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# BREAST CANCER PRESENTATION DELAY AMONG WOMEN IN THE UNITED ARAB EMIRATES

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BREAST CANCER PRESENTATION DELAY AMONG WOMEN IN THE
UNITED ARAB EMIRATES

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degree of Doctor of Philosophy

Under the direction of Professor Tar Ching Aw

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# DECLARATION OF ORIGIONAL WORK

I, Yusra E. Elobaid, the undersigned, a graduate student at the United Arab Emirates University (UAEU) and the author of the thesis/dissertation titled "Breast Cancer Presentation Delay among Women in the UAE", herby solemnly declare that this thesis/dissertation is original work completed and prepared by myself under the guidance of Prof. Tar Ching Aw, in the College of Medicine and Health Sciences at UAEU. This work has not previously formed the basis for the award of any degree, diploma or similar title at this or any other university. The materials borrowed from other sources and included in this thesis/dissertation have been properly acknowledged.

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# ABSTRACT

Breast cancer is the commonest type of malignancy in the United Arab Emirates (UAE) with more than 65% of women diagnosed at an advanced stage. Routine clinical screening has aided in the early detection of breast cancer. However, more than 71% of breast tumors are self-detected. Therefore, exploring factors influencing delayed presentation to treatment after self-detection of breast tumors by Emirati and Arab women in the UAE is essential for improving the survival and the development of effective and targeted health intervention programs. This project explores the reasons behind delayed presentation to treatment by symptomatic women. It uses several approaches, including the development of a multidimensional model of help-seeking grounded in data from in-depth interviews with late presenters and nested in the theory of illness behavior. The study shows that despite continued emphasis on screening for breast cancer, delay is still prevalent amongst women. In the UAE, there is therefore a need for continued emphasis on the message regarding early detection for breast cancer symptoms. The results include the significant influence of social and cultural factors and life expectations on women with breast cancer. The suitability of the national breast cancer screening guidelines was reviewed through a 5- year survival analysis of breast cancer cases. The results show the importance of cultural and psychosocial beliefs in women's decision to seek medical attention. Delays of more than 3 months were highly associated with a decrease in survival time (pvalue=0.039), although lead-time bias could well be a possible explanation. The relatively younger age at diagnosis in Arab women compared to Western women indicates a need to start clinical screening at younger ages. The

establishment of a national cancer registry could help in the generation of accurate data to determine trends and for comparison with other countries in the region. The delayed presentation model can also serve as a reference for future studies on health behaviors modification and health promotion initiatives.

**Keywords:** Breast cancer, delayed presentation, qualitative methods.

**الملخص**

سرطان الثدي من أكثر السرطانات شيوعا في دولة الامارات العربية المتحدة (ا ع م) مع وجود اكثر من 65% امرأة في مراحل متقدمة من السرطان. الابكار من التشخيص و العلاج يحسن من فرص العلاج و النقاهة. الفحص الدوري الكلينيكي يساعد على الكشف المبكرلسرطان الثدي. ولكن أكثر من 71% من حلات سرطان الثدي تكتشف ذاتيا. ولذلك البحث عن الأسباب التي تؤدي الى التأخر في طلب العلاج لدى النساء الاماراتيات و العربيات اللاتي اكتشفن سرطان الثدي ذاتيا مهم جدا للحد من الوفيات و لتصميم برامج صحية و توعوية هادفة و عملية. هذا المشروع يبحث عن الأسباب المؤدية للتأخر في طلب العلاج من قبل النساء اللاتي يكتشفن سرطان الثدي ذاتيا مستخدما عدة طرق منها بناء نظرية متعددة الأوجه واستخدام نظرية الفعل المرضي من خلال مقابلات فردية متعمقة مع نساء مصابات بحالة متقدمة من سرطان الثدي بعد التأخر في طلب العلاج. نحن نقدم تحليل يبين ان الاحساس البدني و الشعور بأعراض المرض مقنن في التفاعل بين عدة عوامل اجتماعية و السيرة الذاتية مع التوقعات الحياتية وتوافقها مع قيم العقيدة و المجتمع. التعرف على أعراض المرض من المشاكل الصحية العامة في دولة الامارات. التوعية المستمرة بسرطان الثدي و أعراضه و الكشف المبكر بالنسبة للنساء و أقاربهم و الرعية الصحية الأولية و العاملين بها مهم جدا. الدعم المستمر للنساء المصابات بسرطان الثدي مهم جدا. بالاضافة لذلك, مناسبة معايير الفحص الدوري لسرطان الثدي في دولة الامارات تمت مراجعتها باستخدام بيانات البقاء على قيد الحياة لخمس سنوات. النتائج تبين أهمية العوامل الاجتماعية و النفسية المؤثرة في اتخاذ القرار للبحث عن المساعدة الصحية. التأخر في البحث عن العلاج كان من أقوى المؤثرات السلبية على البقاء على قيد الحياة. مع أن التحيز للمهلة يمكن أن يكون سبب قوة المؤثر. صغر سن النساء المصابات بسرطان الثدي في دولة الامارات مقارنة بالنساع في دول الغرب يؤيد أهمية تطبيق الفحص الدوري للكشف المبكر في سن مبكرة. تأسيس سجل للسرطانات سيمكن من وجود معلومات مكتملة وواضحة للمقارنة في المستقبل مع دول مجاورة. النظرية المبنية من هذا البحث يمكن أن تستخدم كمرجع لفهم السلوكيات المرضية و لتصميم برامج توعوية في المستقبل.

**الكلمات المفتاحية**: سرطان الثدي, التأخر في التقدم للعلاج, الطرق النوعية

## ACKNOWLEDGMENTS

# DEDICATION

To my family ……..with love

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# LIST OF ABBREVIATIONS

**ABCCR:**    Abu-Dhabi Central Cancer Registry

**AJCC:**    American Joint Committee of Cancer

**ASR:**    Age Standardized Incidence Rate

**BCD:**    Breast Cancer Delay

**BSE:**    Breast Self-Examination

**CAM:**    Cancer Awareness Measure

**CBE:**    Clinical Breast Examination

**CM:**    Centimeter

**DCIS:**    Ductal Carcinoma In Situ

**ER:**    Estrogen

**FNA:**    Fine Needle Aspiration

**GCC:**    Gulf Cooperation Council

**HBM:**    Health Belief Model

**GMHSB:**    Grounded Model for Help-Seeking Behavior

**HAAD:**    Health Authority-Abu Dhabi

**HCP:**    Healthcare Provider

**HER2:**    Human Epidermal Growth Factor Receptor 2

**HSB:**    Help Seeking Behavior

**M:**    Distant metastasis

**MM:**    Millimeter

**N:**    Lymph nodes

**OR:**    Odds Ratio

**PR:**    Progesterone

**SD:**    Standard Deviation

**SPSS:**       Statistical Package for Social Sciences

**T:**       Primary Tumor

**UAE:**     United Arab Emirates

**UK:**      United Kingdom

**USA:**     United States of America

**WHO:**    World Health Organization

# LIST OF DEFINITIONS

**Age Standardized Incidence Rate (ASR):** The summary rate that would have been observed, given the schedule of age-specific rates in a population with the age composition of some reference population.

**Breast Cancer Delay:** A lapse of more than three months between symptom discovery by the patient and the beginning of definitive treatment.

**Breast Self-Examination:** A diagnostic technique used by women to examine the breasts and palpate the tissues to detect the presence of abnormal tissues like tumors.

**Clinical Breast Examination:** A diagnostic technique used by healthcare professionals to examine the breasts and palpate the tissues to detect the presence of abnormal tissues like tumors.

**Culture:** Taken in its wide ethnographic sense the complex whole which includes knowledge, belief, art, morals, law, customs and any other capabilities and habits acquired by man as a member of a particular society.

**Differentiation:** This describes how much or how little tumor tissue resembles the normal tissue it came from. Well-differentiated cancer cells look more like normal cells and tend to grow and spread more slowly than poorly differentiated or undifferentiated cancer cells. Differentiation is used in tumor grading systems, which are different for each type of cancer.

**Kaplan Meier Survival Curve:** An estimator for estimating survival function from lifetime data.

**Logistic Regression:** A type of regression analysis used for predicting the outcome of a categorical dependent variable based on one or more predictor variables (features).

**Mammography:** X-ray examination of the breasts to detect and diagnose breast tumors.

**Negative Predictive Value (NPV):** The NPV of a test answers the question 'How likely it is that this patient does not have the disease given that the test result is negative?'

**Odds Ratio:** A measure of association between an exposure and an outcome.

**Patient Delay:** An interval longer than three months between symptom discovery by patient and first medical consultation.

**Provider Delay:** A period of more than one month between the first medical consultation and initiation of treatment.

**Positive Predictive Value (PPV):** The PPV of a test is a proportion that is useful to clinicians since it answers the question 'How likely is it that this patient has the disease given that the test result is positive?'

**Sensitivity:** The ability of the test to correctly identify those patients with a disease. A screening test with 100% sensitivity correctly identifies all patients with breast cancer. A test with 80% sensitivity detects 80% of patients with breast cancer (true positives) but 20% with breast cancer go undetected (false negatives).

**Specificity:** The ability of the test to correctly identify those patients without a disease. Therefore, a test with 100% specificity correctly identifies all patients without a disease. A screening test with 80% specificity correctly reports 80% of patients without breast cancer as test negative (true negatives) but 20% patients without the disease are incorrectly identified as test positive (false positives).

**Conceptual framework**: It is a structure of concepts and/or theories which are pulled together as a map for the study.

**Theoretical framework**: It is structure of concepts which exists in the literature, and acts as a ready-made map for the study.

# Chapter one

# INTRODUCTION

Breast cancer is the most common form cancer among women worldwide. The most recent estimate by Forouzanfar et al. (2010) indicates that more than 1.6 million new cases of breast cancer occurred among women worldwide in 2010. The number of breast cancer cases has been steadily increasing. Global breast cancer incidence increased from 641, 000 cases in 1980 to 1, 643, 000 cases in 2010, an annual rate of increase of 3.1% and a cumulative incidence increase of more than 25% between 1980 and 2010. The increase of another known reproductive health problem for women, cervical cancer, is less pronounced, increasing from 378, 000 cases to 454, 000 during the same period, an average annual increase of 0.6%. The global total number of deaths per year from breast cancer has increased from 250, 000 in 1980 to 425, 000 an annual rate of increase of 1.8%, compared to the lower annual rate of increase of 0.46% for cervical cancer (Forouzanfar et al., 2010).

Control of modifiable breast cancer risk factors such as maintaining a healthy weight, regular exercise and reducing alcohol intake could eventually have an impact in reducing the incidence of breast cancer. However, these strategies cannot eliminate the majority of breast cancers. Therefore, early detection in order to improve breast cancer outcome and survival remains the cornerstone of breast cancer control (Anderson & Jakesz, 2008). Early detection involves the use of two methods: (1) first, improving and increasing the awareness of breast cancer risk factors and signs and symptoms in symptomatic populations in order to facilitate early detection and early treatment, and (2) second, the adoption of screening tests in a presumably asymptomatic population to detect the disease in its early stages. For breast cancer screening programs to be effective, regular and periodic participation of women is needed.

The lack of participation of women in breast cancer screening programs and delays in seeking medical attention when symptoms appear might be attributable to economic and healthcare access issues (Alkhasawneh, 2007; Hatefnia et al., 2010; Lamyian et al., 2007; Seif & Aziz, 2000). In the Arab world, culture and religion play a major role in facilitating or hindering screening and early detection of breast cancer (Azaiza & Cohen, 2008; Hatefnia et al., 2010; Baron-Epel, 2010). The social and the religious role that women play in the Arab community and the social stigma around breast cancer may have prevented the early detection of the disease. Many factors play a role in creating cancer disparities. Some of these factors are socio-economic status, culture, and social injustice, with poverty being the dominant factor (Freeman, 2004). The American Cancer Society (2008) reports that "Complex and interrelated factors contribute to the observed disparities in cancer incidence and death among racial, ethnic, and underserved groups. The most obvious factors are associated with a lack of health care coverage and low socioeconomic status". The goal of many researchers investigating disparities in cancer between communities is to improve rates of cancer screening and better cancer outcomes by increasing the medical community's understanding of this complex interplay of socio-cultural and religious factors in cancer outcomes.

**Significance of study**

In the UAE, breast cancer is the commonest type of malignancy. It is at the top of the list of the leading types of cancer (Tawam Cancer Registry, 2012). Breast cancer is therefore a growing public health issue in the UAE. Despite the inaccurate estimation of breast cancer burden in the UAE due to under-reporting of breast cancer cases and the lack of a national cancer registry and death registry

to confirm the occurrence and mortality of cases, the cumulative probability of breast cancer incidence in the UAE increased over the past three decades, being 2% in 1980, 2.4% in 1990, 3.9% in 2000 and 5.2% in 2010 (Forouzanfar et al., 2010). This rising incidence is the not only cause for concern in the UAE, but also the advanced stage at presentation (Sabih et al., 2012). In women of all nationalities in the UAE, between 2005 and 2007, more than 65% presented at a late stages of the disease (either with regional or metastatic disease) at first diagnosis (Taher et al., 2008).

There is evidence that women with relevant symptoms who wait more than three months before seeking medical advice have significantly lower survival rates than women who seek early medical attention (Ramirez et al., 1999). Common underlying causes related to patient delay are lower education (Arndt et al., 2003), lower socioeconomic status (Harirchi et al., 2005), and an apparent lack of concern regarding painless breast lumps (Piñeros et al., 2009). In the Gulf region, it has been commonly assumed that late diagnosis is due to the lack of knowledge about breast cancer, cultural beliefs and deficient coverage of screening programs (Lodhi et al., 2010). However, there is scant research in GCC countries regarding reasons for delayed presentation of female breast cancer.

**The breast cancer situation in the UAE**

The United Arab Emirates is a federation of seven emirates situated in the southeast of the Arabian Peninsula in Southwest Asia on the Arabian Gulf. The country has land borders with Oman and Saudi Arabia and shares sea borders with Iraq, Kuwait, Bahrain, Qatar and Iran. Of the

total 6 million residents, less than 20% are Emirati and more than half are South Asian. The religious background of UAE residents includes Muslim, Hindus and Christians (Taher et al., 2008).

