detection (BSE, CBE and mammography), not all of them practice early detection, and the reason was usually related to either lack of knowledge or prevalence of wrong beliefs.

In all three communities, there were wrong beliefs about BC among all women in their community. The most common community beliefs were similar in all three communities: (1) BC affects the woman's femininity; (2) lactation will definitely prevent BC; (3) BC will definitely lead to death; (4) daughter of a BC patient/survivor will not be asked for marriage; and (5) Mammography can lead to BC since the woman is exposed to radiation.

Community leaders in all three communities have reported that breast health services are either inadequate, insufficient or completely absent. There seems to be a consensus on the need to put breast health on the NGO and Media agenda.

Based on the community profile findings and the similarity in gaps and needs of all three communities, common strategic goals were developed;

- Increase overall community awareness and knowledge of breast cancer and early detection.
- Reduce community beliefs and misconceptions about breast cancer, especially those related to fear.
- Encourage non-governmental organizations (NGOs), especially those already working in health or women's development, to put breast health on their awareness agenda.

- Improve women's practice of breast cancer early detection including BSA, BSE, CBE and mammography
 - Improve service providers' (doctors, nurses and health educators) knowledge about breast cancer and early detection.
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List of Acronyms

BC	Breast Cancer
BH	Breast Health
BSA	Breast Self Awareness
BSE	Breast Self Examination
CAPMAS	Central Agency of Public Mobilization and Statistics
CBE	Clinical Breast Examination
CL	Community Leaders
EDHS	Egypt Demographic and Health Survey
IARC	International agency for research on cancer