UAE health standards are rising rapidly and citizens and residents have taken advantage of healthcare facilities throughout the country. The health system in the country is administered by three authorities, (1) Abu Dhabi Health Authority (HAAD), which is responsible for the healthcare sector in the capital and emirate of Abu Dhabi; (2) the Dubai Health Authority which runs the healthcare sector in the commercial emirate of Dubai; (3) the Ministry of Health which oversees the entire healthcare delivery systems in the United Arab Emirates, but mainly the remaining five emirates (Sharjah, Ajman, Ras Alkhaimah, Fujairah, Umm AlQwain). In 2007, a health insurance system started in the emirate of Abu Dhabi and all residents are now required to be insured as a part of obtaining a residency visa in the UAE. In the emirate of Dubai, health insurance is not yet mandatory, however it will be part of obtaining a residency visa by 2014. In the other five emirates, the Ministry of Health issues health cards to all citizens which covers the cost of most emergency and chronic health conditions.

Cancer moved from the third leading cause of death in the UAE to be the second leading cause of death after cardiovascular diseases (HAAD, 2010). Cancer caused 13.9% of all reported deaths in the emirate of Abu Dhabi in 2009 (HAAD, 2010). Breast cancer is the most common diagnosed cancer among females in Abu Dhabi. The exact number of cancer patients in the whole of the UAE is difficult to determine. There is no centralized cancer registry system in the UAE, and data often only becomes available after patients are admitted to

hospitals in advanced stages of the disease. A number of patients seek diagnosis and treatment overseas and their cases may not be registered with UAE hospitals or local health authorities.

**The health system in the emirate of Abu Dhabi**

The population of the emirate of Abu Dhabi has grown rapidly in recent years. One in five residents is national citizens of whom two thirds are under 30 years old and half under 19 (Taher et al., 2008). The introduction of mandatory health insurance in 2007 in the emirate of Abu Dhabi has provided all residents access to high quality care (Taher et al., 2008). Late detection of breast cancer has historically led to significant increases in mortality rates. Female adult nationals between 40 and 69 are being given an option for breast cancer screening as part of their insurance card renewal process. For expatriates, screening campaigns have helped in early detection of breast cancer, however, screening is not performed on an organized basis and some insurance companies do not cover screening cost (Taher et al., 2008). Some preventive medicine centers provide free screening, but its availability is not widely publicized.

**Statistics**

Data from the Tawam Hospital cancer registry are limited. However, current available data shows that breast cancer is the commonest cancer in women in UAE (Taher et al., 2008). It is the second leading cause of death among women and accounts for 28% of all female deaths. Every year there are more than 130 new cases of breast cancer diagnosed in the emirate of Abu Dhabi. 87% of breast cancer cases occur after the age of 40 years. More than 65% of women with breast cancer,

regardless of nationality, present at late stages of the disease (either with regional or metastatic disease) at first diagnosis (Figure 1), compared with approximately 15% in the USA (Taher et al., 2008).
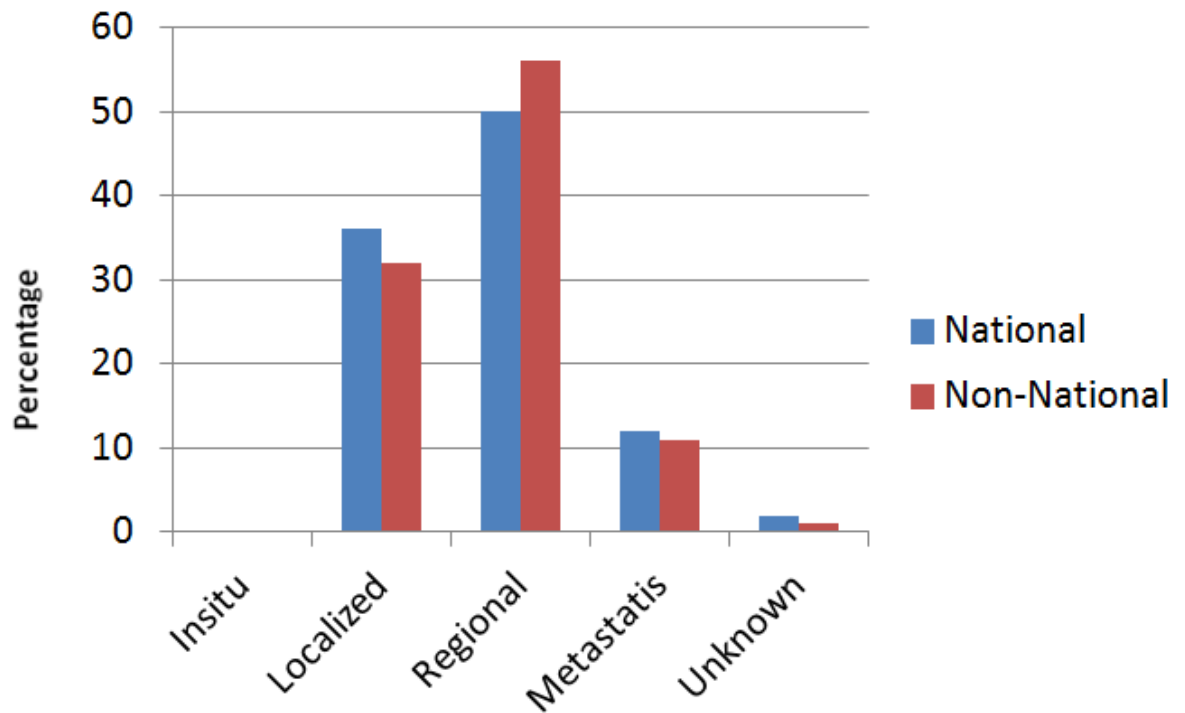


Figure 1: Stage of breast cancer at diagnosis by nationality, Abu Dhabi 2005-2007
(Tawam hospital cancer registry, 2009)

The mortality rate for breast cancer is 44%, compared with 10-15% for the USA. This is likely to be because of late presentation at first diagnosis and due to the larger proportion of the younger women in the population of the UAE. Breast cancer affecting younger women tends to be more aggressive (Swanson & Lin, 1994). In the emirate of Abu Dhabi, the estimated total number of females was 672,512 in mid-2012 and 64% of them were over the age of 20. 66% are non-nationals. The total number of women aged 40-69 years was 113,633 (16.9% of all females). Figure (2) illustrates female breast cancer incidence rates by nationality

and gender in 2012. The incidence rate is higher in UAE nationals as compared to non-nationals.
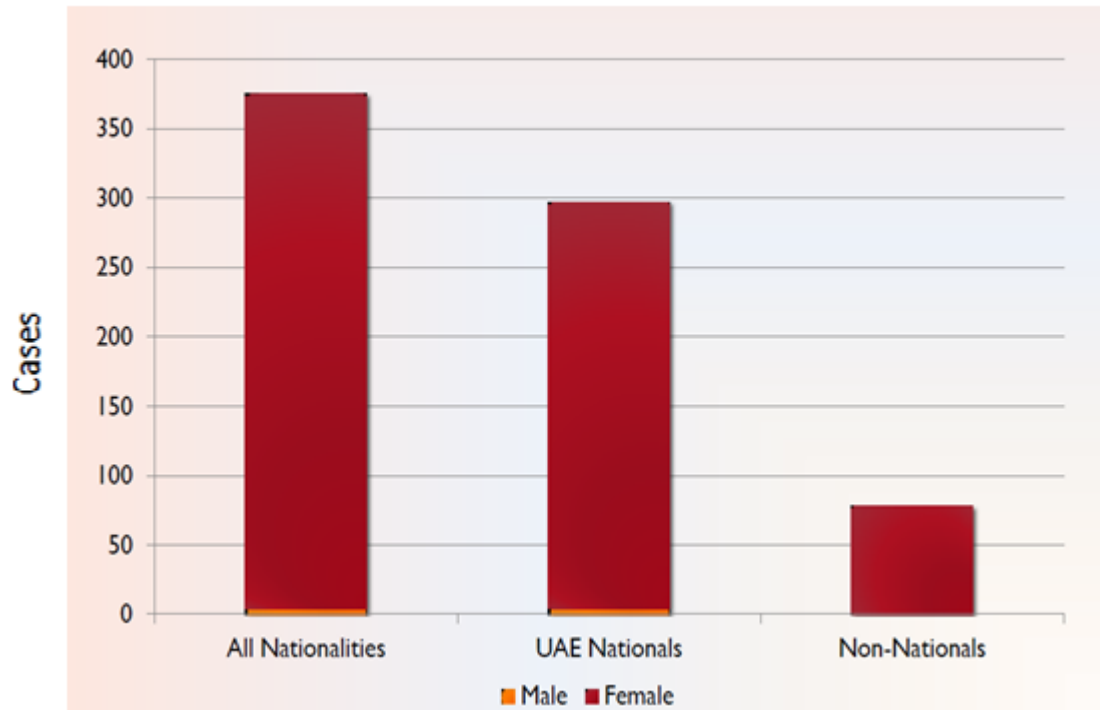


Figure 2: Female breast cancer cases by nationality and gender in 2012 (Tawam hospital cancer registry, 2012)

**Survival and prognosis**

Early diagnosis and treatment of breast cancer improves prognosis. Detection of cancer in its preclinical stage requires routine screening of asymptomatic women (Tabar et al., 2005). Improving survival and preventing death is the goal of healthcare professionals when dealing with breast disease. The prognosis for diagnosing breast cancer at a later stage has been poor regardless of therapy given and death within that period of diagnosis is usually the outcome. Women with mammographically detected non-palpable breast lump localized to the breast will have a

favorable chance of survival compared to women who self-discover a palpable larger breast lump which has a higher chance of spread beyond the breast tissue (Tabar et al., 2011). See figure (3).
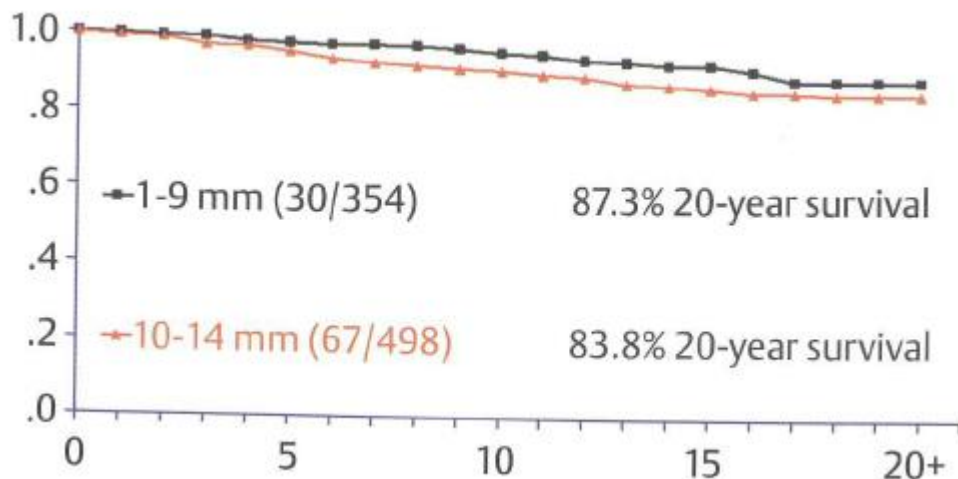


Figure 3: 20+ year outcome of patients with 1-9mm and 10-14mm breast cancer (Tabar et al., 2011)

According to the National Cancer Institute (2012), several types of statistics may be used to estimate a cancer patient's prognosis. The most commonly used statistics are listed below.

- Cancer-specific survival: This statistic calculates the percentage of patients with a specific type and stage of cancer who have survived that is, not died from their cancer during a certain period of time (1 year, 2 years, 5 years, etc.) after diagnosis. Cancer-specific survival is also called disease-specific survival. In most cases, cancer-specific survival is based on causes of death in medical records, which may not be accurate. To avoid this inaccuracy, another method used to estimate cancer-specific survival that does not rely on information about the cause of death is relative survival.

- Relative survival: This statistic compares the survival of patients diagnosed with cancer (e.g., breast cancer) with the survival of people in the general population who are of the same age, race, and sex and who have not been diagnosed with that cancer. It is thus the percentage of cancer patients who have survived for a certain period of time after diagnosis relative to people without cancer.

- Overall survival: This statistic is the percentage of patients with a specific type and stage of cancer who are still alive, that is, have not died from any cause during a certain period of time after initial diagnosis.

- Disease-free survival: This statistic is the percentage of patients who have no evidence of cancer during a certain period of time after treatment. Other similar terms are recurrence-free or progression-free survival.

**Prognostic factors/ predictors**

"A prognostic factor is capable of providing information on clinical outcome at the time of diagnosis, independent of therapy". These markers are usually indicators of growth, invasion, and metastatic potential (Foukakis & Bergh, 2013). During the past few decades, there has been major improvements in the management of breast cancer. Identification of prognostic factors helps in the management of the disease (Singletary, 1999). Prognostic factors include tumor size, lymph nodes, histologic grade, stage, estrogen and progesterone receptors and HER2/neu (erB-2) oncogene alteration (Rubin & Reisner, 2009).

**Tumor size**

Early detection of non-palpable breast lumps or smaller size lumps improves the prognosis. Figure (4) shows the effect of tumor size upon discovery on long term survival (Tabar et al., 2005).
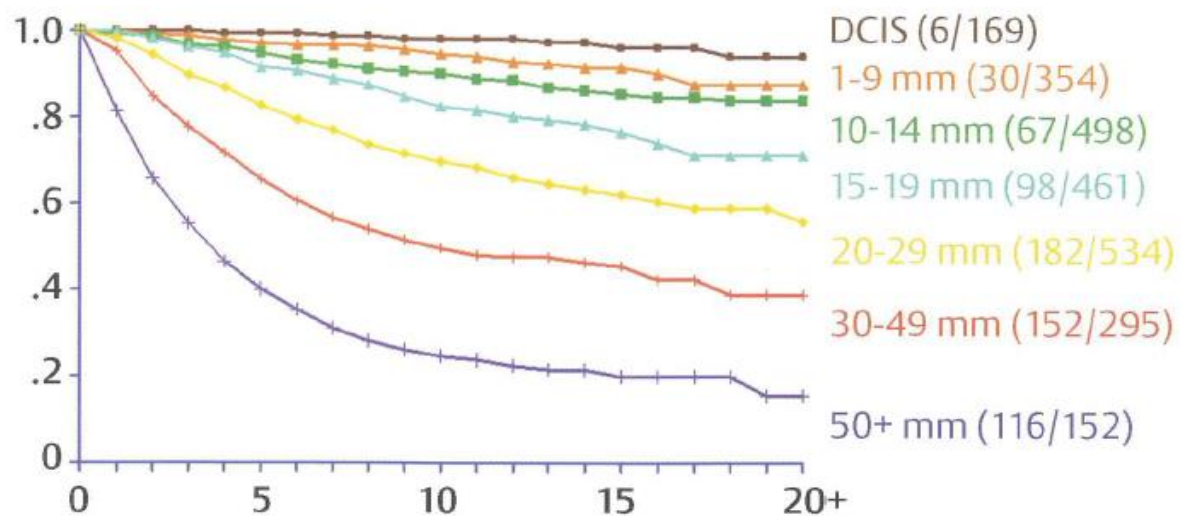


Figure 4: Cumulative survival of breast cancer patients aged 40-74 (Tabar et al., 2011)

The shape of the tumor (differentiation/see definition of terms) is also considered a prognostic factor; tumors with indistinct margins (poor differentiation) tend to be more aggressive (Rubin & Reisner, 2009).

**Node status**

Breast cancer spreads regionally by direct extension (e.g., to the chest wall) or through the lymphatic channels to the axillary or supraclavicular lymph nodes (Rubin & Reisner, 2009). Metastasis to the axillary lymph nodes and the number of lymph nodes involved is the single most important prognostic factor for breast cancer (Masood, 1997). When axillary lymph nodes are negative for

metastasis, the 10 year disease free survival rate is improved. With each positive lymph node the survival declines (Masood, 1997). If the cancer is ductal carcinoma in situ (DCIS) "the presence of malignant epithelial cells that have not penetrated the basal membrane" (Rubin & Reisner, 2009, p. 428) or has not spread to the lymph nodes (node negative), the 5-year survival rates with treatment can reach 98%. If the cancer has spread to the lymph nodes or beyond the primary tumor site (node positive), the 5-year survival rate is approximately 84%. If the cancer has spread (metastasized) to other sites (most often the lung, liver, and bone), the average 5-year survival rate is 23% (National Breast Cancer Foundation, 2010).

**Histologic grade**

Tumor grade is a description of how abnormal the tumor cells and the tumor tissue appear under the microscope. If the cells of the tumor are close to the normal tissue structure, the tumor is termed well differentiated. These tumors tend to grow and spread at a slower rate than tumors that are "undifferentiated" or "poorly differentiated," which have abnormal looking cells and may lack normal tissue structures. Breast tumors progress gradually to higher grades with time. Early detection aids in detecting smaller tumors at lower histological grades (Tabar et al., 2005). Tumors are graded as 1, 2, 3, or 4, depending on the amount of abnormality. The American Joint Committee on Cancer (AJCC) classified the tumor grade as following:

GX: Grade cannot be assessed (undetermined grade)

G1: Well differentiated (low grade)

G2: Moderately differentiated (intermediate grade)

G3: Poorly differentiated (high grade)

G4: Undifferentiated (high grade)

In Grade 1 tumors, the tumor cells and the organization of the tumor tissue appear close to normal. These tumors tend to grow and spread slowly. In contrast, the cells and tissue of Grade 3 and Grade 4 tumors do not resemble normal cells and tissue. Grade 3 and Grade 4 tumors tend to grow rapidly and spread faster than tumors with a lower grade.

**Staging**

Breast cancer is characterized using the Tumor, Node, Metastases system (TNM), see table (1). The AJCC, provides cancer classification to aid in the process of assessing prognosis and assigning treatment protocol. The classification involves three criteria, Primary tumor (T), Regional lymph nodes (N), and distant metastasis (M).

**Primary tumor (T)**

T stands for the primary tumor and the primary tumor is classified as follows:

T1: Tumor 2.0 cm or less in greatest dimension

T1mic: Micro-invasion 0.1 cm or less in greatest dimension

T1a: Tumor more than 0.1 but not more than 0.5 cm in greatest dimension

T1b: Tumor more than 0.5 cm but not more than 1.0 cm in greatest dimension

T1c: Tumor more than 1.0 cm but not more than 2.0 cm in greatest dimension

T2: Tumor more than 2.0 cm but not more than 5.0 cm in greatest dimension

T3: Tumor more than 5.0 cm in greatest dimension

T4: Tumor of any size with direct extension to (a) chest wall or (b) skin,

T4a: Extension to chest wall

T4b: Edema (including peaud'orange) or ulceration of the skin of the

T4c: Both of the above (T4a and T4b)

T4d: Inflammatory carcinoma

**Regional lymph nodes**

N describes the axillary lymph nodes involvement. It is documented as follows:

NX: Regional lymph nodes cannot be assessed (e.g., previously removed)

N0: No regional lymph node metastasis

N1: Metastasis to movable ipsilateral axillary lymph node(s)

N2: Metastasis to ipsilateral axillary lymph node(s) fixed to each other or to other structures N3: Metastasis to ipsilateral internal mammary lymph node(s)

**Distant metastasis (M)**

Distant metastasis describes the status whereby the cancer has moved out of the breast to body organs other than the regional lymph nodes.

MX: Presence of distant metastasis cannot be assessed.

M0: No distant metastasis

M1: Distant metastasis present (includes metastasis to ipsilateral supraclavicular lymph nodes) see table (1).

| ANATOMIC STAGE/PROGNOSTIC GROUPS | | | |
|---|---|---|---|
| Stage 0 | Tis | N0 | M0 |
| Stage IA | T1* | N0 | M0 |
| Stage IB | T0 | N1mi | M0 |
| | T1* | N1mi | M0 |
| Stage IIA | T0 | N1** | M0 |
| | T1* | N1** | M0 |
| | T2 | N0 | M0 |
| Stage IIB | T2 | N1 | M0 |
| | T3 | N0 | M0 |
| Stage IIIA | T0 | N2 | M0 |
| | T1* | N2 | M0 |
| | T2 | N2 | M0 |
| | T3 | N1 | M0 |
| | T3 | N2 | M0 |
| Stage IIIB | T4 | N0 | M0 |
| | T4 | N1 | M0 |
| | T4 | N2 | M0 |
| Stage IIIC | Any T | N3 | M0 |
| Stage IV | Any T | Any N | M1 |

Table 1: Breast cancer staging according to TNM grouping, (AJCC)

The frequency of advanced breast cancer in a population is a strong predictor for the mortality rate in the same population. The five-year survival rate can be calculated. Based on the prognostic factors the survival rate increases or decreases. (See table 2).

| Stage | Five years relative survival rate |
|---|---|
| 0 | 100% |
| I | 100% |
| IIA | 92% |
| IIB | 81% |
| IIIA | 67% |
| IIIB | 54% |
| IV | 20% |

Table 2:  Stages and survival of breast cancer (American Cancer Society, 2010)

**Estrogen and progesterone receptors status**

The hormones estrogen and progesterone can bind or connect to breast cancer cells if they contain receptors, or binding sites. Cells containing these binding sites are known as hormone receptor-positive cells. Women whose cancers express hormone receptors are typically older and have low grade tumors and a better prognosis (Rubin & Reisner, 2009). Approximately 75% of breast cancers are estrogen receptor-positive (ER-positive, or ER+). Approximately 65% of ER-positive breast cancers are also progesterone receptor-positive (PR-positive, or PR+) (Jatoi et al., 2007). Cells that have receptors for one of these hormones, or both of them, are considered hormone receptor-positive. The presence of these receptors indicates a greater probability of response to hormonal therapy (Rubin & Reisner, 2009).

**Human Epidermal Growth Factor Receptor 2 (HER2)**

"This is a protein involved in normal cell growth. It is found on some types of cancer cells, including breast and ovarian. Cancer cells

removed from the body may be tested for the presence of HER2/neu to help decide the best type of treatment" (National Cancer Institute, 2012). Approximately 25% of breast cancers, the HER2 gene does not work correctly. In response, breast cells increase the HER2 receptors. This makes breast cells grow and divide in an uncontrolled way. Over expression of HER2/neo is identified in between 10% and 35% of primary breast tumors and is mostly attributable to gene amplification. A monoclonal drug (Herceptin/trastuzumab) has been shown to benefit patients with HER2/neo gene amplification. Herceptin attaches to the HER2 receptors on breast cancer cells and blocks them from receiving growth signals (Rubin & Reisner, 2009). In this way, the growth of breast cancer is controlled.

**Early detection**
**Awareness and education**

Increasing awareness and education are effective ways for early detection of breast cancer. Simple and popular means of education include television advertisements, radio and newspaper campaigns. The highest benefits of educational programs can be achieved through well designed culturally sensitive programs. Education should also target men, as men could be a positive influence for women in regards to participation in screening programs (Smith et al., 2006). In the UK, Stockton et al (1997) reported a dramatic increase in the early detection of breast cancer in the 1980s after the launch of an education and awareness program.

In the UAE, information on breast health varies between different healthcare providers (Taher et al., 2008). Education activities are especially active during October because it is assigned internationally as the breast cancer

awareness month, and screening is widely offered, leading to sharp

increases in mammography uptake during October and dropping to lower

levels for the rest of the year. At this time community outreach programs

are insufficient and screening is opportunistic rather than regular.

Healthcare professionals have a major role to play in improving awareness

and early detection as they have regular contact with women in the

community (Yarbo, 2003). Unfortunately, UAE healthcare professionals

often lack awareness of screening guidelines and the availability of

existing screening programs (Taher et al., 2008).

Breast cancer screening is a way for reducing morbidity and

mortality and improving the survival rate (Anderson et al., 2003).

Mammography has been widely used and accepted as a mean for early

detection of breast cancer and its use has been linked to early diagnosis of

the disease and reduced mortality (Stockton et al., 1997). A two country

Swedish trial (Tabar et al., 2011) has the longest follow up of any breast

screening trial to date, with a maximum of 29 years follow up for cancer

mortality. This trial reported 30% mortality reduction from invitation to

screening. Table 3 shows the absolute numbers of deaths prevented and

the estimated numbers of women needed to be screened during the 7 years

of screening to save one life (Tabar et al., 2011). This in turn would mean

that for 1,000 women screened every 2 years from ages 40 through 69

years, between 8 and 11 breast cancer deaths would be prevented. In the

UK National Breast Screening Program, for every 1,000 women attending

three yearly screenings from ages 47 to 73 years (nine screening episodes),

five to seven breast cancer deaths would be prevented. (See table 3)

| Time between Randomization and Follow-up (y) | RR* | Deaths from Breast Cancer in ASP Group | Expected Deaths in ASP Group* | Deaths Prevented in ASP Group | No. of Women Needed to Screen† |
|---|---|---|---|---|---|
| 10 | 0.80 (0.62, 1.05) | 207 | 257 | 50 | 1303 (621, 13169) |
| 15 | 0.73 (0.59, 0.92) | 274 | 373 | 99 | 663 (412, 1695) |
| 20 | 0.73 (0.60, 0.90) | 311 | 425 | 114 | 577 (370, 1315) |
| 25 | 0.73 (0.60, 0.90) | 335 | 457 | 122 | 539 (346, 1217) |
| 29 | 0.73 (0.59, 0.89) | 339 | 465 | 126 | 519 (336, 1144) |

Table 3: The absolute numbers of deaths prevented and the estimated numbers of women needed to screen during the 7 years of screening to save one life (Tabar et al., 2011)

At a national level, the UAE Ministry of Health is the key provider of breast cancer screening programs, which began in 1995. These programs follow international recommendations which include a combination of monthly Breast Self-Exam (BSE), regular Clinical Breast Exam (CBE) and a mammography every two years after the age of forty (Sadler et al., 2001a; Pearlman et al., 1999). UAE society has experienced major shifts in lifestyle over the past five decades because of acquired oil wealth (Bener et al., 2001). Screening services are widely available and free of charge for national women over the age of forty. Despite this, the participation of women in screening activities is very low (10%) (Taher, et al., 2008).  The overall goal of the program is to achieve a70% participation rate by 2013 (Taher et al., 2008). Many barriers to breast cancer screening and underutilization of services have been studied worldwide, but in the UAE very few studies have been conducted.

**Screening**

Screening patients for preclinical disease is an established part of day to day medical practice. A screening test must detect cases in sufficient numbers and at an acceptable cost, and it must not carry side effects that outweigh the benefits of screening. As with all diagnostic tests, there is a tradeoff between sensitivity and specificity, and the competing needs for each must be balanced. In addition to its sensitivity and specificity, the performance of a test is measured by its predictive value. The predictive value of a positive result is the probability that a person who reacts positively to the test actually has the disease. The predictive value varies with the prevalence of disease in the population to whom the test is applied. If the prevalence is low then there are more false positive results than true positives, and predictive value falls. At the extreme, if nobody has the disease then the predictive value will be zero, all positive test results will be false positives. It follows that a test that functions well in normal clinical practice will not necessarily be useful for screening purposes.

**Breast self-examination (BSE)**

For BSE, the steps are similar to Clinical Breast Examination (CBE) with the difference being that the woman will be performing it for herself. The optimal time to do it is a few days after the cessation of the menstrual flow. It is recommended that women start regular BSE by the age of 20, to be aware of her breast anatomical and physiological features and to detect any. Optimal benefits of BSE could be attained through effective and detailed step by step instructions by healthcare professionals (Hindle, 1999). The National Breast Cancer Foundation (2010) reported that 70% of breast cancers were discovered by women performing regular BSE. Women's recall of the method of breast cancer

detection in a population based study in the USA found that the proportion of breast cancers that were self-detected by women aged 20-44 years using BSE was 71.2%  much higher than either the proportion of cancers detected using CBE 9.3% or the proportion identified by mammography (19.6%) (Coats et al., 2001). In a survey of Arab women in the UAE, 12.7% women practiced regular BSE (Bener et al., 2001). The 5 steps to perform BSE are:

1. Stand in front of a mirror that is large enough for you to see your breasts clearly. Check each breast for anything unusual. Check the skin for puckering, dimpling, or scaliness. Look for a discharge from the nipples.

2. Watching closely in the mirror, clasp your hands behind your head and press your hands forward.

3. Next, press your hands firmly on your hips and bend slightly toward the mirror as you pull your shoulders and elbows forward.

4. Gently squeeze each nipple and look for a discharge.

5. The breasts are best examined while lying down because it spreads the breast tissue evenly over the chest. Lie flat on your back, with one arm over your head and a pillow or folded towel under the shoulder. This position flattens the breast and makes it easier to check.

**Clinical breast examination (CBE)**

The clinical breast examination is a diagnostic technique used by healthcare professionals to examine the breasts which includes palpation of the breast to detect the presence of abnormal masses, e.g., tumors. It is these similar to BSE. The steps used are the same whether the examination is a routine annual examination or a diagnostic examination following a breast complaint. The procedure generally should be done in a relaxed and private atmosphere. Culture and personal preference need to be considered and respected as most women would prefer a female physician or nurse to perform the procedure (Hindle, 1999). This is especially so in the conservative societies in the Middle East. The sensitivity (refer to definitions) for CBE ranges from 40% to 70%, and specificity (refer to definitions) ranges from 86% to 99% (Agency for Healthcare Research and Quality, 2008). CBE and BSE are not primarily cancer prevention methods. Several studies have demonstrated benefits from these techniques through the detection of smaller lumps by women performing regular CBE and BSE (Hindle, 1999). During periodic health visits, CBE might play a particularly important role in identifying cancers among the significant proportion of women who do not adhere to mammography screening guidelines, but who see their primary care provider on a regular basis (McDonald et al., 2004).

**Screening mammography**

The best documented technique for early breast cancer detection is a combination of regular breast examination and mammography. Mammography employs the use of imaging x-rays to see the breast tissues and detect abnormalities. Mammography could be a screening or diagnostic test. There is strong evidence in favor of mammography as the best technique to detect breast

tumors that are not even palpable. It has been shown that mammography can reduce mortality by up to 30% (Tabar et al., 2005) and in a recent study by 20% (Independent UK Panel on Breast Cancer Screening, 2012). Studies showed that sensitivity of mammography is approximately 90% for palpable breast tumors (80%-85% for both palpable and nonpalpable breast tumors). Humphry et al., (2002) reported that for a 1-year screening interval, the sensitivity of first mammography ranged from 71% to 96%. Sensitivity was substantially lower for women in their 40s than for older women. Regarding the specificity and positive predictive value (PPV/ refer to definitions), they reported that in the randomized trials, the specificity of a single mammographic examination was 94% to 97%. This indicates that 3% to 6% of women who did not have cancer underwent further diagnostic evaluation, typically a clinical examination, more mammographic views, or ultrasonography. The positive predictive value of one-time mammography ranged from 2% to 22% for abnormal results requiring further evaluation and from 12% to 78% for abnormal results requiring biopsy. In conclusion, mammography is less specific than sensitive, therefore further confirmatory investigations are needed to confirm the diagnosis (Hindle, 1999). The American Cancer Society (2010) recommends that regular routine mammographic screening begin at age of 40. The same guidelines specify that women between 40-49 years of age should undergo regular mammography at one to two year intervals in combination with BSE and CBE.

# Chapter two

# OBJECTIVES

**Statement of the problem**

A delay in the presentation to treatment after self-discovery of breast cancer symptoms by women in the UAE results in poor prognosis and lower survival rates.

General objective:

This study aims to describe the pattern of breast cancer presentation in the UAE and to explore the factors influencing delayed presentation to treatment of Emirati & Arab women. This study also intends to highlight areas within this field which may be in need of assessment and improvement to improve standards and quality of breast cancer screening and early detection programs.

**Objectives:**

1. Describe breast cancer presentation patterns in the UAE.

2. Assess breast health awareness among women at screening age (≥40 years old) and to explore barriers to regular screening.

3. Explore factors influencing delayed presentation to treatment of Emirati and Arab women in the UAE.

4. Examine the use of a health seeking model to predict and explain facilitators and barriers to women's health seeking behavior in a complex society.

**Benefits of the study**

This study will not only contribute to the existing knowledge on this topic but will also help suggest, develop and establish national health policies for early detection of breast cancer.

**Hypothesis**

The lack of awareness about breast cancer and cultural and psychosocial beliefs play a major role in delayed presentation to treatment and act as a barrier for screening and thus early detection. Understanding the determinants of delayed presentation to treatment by women in the UAE is important for the development of effective and targeted health interventions.

# Chapter three

# REVIEW OF THE LITERATURE

**Methods of literature search**

A literature review was conducted by using the Pubmed and Medline databases. A manual search was also undertaken for relevant journals identified by the electronic search and additional articles identified from the reference lists of key articles. A number of articles were found on breast cancer knowledge, attitude and practice in the Middle East but only one article in the UAE. No literature was found regarding delayed presentation to treatment by women in the UAE. The search strategy was based on the terms: breast cancer survival, pattern/trend of presentation, Patient Delay, Early/Late/Delayed Presentation/Diagnosis, Care/Help/Help seeking, early detection/screening, attitude/practice/knowledge and Breast Cancer (MeSH terms applied). Around 350 eligible articles were identified and further filtered to 150 articles. To eliminate search bias, another researcher adopted the same search procedure independently. There was no discrepancy in regards to articles retrieved. See figure (5).
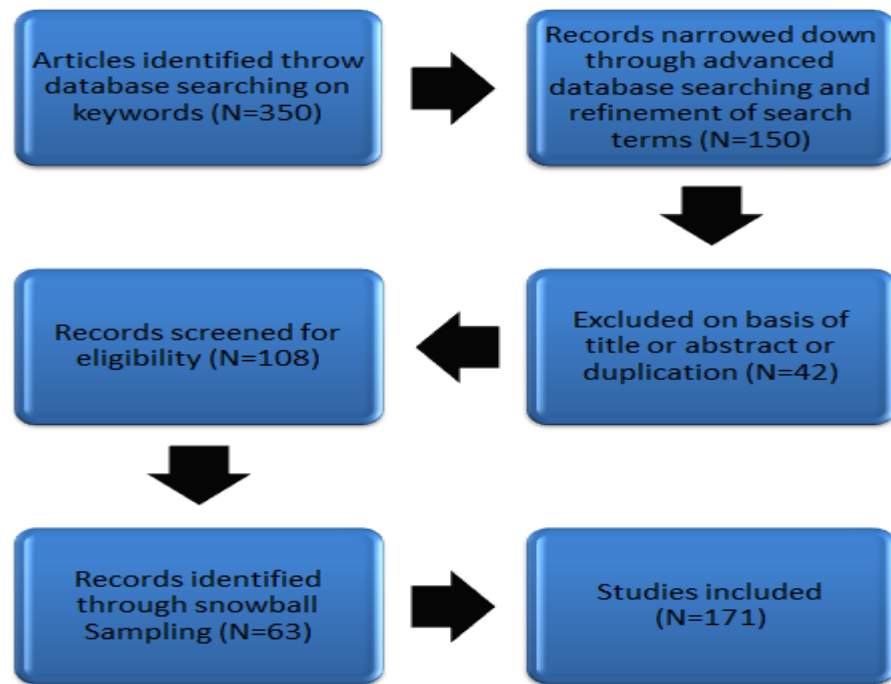
Figure 5: Flow diagram of literature search

**Extent of the problem**

Breast cancer in developing countries is characterized by late presentation, advanced stage of disease at diagnosis, worse biologic behavior and occurrence in younger women than reported in developed countries (Lodhi et al, 2010). Prior studies have estimated that approximately one third of women experiencing symptoms of breast cancer delay seeking help for at least 3 months, and approximately 25% of women will delay 6 months or longer (Lannin et al, 1998; Piñeros et al, 2009). Among poor or minority populations, the percent of women who delay at least 3 months may be as high as 45% (Lodhi et al, 2010).

Alwan (2010) reported that although women self-detected breast lumps in 90.6% of cases in Iraq, only 32% sought medical advice within the first month. These observations reflect the poor breast health education of women and the lack of knowledge about breast cancer screening. The literature from developing

countries suggests that the advanced disease at presentation is a reflection of the cultural norms which downplay women's health problems (Miller, 1989). It is believed that the improved survival rates of breast cancer in the USA and Europe are related to an earlier stage at presentation instead of improved treatment (Etzioni et al., 2003).

**Breast cancer pattern of presentation and survival**

The age adjusted incidence rates (ASR) for breast cancer are increasing in many Arab countries, e.g., Lebanon (from 20 in 1996 to 46.7 in 1998) and Jordan (increase from 7.6 in 1982 to 32.8 in 1997). Under-reporting of breast cancer cases is suspected. Many differences with respect to age, biological characteristics and stages at presentation exist between countries. In the United States, approximately 50% of all women with newly diagnosed breast cancer are older than 63 years while in many developing countries almost half of women with newly diagnosed breast cancer are younger than 50 years of age (Rodriguez et al., 2001). Elsaghir et al (2007) reviewed published literature and obtained data from cancer registries of several Arab countries. They attempted to describe the trends and management of breast cancer in the developing Arab countries. See table (4) for a summary of findings.

| Country | Year(s) | No. of patients | ASR | Age at presentation | Mastecto-my rate | Tumor size(cm) | Stage | Ref. |
|---|---|---|---|---|---|---|---|---|
| **Algeria** | 1990-93 | - | 9.5 | - | - | - | - | Parkin et al., 2002 |
| **Bahrain** | 1982-94 | 117 | - | - | - | 70% > 2 | I: 6.8%; II: 51.3%; III: 21.4%; IV: 11.1% | Fakhro et al., 1999 |
| **Egypt** | 2002-03 | Hospital-based | - | Median age 49 | 79.9-82% | - | III and; IV: 68% | Abdel-fattah et al., 2001, Elattar et al., 2005 |
| **Jordan** | 1997 | National | 21.3 | - | - | - | - | Freedman et al., 2003 |
| **Kuwait** | - | 258 (National) | 32.8 | 78% < 50 | - | - | - | Paszko et al., 1993 |
| **Saudi Arabia** | 1994-96 | 1430 (National) | 11.2 | 48.3 | - | - | I: 9%; II: 44%; III: 30%; IV: 16% | Elhaj et al., 2002, Ezzat et al., 1999 |
| **Lebanon** | 1964<br><br>1984<br>1982-20<br>1998 | Hospital-based 1094<br>2673<br>2092 | 20<br>-<br>30.6<br><br>46.7 | -Medianage 49,<br>49% < 50<br>Medianage5,<br>50% < 50 | - | - | - | Geahchan & Taleb, 1986 Ghosn et al., 1992 Elsaghir et al., 2002 Shamseddine et al., 2004 |
| **Morocco** | 1986-87 | 5148 | - | - | - | - | - | Chaouki et al., 1991 |
| **Oman** | 1993-97 | 1809 | 13 | - | 65% | 4.6 | III: 34.9%; IV: 15.8% | Al-lawati et al., 1999 Al-Moundhri et al., 2004 |
| **Palestine** | 1995 | - | 13.6 in Arabs vs 102.2 in Jews | - | 70% | 3.9 | I: 23%; II: 43%; III: 33%; IV: 2% (+ve LNs 53%) | Nissan et al., 2004 |
| **Syria** | 1998-99 | 230 | 30.4 | 88% | - | - | - | Semaan et al., 2003, Mzayek et al., 2002 |
| **Tunisia** | 1994 | 689 | 16.7 | Average 50 | 82.40% | 4.95 | T1: 7.2%;T2: 48.9%; T3: 18.5%; T4: 23.4%; CIS: 3.3%; M1:22.1% | Maalej et al., 1999 |
| **Yemen** | 1989-96 | 225 | - | 69% < 50 | - | - | - | Abdul Hamid et al., 2001 |

Table 4: Clinical data for breast cancer in Arab countries

Breast cancer that presents at a younger age generally has more aggressive cellular features resulting in more aggressive clinical behavior, a more advanced stage at presentation, and poorer prognosis (Swanson & Lin, 1994). A study conducted in southern Iran showed a relatively low five-year survival rate of breast cancer (Rezaianzadeh et al., 2009). The study also considered 44 different influencing factors of survival and suggested that the survival is affected mainly by late diagnosis and therefore late stage disease. The authors hypothesized that delay in presentation to treatment and late diagnosis is due to lack of awareness, cultural barriers and access to treatment (Rezaianzadeh et al., 2009). Fakhro et al (1999) conducted a survival analysis on Bahraini women diagnosed with breast cancer at Alsalmaniya Hospital, Manama. They reported that 93.2% of women were first diagnosed with disease progression beyond stage I, including 21.4% in clinical stage III and 11.1% in clinical stage IV. Axillary lymph node involvement was found in 50.4% of cases.

Papers from the Arab world did not only report the early age of onset of breast cancer among women, but also described the aggressive breast cancer phenotype in Arab women (Akhtar et al., 1993; Al Idrissi et al., 1992; Ibrahim et al., 1998; Elsaghir et al., 2002; Abdel Rahman et al., 1993; Soliman et al., 1999). Researchers from Tunisia reported cases of rapidly progressing breast cancer in young women (Tabbane et al., 1977; Tabbane et al, 1985).

**Factors influencing delayed presentation to treatment**

In the literature, many factors were found to be influencing delayed presentation to treatment. These factors include lack of knowledge, psychosocial and cultural beliefs, lack of or deficient screening programs, lack of specialized treatment facilities, poverty, lack

of awareness, fear of disease/death and illiteracy (Lodhi et al., 2010). Factors influencing delay are divided into two types, patient delay and system delay. Patient delay factors may include, demographics, socio-economic, psychosocial or cultural beliefs and knowledge and awareness. System delay factors are related to the health delivery system which result in diagnosis, referral or treatment delay of breast cancer.

**Breast Cancer Delay**

Breast cancer delay (BCD) or total delay is defined as "more than three months between symptom discovery by the patient and the beginning of definitive treatment" (Pack & Gallo, 1938 p124). This delay influences prognosis negatively as it is associated with an advanced stage of the disease at presentation and with a reduced chance of survival (Richards et al., 1999). Pack and Gallo (1938) proposed the conventional classification of BCD. (1) Patient delay and (2) Provider delay. Patient delay is defined as the time elapsed from the discovery of symptom by the patient to first medical consultation. Provider delay is defined as more than one month between the first medical consultation and the initiation of definitive treatment (Pack & Gallo, 1938).

Unger & Infante (2009) schematized the conventional classification of delay proposed by Pack & Gallo in 1938, figure (6). The white boxes in the middle of the diagram are the most important steps in a cancer patient's help-seeking trajectory, represented linearly as is generally conceived in the literature. A triple-line bar cuts the two types of delay, patient and provider, to represent that each type has traditionally been studied independently. That is, any delay between symptom discovery and first medical consultation has implicitly been considered to be the patient's responsibility. In the same way, delay occurring after the first medical consultation has been assumed to be the health providers' responsibility.
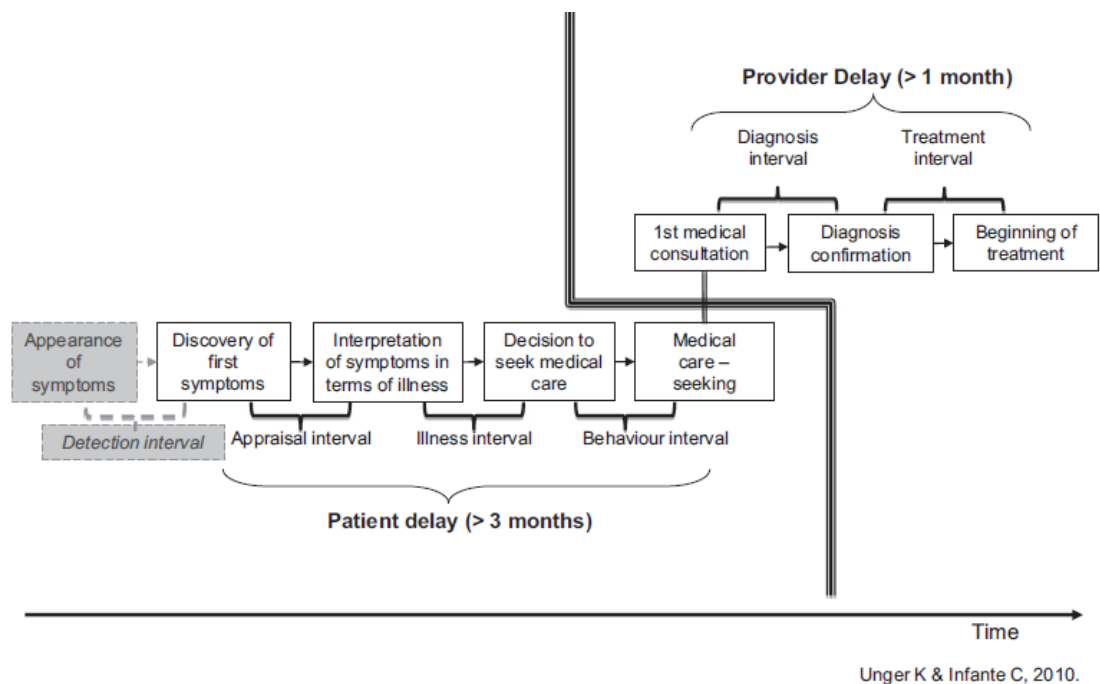


Figure 6: Conventional classification of delay

**Patient delay**

**Health care services access, utilization and Socio-economic factors**

Socioeconomic status is influential in a woman's health. Evidence showed that women with late stage breast cancer often live in poverty and

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in low income communities and act as care providers both in their families and in the larger community (Lodhi et al., 2010). A low level of education and low socio-economic status leads to poor uptake of screening by women. Women with low socio-economic status are more likely to be diagnosed with advanced breast cancer compared to more economically privileged women (Miller et al., 2002). Regardless of age or ethnicity, poverty has a strong effect on the probability of being diagnosed at an advanced stage (Campbell et al., 2009). Yusuf et al. (2001) conducted a study on 400 Pakistani women with breast disease, and almost 33% mentioned economic factors as their reason for delay in seeking help.

Access to health care services, utilization and insurance play a major role in prolonged delay (Rauscher et al., 2010). Recommendations for improving access to screening facilities involve two approaches: reducing structural barriers and reducing out-of-pocket costs. Health insurance plays a major role in reducing costs of screening paid by women and increasing the compliance with screening guidelines (Baron et al., 2008). The benefit of providing access cannot be fully realized if women are not aware of breast cancer screening needs and options, or are resistant to screening. Healthcare providers should avoid missing opportunities to discuss screening recommendations with women and be proactive rather than passive and to offer options during healthcare visits.

Some studies investigated the demographic factors of women presenting late for medical treatment. It was observed that women were more likely to be diagnosed in later stages if they were older (50 years and above) or post-menopausal women, in lower income areas, delay was seen in widowed, divorced or unmarried women who have lower educational level (Ali et al., 2008). Unmarried women have longer duration of symptoms before seeking help unlike

married women; this might be due to the lack of family support or the spouse to seek help when symptoms start. Married women have the ability to rely on their husbands for household support in order to have time to go for screening or to seek help. For women with low socio-economic status, their spouses usually provide economic support for the family.

**Psychosocial factors and cultural beliefs**

Psychosocial factors and cultural beliefs create variation in the reaction to initial breast cancer symptoms. Painless lumps, as an initial breast cancer symptom is an important determinant of delayed response to the disease. The association of late presentation with painless breast lump is related to the social and cultural belief of women that painless breast lumps hve no danger to life and pain is the body's language to alert individuals to seek help (Lodhi et al, 2010). Misconception of breast lumps is common among women who are defined as disadvantaged, ethnic minorities with lower socioeconomic status and poorer access to care (Rauscher et al, 2010). Yau et al (2010) stated that there are two psychological reasons why patients delay seeking medical attention, namely optimistic bias or defensive bias which leads to psychological minimization of threat and immobilization by fear, embarrassment, or denial after recognizing the seriousness of the symptom. Perception that cancer is not curable and surgical intervention promotes the spread of cancer and fear of losing a body part by surgery are factors which have been addressed by many researchers. Lamptey et al (2009) reported that women's fear of mastectomy (surgical removal of the breast) is the main reason for women to abscond from hospitals in Nigeria after diagnosis.

Many women link mastectomy to death. This is often due to the lack of proper counseling at diagnosis and the lack of support services that offer the opportunity to express fears. Lamptey et al. (2009) supported the idea of offering newly diagnosed women the chance to meet and talk with breast cancer survivors to overcome the issue of absconding from hospitals. Other psychosocial common behaviors described in the literature are spiritual healing and prayer to cure breast cancer. Resorting to alternative medicine is a common practice worldwide. In the USA, 28% of early diagnosed breast cancer patients are known to utilize various forms of alternative medicine while on medical treatment (Lamptey et al., 2009). Women in developing countries often opt for alternative treatment as the first choice, e.g., traditional healers and spiritualists, a standard medical treatment is used as a last resort when the disease becomes more advanced with obvious symptoms such as discharging fungating breast lumps. The reasons for seeking alternative treatment are various, and for some it offers a convenient escape from mastectomy or is an extension of denial. Other reasons may be that alternative medicine is accessible and affordable by many women especially those in low socio-economic status (Ukwenya et al., 2008). Other psychosocial factors include a non-serious attitude to seeking help, a hesitation to seek help and disclose symptoms to strangers, and shyness regarding male doctors (Khan et al., 2008). Many women are keener to seek unconventional therapies and herbal treatment rather than medical treatment (Lodhi et al, 2010). One of the main causes of this is a lack of trust in medical treatment and local healthcare providers or a failure to provide female physicians in gender sensitive communities (Rauscher et al, 2010).

**Knowledge and awareness**

Although awareness is something of an elusive concept, it nevertheless influences the disease outcome. A great majority of women diagnosed with breast cancer are symptomatic at the time of diagnosis, probably with no access to screening mammography. Therefore, the effect of awareness about other breast cancer screening methods such as BSE and CBE would have a great impact on women's health in countries with limited resources. Breast cancer awareness, examination and screening practices of women presenting with newly diagnosed breast cancer is generally poor. Linsell et al (2008a) reported that older women are less aware about the symptoms and risk of breast cancer than younger women. Based on the survey carried out in the same study for women aged 60 to 80 years, 50% of women believed that the life time risk of developing breast cancer is less than 1 in 100 women and 75% were not aware that age is a risk factor.

Stockton et al. (1997) reported that in the UK during the 1980s before the introduction of the national screening program, public awareness was increased through public education and messages about early detection and this resulted in a dramatic decrease in advanced breast cancer cases in the following years. One important message to be disseminated through public awareness campaigns is that breast cancer is not rapidly fatal if diagnosed early. New techniques for diagnosis and advanced treatment modalities could enable women to survive breast cancer for longer period of time (Smith et al, 2006). Linsell et al. (2009) stressed the importance of awareness and knowledge of breast cancer

symptoms and risk factors in promoting early presentation to treatment. Lack of awareness about risk factors, initial symptoms, screening and treatment was one of the major findings of many research targeting the factors affecting delayed presentation of women to treatment (Lodhi et al, 2010). The effective and timely diagnosis of breast cancer relies on breast health awareness. Thus, increased breast health awareness is an important key element of intervention at all resource levels including countries with limited resources. Linsell et al (2009) claim that breast cancer awareness programs, which include breast cancer knowledge and the confidence, skills and motivation needed to self-detect symptoms and seek help accordingly, reduce delays in presentation. Symptoms interpretation, the initial and most important step in symptom recognition, is highly affected by breast cancer perceived risk and symptoms knowledge regarding breast cancer (Lim & Edlin, 2009). When the symptom is inconsistent with women's lay knowledge of breast cancer, women are more likely to downplay the significance of minimal symptoms and delay seeking medical care (Lim & Edlin, 2009). Pineros et al (2009) reported that approximately 40% of women delay in seeking help due to lack of knowledge about initial breast cancer symptoms and they do not consider symptoms to be important. Taj et al (2009) recommend the use of breast clinics in hospitals and the utilization of the mass media to promote awareness.

**Provider / System delay**

Many studies discuss the patient delay factors, however, provider delay from diagnosis to start of treatment has not been fully examined. Delays in the diagnosis process, referral of women after diagnosis or delay in treatment initiation is likely to result in tumor progression and poor prognosis (Arndt et al., 2003). Provider delay has been further divided by some authors into (1) diagnosis

delay, time between the first clinical consultation and cancer diagnosis,
and (2) treatment delay, time between diagnosis and beginning of
treatment (Caplan et al., 1996 & Gwyn et al., 2004). Although less
frequently, it has also been divided into (1) referral or general practitioner
delay; time elapsed between first consultation to a primary care service
and referral to a hospital, and (2) hospital delay, time from referral to
beginning of definitive cancer treatment (MacArthur & Smith, 1981;
Sainsbury et al., 1999). Arndt et al (2003) conducted a population based
study on provider delay among breast cancer patients in Germany. 380
women diagnosed with breast cancer were interviewed to discuss the
diagnostic process they went through.  Median provider delay was found
to be 15 days and did not differ by physician specialty in the first visit.
Delays in diagnostic work up were found to be related to the erroneous
initial suspicion of a benign breast disease. Other reasons were time
constraints by patient or physician. Provider delay over 3 months was
found in 11% of all breast cancer cases and was associated with patient
characteristics such as lower education, full time employment and
presenting with a non-breast symptom. Bright et al. (2011) conducted a
study in Mexico to examine the role of health system factors in delaying
final diagnosis and treatment of breast cancer. 32 patients were
interviewed using a semi-structured questionnaire. Participants were asked
to provide an account of what took place between the discovery of a breast
symptom/sign and subsequent primary, secondary, and specialty clinic
visits. Results showed prolonged delay. Women interviewed in this study
experienced a total diagnostic delay of 7.8 months and a total treatment

delay of 8.4 months. The average delay from symptom discovery to first consultation was shorter (1.8 months) and mainly related to patient factors. In Scotland, Baughan et al (2009) conducted a two year audit to follow the diagnosis of cancer and referral. The audit included all types of cancer and 4181 patients were identified in the first year and 12, 294 in the second year. The priority with which general practitioner referred patients varied considerably between tumor groups (77.5% of breast cancer cases were deemed 'urgent' compared with 44.7% of prostate cancer cases). The proportion of cancer patients being referred urgently increased from 46% to 58% between the first and second audit. Finally, they concluded that there are very different patterns of presentation and referral of patients. Following a unified care pathway may greatly help in reducing these differences.

**Factors influencing late presentation for breast cancer in the Middle East**

Many reviews have been conducted to examine the factors explaining breast cancer delay. However, none of these reviews have specifically addressed the evidence in the Middle East (Alhuraishi et al., 2011). Alhuraishi et al. (2011) conducted a systematic review to assess and examine the strength of the factors influencing breast cancer delayed presentation in the Middle East. They adopted a strength of evidence assessment tool developed by Ramirez et al. (1999) to assess studies selected for the review.

On assessing the influencing factors for delayed presentation, Alhurishi et al. (2011) found that there is strong evidence supporting the effects of older age and lower educational level on late presentation. The strength of evidence on the effects of family history, marital status and presence of symptoms other than lumps was moderate.

**Screening and early detection**

 Screening is the only available way to detect the cancer in its early stages. Delayed presentation to treatment and the underutilization of screening services are closely connected to women's knowledge of breast cancer and available screening methods. Screening methods recommended for early detection of breast cancer include BSE, CBE and mammography. CBE and mammography require visiting the hospital or clinic to be performed by specialized healthcare staff but BSE is conducted by the woman herself and it is cost-effective if performed correctly.

 Okobia et al (2006) tried to account for the 70% late presentation in Nigerian women through a cross sectional survey aimed to assess the knowledge level of Nigerian women regarding breast cancer and screening methods. In the study sample, the mean knowledge score was 42.3%. They found significant level of ignorance about risk factors and common symptoms of breast cancer. The use of screening methods was very low among the study subjects, only 34.9% practice BSE and only 9.1% had had CBE in the past year and none had ever had a mammogram. They concluded that routine breast cancer screening is rarely practiced in Nigeria.

 Another study done in Malaysia by Kanaga et al (2011) showed differences in awareness of screening procedures between women living in urban and rural areas. They also reported a significant positive relationship between awareness and education level. Dahlui et al (2013) investigated the knowledge of Malaysian women about screening procedures and practices. The uptake of BSE, CBE and mammogram was 59%, 51% and 6.8%, respectively. Noroozi & Tahmasebi (2011) reported the poor practice of BSE among Iranian women. Their

result showed that only 7.5% of women in their study monthly practiced BSE monthly and 14.3% reported having at least one mammogram in their lifetime.

**Breast cancer screening practices among Arab women**

Donnelly and Hwang (2013) performed a literature review of studies in the Arab world addressing screening practices. They included studies from Arab countries in North Africa (Egypt & Sudan), the Eastern Mediterranean region and the Arab peninsula. Because screening programs in the Arab world are new and opportunistic in nature, few studies have been published regarding the participation rate in screening activities. Table (5) summarizes all studies found in the Arab world reporting women participation rates. All studies reported low participation rates.

| Region | Country | Main study outcome | Author (s) |
|--------|---------|--------------------|------------|
| Arab peninsula | UAE | 12.7% of 1367 women practiced BSE, 13.8% had undergone CBE, 10.3% had undergone mammography. | Bener et al., 2001 |
| | Qatar | 24.9% of 1200 Qatari women aged 30–55 practiced BSE, 23.3% underwent CBE, 22.5% underwent mammography. | Bener et al., 2009 |
| | KSA | 23.1% of 719 women practiced BSE, 14.2 had undergone CBE, 8.1%, had mammogram. | Rachivandran et al., 2011 |
| | | 5.7% of 1315 women age 40-50 and 21.1% of women aged >50 adhering to screening of CBE and mammography according to age specified guidelines. | Amin et al., 2009 |
| | | Of 700 women, 20.5% had breast cancer screening. 79% heard of BSE, 47% knew how to perform BSE. | Radi, 2013 |
| | Yemen | 17.4% of 500 university students practiced BSE. | Ahmed, 2010 |
| Eastern Mediterranean | Jordan | 7% of 519 Jordanian women practiced BSE regularly. | Petro-Nustas and Mikhail, 2002 |
| | Palestine | 397 Palestinian women aged 50, more than 60% had never attended mammography, 18% had ever attended mammography, 28% had ever undergone CBE. | Azaiza et al., 2010 |
| | Lebanon | 18% of 1200 women had mammogram | Rachivandran et al., 2011 |

| | | 20% of 510 Muslim Arab women aged 50–69 had mammography screening according to age specified guidelines. | Soskolne et al., 2007 |
|---|---|---|---|
| | Israel | Telephone survey of 1550 women, 66.8% of Arab women and 74.2% of Jewish women had undergone mammography during the past 2 years. | Baron-Epel, 2009c |
| | | CBE participation rates were 69.5% for 305 Arab Muslim women, 88.7% for 159 Christian women, 65.4% for 104 Druze women. Mammography rates were 39.7% for Muslims, 58% for Christians, and 36.6% for Druze. | Azaiza and Cohen, 2006 |
| North Africa | Sudan | 7.2% of 200 medical students practiced BSE, 66.5% had heard of BSE. In addition, of a 300 asymptomatic female sample, 6.4% practiced BSE, 12% had heard of BSE. | Abdelrahman and Yousif, 2006 |
| | Egypt | 10.4% of 565 women practiced BSE, 2.7% reported monthly BSE. | Abdel-Fattah, 2000 |

Table 5: Participation rate in screening activities in the Arab world

**Barriers toward breast cancer screening**

Despite the proved efficacy of mammography and other screening methods, participation rates are very low in target groups. For example, in the state of Ontario, Canada, the participation of the target group was only 60%, while their goal is a participation rate of 90% (Ontario Women's Health Council, 2006). Similarly in the UAE, in 1995, the Ministry of Health had a target participation rate of 70% by 2013. Thirteen years later in 2008, the participation rate was only 10% (Taher et al., 2008). Barriers related to breast cancer screening have been widely studied. Many factors influence participation in screening programs. These factors include personal, religious, psychological, cultural, environmental and social factors (Theisen, 2004).

**Individual and community barriers**

Individual barriers to breast cancer screening are numerous and diverse. These barriers exist regardless of ethnicity, age, nationality, education level or income level. Knowledge about the benefits of early detection has been reported to be an important determinant for breast cancer screening (Bener et al., 2009). Sources of knowledge varied but mainly Arab women acquired their knowledge from healthcare providers, friends and the mass media (Montazeri et al., 2008). Knowledge includes misconception about breast cancer and breast cancer screening (Medline plus, 2007). Women may have misconceptions such as believing that a state of being free of symptoms indicates absence of the disease or exposure to mammography radiation may lead to cancer. Such misconceptions may de-motivate women from regularly attending screening. In the UAE, screening is widely available but participation rates remain low (Taher et al.,

2008). Bener et al. (2009) reported that despite having knowledgeable women, participation in breast cancer screening activities remained low.

Socioeconomic characteristics also play a major role in facilitating or hindering participation in screening. Demographic barriers include age, education; residence and income interchangeably play the role as barriers. Income is well known to have an influence on screening practice especially for women living in poverty. Surviving the day has priority over seeking screening of a perceived low-risk disease (Powe & Finnie, 2003).

The culture and social environment of the woman plays a major role in screening behavior. Despite higher incidence rates of breast cancer among white women, the disease actually kills more minority women and this is attributable to the fact that minority women are less likely to be screened (Siahpush & Singh, 2002; Baron-Epel, 2009a; Remmenick, 2006). Fatalism and fear from discovering breast cancer were found to be major barriers to screening attitude (Seif & Aziz, 2000; AlQattan et al., 2008, Bener et al., 2009). In the UAE, Sabih et al. (2012) reported that fear, fatalism and shyness were the most contributing factors to non-participation in screening activities.

In the Arab world, the role of women is often defined by marriage and children. Exposing women to screening may lead to cancer diagnosis which disfigures this image and role. Although Islam plays a big role in defining different aspects of Muslims' lives including health and illness, its impact on health seeking behavior is controversial (Hatefnia et al., 2010). In Islam, the individual is held responsible for his/her own health and failing to care for one's health is considered a sin (Hatefnia et al., 2010). Passivity regarding self-care is

sometimes related to "ignorance about Islam'' or deferring self-responsibility to God, or fate (Azaiza & Cohen, 2008).

**Health care providers**

Healthcare providers play a major role in attracting Arab women for screening (Montazeri et al., 2008). Bener et al. (2009) found that despite 80% of women in the UAE being willing to have CBE; only 33% had been offered CBE by healthcare providers. Nurses were found to lack knowledge about screening and this discourages women from participating in its activities (Madanat & Merrill, 2002). In Yemen, among 105 female physicians, 36.6% did not refer asymptomatic women for mammography (Al-Naggar et al. , 2009). The main barriers of breast cancer screening in the Arab world are summarized in table (6).

| Barrier | Description | Country | Author |
|---------|-------------|---------|--------|
| Lack or inadequate knowledge | Inadequate knowledge of breast cancer and screening activities | Saudi Arabia, Egypt, Jordan, Israel, Yemen, Sudan, Iran, Palestine, UAE | Abdelrahman & Yousif, 2006; Alam, 2006; Amin et al., 2009; Ahmed, 2010; Aghamolaei et al., 2011; Azaiza& Cohen, 2010; Bener et al., 2001; Dandash & Al Mohaimeed, 2007; Heidari et al., 2008; Milaat, 2000; Montazeri et al., 2008; Seif & Aziz, 2000; Rashidi & Rajaram, 2000; Soskolne et al., 2007 |
| Healthcare providers knowledge and recommendations | Health care providers were found to have inadequate knowledge of breast cancer screening.<br><br>Professional recommendation was found to be an important facilitator however low percentages of health care providers were found to provide recommendation for breast cancer screening. | Jordan,  Iran, Israel, Yemen | Alkhasawneh, 2007; Jaradeen, 2010; Haji-Mahmoodi et al., 2002; Madanat & Merrill, 2002 Al-Naggar et al., 2009; Harirchi et al., 2009; Soskolne et al., 2007 |
| Culture and religion | Informal social support-objection of spouse to breast cancer screening only mentioned by small minority. Fear of breast cancer diagnosis as a barrier Fear of losing traditional role as woman as a result of cancer diagnosis. Embarrassment regarding breast cancer screening activities. Fear of gossip regarding breast screening practices. Religious influences regarding breast cancer screening. | UAE, Qatar Israel, Saudi Arabia, Jordan, Egypt, Israel, Iran | Akhtar et al., 2010; Amin et al., 2009; Bener et al., 2009; Bener et al., 2001; Petro-Nustas, 2002; Seif & Aziz, 2000 Baron-Epel, 2009a; Remmenick, 2006 Baron-Epel et al., 2004 |
| Cost and accessibility | Accessibility to breast cancer screening facilities. Cost and lack of health insurance to cover breast cancer screening as barrier | Qatar, UAE, Iran, Egypt, Iran Turkey, Jordan, Iran, Israel | Bener et al., 2001; Bener et al., 2009; Hatefnia et al., 2010; Lamyian et al., 2007; Seif& Aziz, 2000 Alkhasawneh, 2007; Azaiza et al., 2010; Cam & Gvmvs, 2009; Petro-Nustas, 2002 |

Table 6: Summary of main barriers for Breast Cancer screening in the Arab World

**Conceptual framework**

This part of the thesis attempts to develop a meaningful understanding of the interaction of the contributing factors to breast cancer delay and the outcome of the decision to delay taken by women within the context of several theoretical frameworks which can be used to identify an appropriate model to guide the analysis of the qualitative part of the thesis. In order to develop a model to guide this study, it has to be derived from a broader evaluation perspective. A deductive reasoning process was used.  It involves starting with the general picture through evaluating and critiquing existing theoretical frameworks used to guide the analysis of previous studies. Deductive reasoning uses two or more related concepts, that when combined, enable suggestion of relationships between the concepts (Feldman, 1998).

No general consensus exists at this time as to which conceptual/ theoretical framework is best used to guide social health research (Lim, 2011), especially when the cultural norms and religious practices are of great concern in a community. Several theoretical frameworks have been applied in different settings to investigate women's delay for help seeking, identify factors that most predict reasons of delay and plan appropriate interventions to prevent this delay. Most studies of cancer delay have relied on the definition of BCD proposed by Pack and Gallo in 1938 to draw theoretical models explaining patient delay. Lim (2011) discussed 6 models which were developed to address delay influencing factors. These models are (1) the Judgment to delay (Facione et al., 2002), (2) Passive detection and help seeking model (de Nooijer et al., 2003), (3) Understanding delayed presentation (Bish et al., 2005), (4) Care-seeking (Reifenstein, 2007), (5) Prolonged delay models (Rauscher et al., 2010), and (6)

Health seeking behavior and influencing factors framework (O'Mahony et al., 2010). Most recently in 2011, (7) the Grounded Model for Health Seeking Behavior (GMHSB) was introduced (Unger-Saldana & Infante-Castaneda, 2011). Current models appeared to be developed for specific populations and settings, and therefore, are not able to be generalized in other settings (Lim, 2011). The models used different health behavioral theories or combinations of constructs and concepts from these theories. For example, individual and interpersonal health behavior theories were integrated with constructs to develop frameworks which better explain and predict the behaviors associated with delay in seeking help (Facione et al., 2002; De Nooijer et al., 2003; Bish et al., 2005; Reifenstein, 2007; Rauscher et al., 2010; O'Mahony et al., 2010 & Unger-Saldana & Infante-Castaneda, 2011). Social and cultural interaction was applied in many models. However, none of the models has yet used community and group theories in their design given that patient delay for medical care of breast cancer requires intervention at the community level (Lim, 2011). Significant constructs within these models can be adopted and integrated to form new models appropriate to other settings or contexts.

**Individual and Interpersonal health behavior theories**

Health behaviors have played an important role in health and illness. Individual and interpersonal beliefs shape the overall understanding of diseases. In the process for developing this study's conceptual framework some relative individual and interpersonal health behavior theories were reviewed. These theories were also used in previously developed models and were helpful in understanding individual and group health behaviors.

**Individual health behavior theories**

**Health Belief Model (HBM)**

The Health Belief Model (HBM) is one of the first models used to explain behaviors. It helped to guide the search for why behaviors occur and the areas for possible change. The main constructs of this model are four: 1) perceived susceptibility, that is, a person's belief about getting a certain condition, 2) perceived severity, that is, a person's belief about how serious this condition is, 3) perceived benefits, a person's belief about the effectiveness of some advised action to reduce the risk of seriousness, 4) perceived barriers, that is, a person's belief about the concrete and psychological costs of this advised action. The HBM is often applied to preventable disease with early screening like breast cancer (Glanz et al., 2008). For some individuals, the belief that cancer always causes recognizable symptoms maybe a critical variable in explaining non-participation in breast cancer screening and that why it is of great applicability to the UAE setting. However, symptoms are central to a patient's experience of disease. The HBM does not address important social, interpersonal and contextual issues, and it may also miss important factors that are not intrinsically health-related which play an important role in shaping health behavior (Glanz et al, 2008). The constructs of perceived threat (perceived susceptibility, perceived severity, perceived barriers) and the cues of action are of great use when explaining the women delay in seeking medical attention or in going to breast cancer screening.

**Theory of reasoned action**

In this theory, a specific behavior is a function of two factors: 1) an attitude which can be positive or negative toward the behavior, and 2) the influence of the social environment on the behavior. The attitude toward the behavior is determined by the person's belief that a given outcome will occur if he/she performs the behavior and by evaluating the outcome. The social environment or the normative belief is determined by a person's belief about what significant others think if he/she should do and his/her motivation to comply with their wishes.

The theory of reasoned action and the HBM share the foundation that behavior reflects expected value. The two theories are applicable to women's behavior and could be used to develop a model to explain Arab and Emirati women's attitudes and subjective norms toward taking actions upon discovery of symptoms.

**Interpersonal health behavior theories**

**Social cognitive theory**

Social Cognitive Theory includes factors beyond the individual, such as environmental and social factors. Although this theory have been used widely in health behavior change programs, health promotion and modification of unhealthy behavior, its constructs can be useful in explaining external factors affecting women's decision to seek help.

**Social Support Theory and community theories**

Individual change is tied with the social environment and a change in the social ecology is supportive for individual change. The social network could be the family or friends and neighbors who socialize and appear in the individual

community. Social groups have certain characteristics such as structural, interactional, and functional. Community models are categorized in three models of practice: 1) locality development, which is the formation of a local group from cross section of members in the community who attempt to identify and solve its own problems: 2) social planning is a task oriented model, it involves the decision makers, organizations and policy development: 3) social action is a mixture of both previous models, it is task and process oriented and involves members of the community and a large organization. Application of social support theories and community theories are most useful in intervention designing and health education planning, however, it can be used in explaining behaviors of women considering the social environment and community surrounding them.

**Patient Delay and Help Seeking Models for Breast Cancer**

**Total Patient Delay Model**

Anderson et al. proposed the total patient delay model in 1995, based on the HBM. It was the first model which attempted to investigate why women did not present themselves to the doctor upon discovering symptoms. They delineated help seeking for cancer symptoms in five stages: (1) appraisal, (2) illness, (3) behavioral, (4) scheduling and (5) treatment delays (Anderson et al., 1995). This model attributes 60% of the delay to the first stage (appraisal delay) as the woman is evaluating the unexplained symptom she has, this evaluation will determine the next step the woman will take. Either to perceive the symptom as an illness and consequently sees medical advice, or ignore the symptom and continue her

life without seeing the necessity of seeking help. The decision is based on her previous knowledge and expectations.

The total patient delay model is explaining the steps leading to delay in simple practical way, however, patient delay is a complex phenomenon and the steps of this model are too simple to tell the complete story (Lim, 2011). The model does not sufficiently illustrate the behavior decision making process and the influencing factors within each stage. Especially when trying to explain the delay phenomena in a complex setting which involves several factors such as cultural, religious, and psychosocial factors. To address this limitation, eight models were developed to determine the factors influencing help seeking behavior upon the discovery of breast cancer symptom(s) between 2002 and 2012.

The application of the Total Patient Delay Model is reasonable when explaining the women's delay of help seeking, especially the first stage, appraisal. However, influencing factors within the stages need to be fully explained (Lim, 2011), otherwise its use will be limited.

**Judgment to delay model**

Developed by Facione et al. (2002), this model proposed that many variables are observed to have a relationship with a patient's help seeking behavior, but how these variables interact to predict a breast cancer delay was not previously described in a model. This model begins with the assumption that the symptom appraisal is a cognitive decision-making process aimed at the estimation of potential risk posed by the symptom. It also assumes that the decision to seek help or delay has the form of an intention formation. See figure (7).
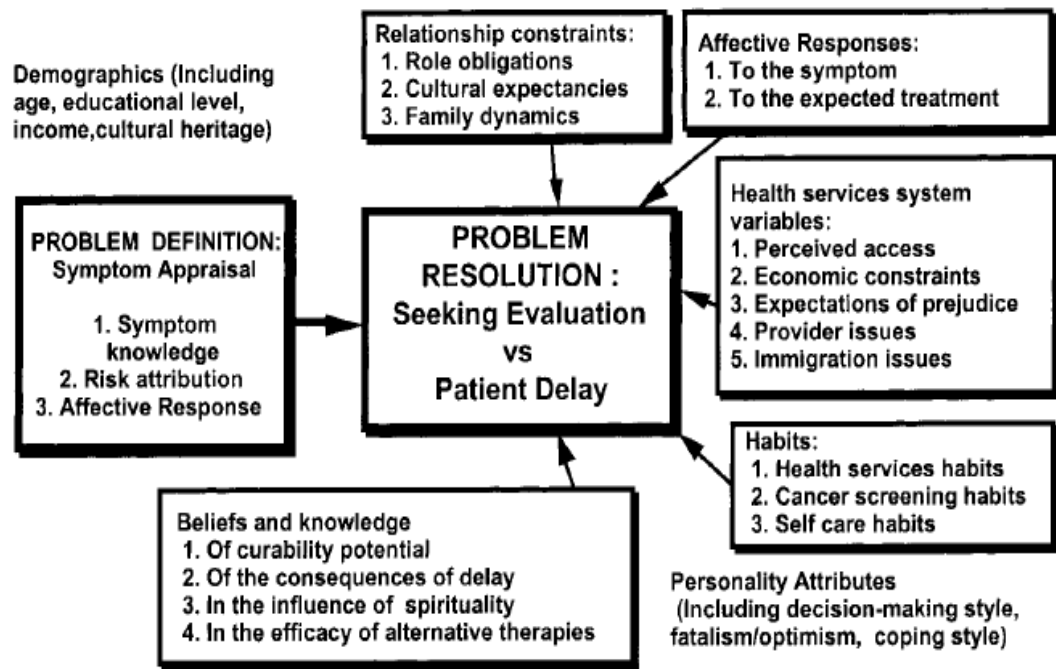
Figure 7: Judgment to delay model

**Passive detection and help seeking model**

Using a determinant model based on the theory of reasoned action, De Nooijer et al. (2003), proposed the passive detection and help seeking model. Their purpose was to identify factors that explained paying attention to cancer symptoms and the intention to seek help for possible cancer symptoms within an appropriate time. Knowledge, advantages, self-efficacy, being female and being more highly educated were associated with passive detection. Knowledge, advantages, moral obligation, anticipated regret, social norm, and self-efficacy were correlated with the intention to seek help. They recommended redesigning the educational programs to cover these two aspects (passive detection and health seeking intention).

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**Care seeking behavior**

This model was developed by Reifenstein (2007) for a specific population, namely, African American women. A number of psychosocial variables have been proposed as factors that could affect care seeking behaviors for a breast symptom. The psychosocial variables of fear, denial, utility (beliefs about the worth of care seeking), and social norms have been studied by many researchers (Caplan & Helzlsouer, 1996; Dunnavant, 1995; Facione, 1993; Facione & Giancarlo, 1998; Lauver, 1992a; Phillips et al., 1999), but the relationship of these variables to care-seeking behaviors for a breast cancer symptom is not sufficiently understood to allow experts to formulate interventions to correct the underlying problem.

**Prolonged delay models**

This model builds on Anderson's Total patient delay model and its stages of delay. It categorizes the measured variables into three groups: sociodemographic variables, variables pertaining to the interpretation of symptoms, and variables pertaining to access and utilization of health care. In this model, sociodemographic variables affect delay primarily by influencing either symptom interpretation or access to care (see figure 8). Within the symptom interpretation box, it conceptualizes that misconceptions about the meaning of breast lumps will affect whether a woman feels the need to present medically, and that women with personal histories of benign breast problems (i.e., who have experienced a false alarm in the past) might be more likely to hold these misconceptions and therefore be less likely to present promptly the next time they find a symptom. A family history of breast cancer might prompt a woman with a self-discovered symptom either to seek help sooner or delay seeking help to avoid

a diagnosis of breast cancer. Within the health care access and utilization box, it conceptualizes that absence of insurance may lead to an absence of a regular provider, and that both of these variables will lead to fewer preventive care visits.
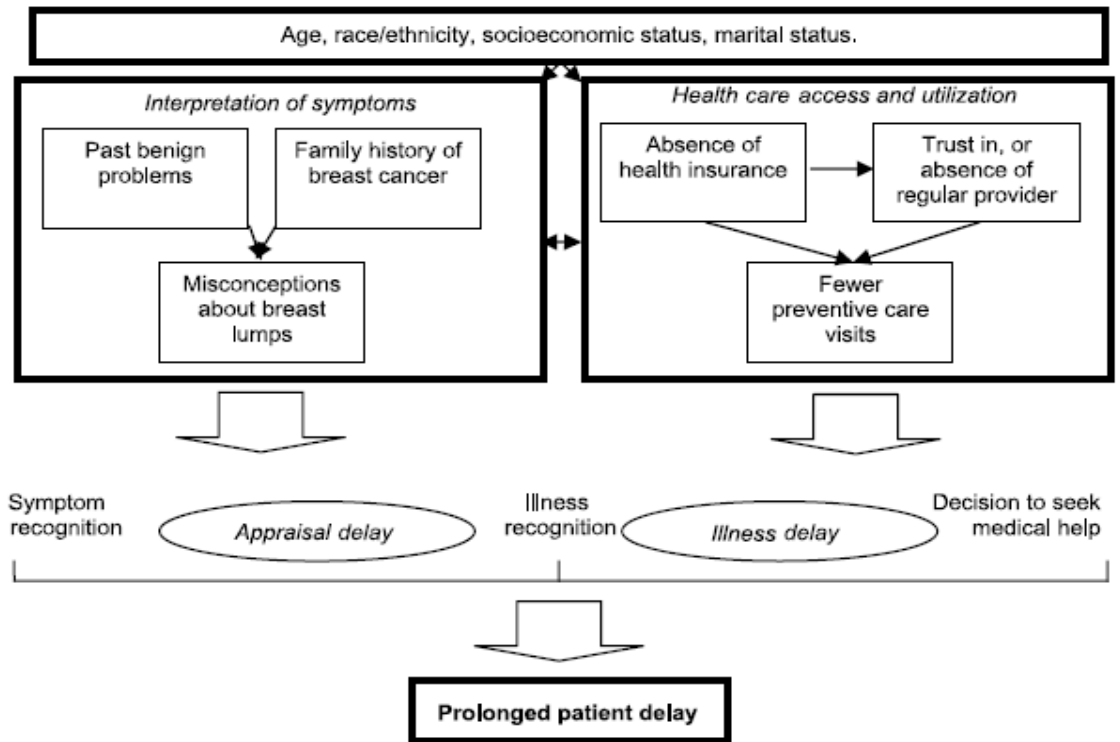


Figure 8: Prolonged Delay Model

**Health seeking behavior and influencing factors framework**

In order to gain an understanding of women's experiences after finding a breast symptom and how this influenced their help seeking behavior, O'Mahoney et al (2010) proposed the health seeking behavior and influencing factors framework. The key variables linked to delayed help seeking were denial, fear, social factors and knowledge and beliefs. The study verified that the variables within the "Help Seeking Behavior and Influencing Factors" framework act as both facilitators and barriers to women's HSB.

**Understanding Delayed Presentation Model**

Developed by Bish et al. (2005), this model acknowledges that delay in help seeking for breast cancer symptoms is influenced by a complex interaction of demographic, clinical, cognitive, behavioral and social factors. It is not, for example, simply lack of knowledge about breast cancer symptoms that leads to delayed help-seeking. An explanatory model that explicitly describes the process and its complexity would be a useful aid to understanding the influences on delay behavior. Bish and his colleagues used the first three stages described in Anderson's total patient delay model (Appraisal delay, Illness delay, behavioral delay) and added the self-regulation theory to explain the complex interaction of several factors around them and how this influences each stage. See figure (9).
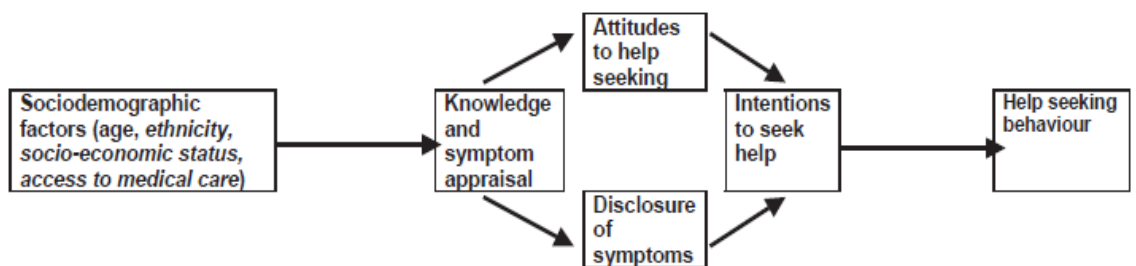


Figure 9: Understanding Delayed Presentation Model

**The grounded model of help-seeking behavior (GMHSB)**

The grounded model of help seeking behavior (GMHSB) illustrated in figure (23) was developed by Unger-Saldana & Infante-Castaneda (2011). They used constructs from the illness behavior theory which had never been in other models. They note the dereliction in the conventional classification of delay which is widely used in many studies and based on empirical time cut-offs that were established arbitrarily. Moreover, breast cancer delay studies aggregate diverse biases that have obstructed a meaningful understanding of the influencing factors

of delay through separating the patient delay concept from provider delay as this is pretty much integrated and well connected (Unger-Saldana & Infante-Castaneda, 2011).

**The illness behavior theory**

Mechanic (1995 p 15) defined illness behavior as the " varying ways individuals respond to bodily indications, how they monitor internal states, define and interpret symptoms, make attributions, take remedial actions and utilize various sources of formal and informal care." Illness behavior has been extensively studied during the past 50 years. The illness behavior was explained by a simple interaction between the patient and the physician, with each party having his/her own obligations and duties. The resolution of sickness, acute or chronic, depends on effective interaction and communication among all the participants of the illness event as well as physiological intervention. This simple and efficient approach to define illness behavior lacked the focus on wider issues of social, psychological and cultural sources of behavior. The interaction will be neither effective, nor productive. Later on it developed to include different other aspects, its micro-sociological concepts were modified and broadened to include economic, cultural, psycho-social, structural, demographic, geographical and organizational factors which affect the individual reaction to illness. The concept has grown to encompass both macrosocial and microsocial aspects of health seeking or illness-avoidance behavior (Young, 2004). Perception of illness is the first step to behavior. Much of illness behavior is really coping with perceived illness before the initiation of physician contact (Young, 2004).

Unger-Saldana & Infante-Castaneda (2011) have developed the (GMHSB) (see figure 10) based on the different multidimensional approaches discussed by Young (2004) and using different relevant illness behavior concepts. These concepts were then used in the analysis of qualitative study interviews and then built on a theoretical model of health seeking behavior. The model comprises 4 dimensions, which were found to be the most important in the interviewees' help-seeking trajectories: 1) the context: social, economic, cultural, family-related, and health system, 2) the woman's symptom interpretation and decision-making processes, 3) the social network's influences, and 4) health services utilization. Context is represented as occurring prior to the other dimensions and exerting an important influence across all of them. Symptom interpretation is placed at the bottom of the diagram, representing that it is the most immediate process to the patient, as it takes place inside of her. The social network comprises the second level, and health service utilization is at the top level, farthest away from the individual. The patient goes back and forth between these three levels. Every interaction with another person, lay or healer, as well as the passing of time, has an influence on symptom interpretation and subsequent help-seeking behavior. With this overview in mind, these dimensions will be explained in greater details.

The experience of Mexican women used in the qualitative study which drew the GMHSB is similar to Emirati and Arab women in the UAE and the Middle East. The four dimensions used could form a foundation for this study's theoretical framework, especially the women's symptom interpretation and decision making dimension. Other constructs from different theories could also be used.
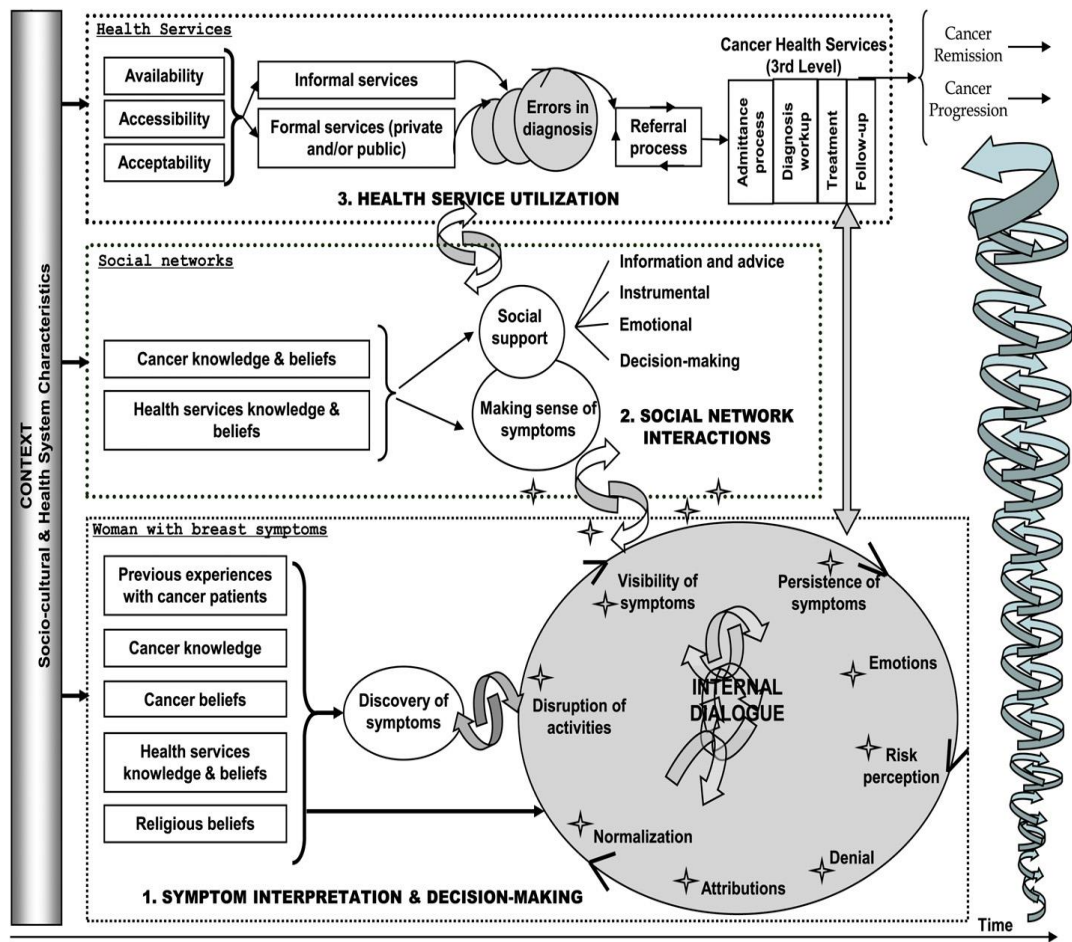
Figure 10: The grounded model of help-seeking behavior

**Dimension (1): The context**

The context includes the interaction of groups and individuals from different classes in the society. The culture, knowledge and social network is impeded in this context and it is very indicative and influential to symptom recognition and the decision making process. The patient's knowledge and beliefs regarding life and illness and attitudes toward and availability of health services influence the symptom interpretation and decision making at the individual level (Young, 2004). In the GMHSB, the context has an effect on all the other three dimensions, and the authors explain that the patient's contextual characteristics determine his knowledge and beliefs regarding life and disease, his social network

knowledge, beliefs, habits and interrelations and the availability and accessibility of different healers (Unger-Saldana & Infante-Castaneda, 2011). In this context, social, economic and cultural factors interact and health services characteristics which contribute to delay.

**Dimension (2): Symptom interpretation and Decision making**

In this dimension many factors interact together and the contextual characteristics play a major role in taking the decision to whether seek or not seek medical treatment. Anderson and colleagues proposed the total patient delay model in 1995, which was the first model which attempted to investigate why women did not present themselves to the doctor upon self-discovering symptoms. They delineated help seeking for cancer symptoms in five stages; appraisal, illness, behavioral, scheduling and treatment delays (Anderson et al., 1995). The appraisal stage was used in most of the subsequent models. Appraisal delay was found to be the major stage in patient delay, accounting for 60% of the total patient delay. However, the illness delay is often difficult to distinguish from appraisal delay but usually when the model is used, the behavioral, scheduling and treatment is simple to distinguish. Moreover, the model does not sufficiently illustrate the influencing factors within each stage. But again, as countered by Unger-Saldana and Infante-Castaneda (2011), this is a conventional classification of delay and it separates between patient delay and provider delay in a chronological way.

**Dimension (3): The social network interactions**

Cockerham (2000) defined social networks as "social relationships a person has during day-to-day interaction that serve as the normal avenue for the exchange of opinion, information, and affection" (Cockerham 2000). This social

network has great influence in the women lives. It influences their decision to seek help and their views of healthcare availability and accessibility. The social network knowledge, beliefs, habits and interaction with the women have an influence on symptom interpretation and decision making. The social network of a woman could enhance or obstruct her path of seeking help (Young, 2004).

**Dimension (4): Health service utilization**

In this dimension, issues of accessibility and quality of health services offered to women once they decide to consult formally about their symptom is a very important determinant for timely medical treatment. Characteristics of local health services in combination with the woman's contextual characteristics and the effect of social network determine what kind of services are used (Unger-Saldana & Infante-Castaneda, 2011).

After reviewing the above model and theories, a larger understanding of the constructs and dimensions used in every one of them was developed. Moreover, the literature review conducted and the personal experience of the researcher with Arab and Emirate women with breast cancer presentation to treatment, gave a basis for what constructs could be utilized to develop a model to be used in the conduction and analysis of interviews. The GMHSB allows for different combination of factors at various levels to explain delay. Especially in our setting in the UAE, many factors play different roles in the woman's journey of disease, and a dynamic model that allows possible interaction between different factors at various levels needs to be adopted in an attempt to understand this delay. The GMHSB is a well-constructed model, however, the structural characteristics of the health system in Mexico is overrepresented

in the model as a result of over discussing it by interviewees and this was mentioned by the authors as a limitation of the model. They are interested to know the applicability of the model in a different setting where the financial burden on patients is limited or nonexistent. The UAE health system is thought to be of interest as discussed earlier in this thesis, as all residents and national citizens of the UAE enjoy excellent health coverage and the financial aspect plays a small or limited role in the decision making of women to seek help. Another limitation of the model discussed by the authors is the interviewees they purposefully selected are those who were privileged in their ability to reach the public cancer hospital, many others due to different circumstances were not able to access the hospital. Therefore women interviewed are not representative of the uninsured Mexican population. Furthermore, women were interviewed first when they reached the hospital at the beginning of their treatment journey, and the confirmation of breast cancer diagnosis was made after that. As a result, not all women interviewed had positive cancer biopsy. Moreover, other factors that interfere between hospital admission and the beginning of treatment were unidentified. To overcome these limitations, our participants were chose purposefully from the regional oncology center at the end of their treatment.

**The proposed model for this study**

**Health seeking model**

**Applicability of models for UAE setting**

Few qualitative studies have been conducted in the Arab world. All of these studies were merely descriptive in nature and lacking a theoretical framework (Abdel-Fatah et al., 1999; Elzawawy, 1999; Elzawawy, 1991; Harirchi et al., 2005; Harirchi et al., 2005; Stapleton et al., 2010). The majority of BCD research has an empirical scientific approach and has described mainly its relation to survival, factors associated to patient delay, and provider delay factors (Ramirez et al., 1999; Richards, Westcombe et al., 1999b; Unger-Saldaña & Infante- Castañeda, 2009). Most studies that include theoretical frameworks base their analysis on psychological theories to explain the patients reasoning for delayed presentation (Bairati et al., 2006; Bish et al., 2005; Katapodi et al., 2005; de Nooijer et al., 2001b). Contextual social and health system characteristics have been ignored by most researchers investigating BCD. The illness behavior theory can enrich the understanding of BCD through its social and psychological aspects of health it accounts for.

The constructs of the previously explained theoretical frameworks can be used in the development of a new model/conceptual framework appropriate for the analysis of the qualitative study in the UAE setting (Lim, 2011). In this study, a conceptual framework was used to guide the analysis mainly based on the illness behavior theory and the GMHSB by Unger-Saldana and Infante-Castaneda (2011). However, some constructs were adopted from other models. The illness behavior theory gives a holistic explanation of the help seeking behavior in the case of illness. It

also discusses the determinants of the help seeking behavior. The developed conceptual framework (see figure 11) shows the interactions of the breast cancer patient at three levels: a) the individual level, including symptom recognition and symptom appraisal, b) the community and social network level, and c) the healthcare delivery system level. The first level uses four aspects identified in Bish's model: 1) Knowledge and symptom appraisal, 2) attitude to help seeking, 3) disclosure of symptoms and 4) intention to seek help. These four aspects interact together to influence patient behavior. At level one, the individual evaluates and interprets the recognized symptom(s) and her perception as being sick or unwell as a prelude to seeking help. At the second level, the social and community network is represented within the environment. This includes the woman's family, her husband (for married women), neighbors and friends. The interaction of the first two levels, the individual level and the community-social network level in the environment, guides the woman in decision making, i.e. whether to seek help or to ignore the symptom(s). If the woman decides to seek help, then the third level, the healthcare services utilization (healthcare delivery level), will influence the two previous levels. The third level includes aspects such as acceptability, errors in diagnosis and the referral process.
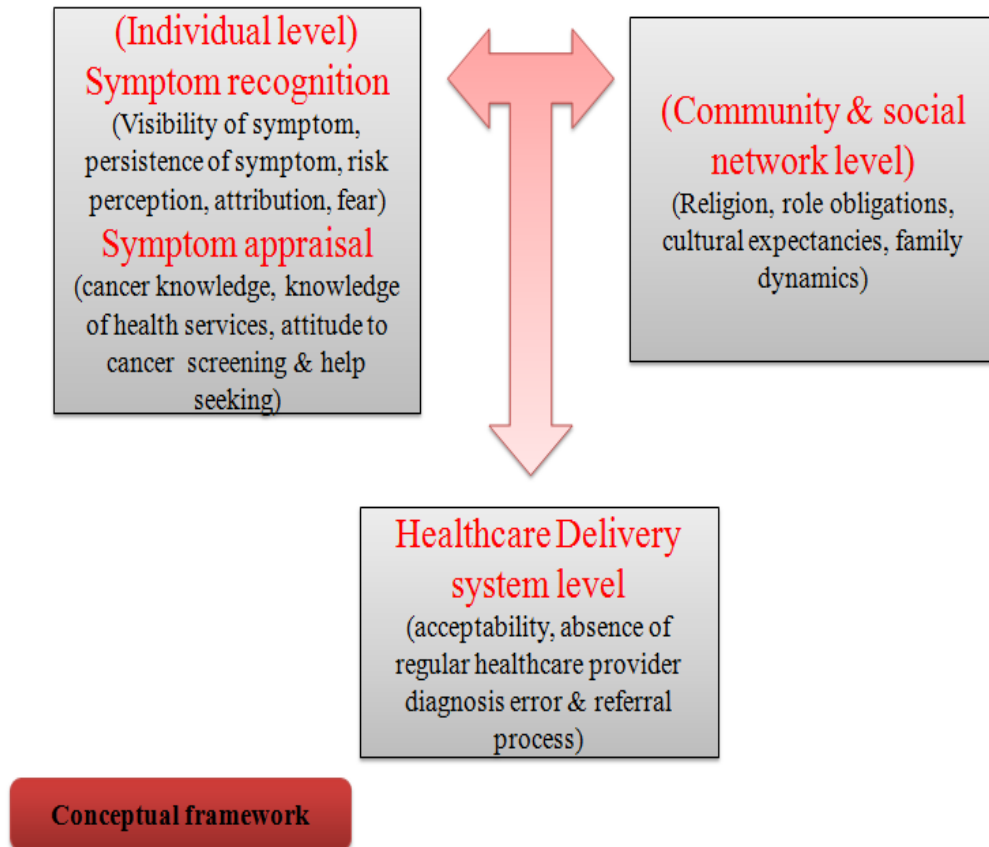
Figure 11: Conceptual framework (The help seeking model)

Chapter four

# MATERIALS AND METHODS

**Study location**

The oasis city of Al Ain (Figure 12) is the second largest city in the emirate of Abu Dhabi and the fourth largest city in the UAE. With an estimated population of 631,000 in mid-2012 (Statistics Center, Abu Dhabi, 2013), it is located approximately 160 km east of the capital Abu Dhabi and about 120 km south of Dubai. It represents about 27% of the total population of the emirate of Abu Dhabi and also represents 35.5% of the female population in the capital.



Figure 12: Map of the UAE

**Tawam Hospital cancer registry**

Tawam Hospital serves as a regional referral center for specialized medical care and is a national referral center for oncology services. Tawam Hospital received program accreditation in 2012 from the American College of Graduate Medical Education – International, and is a recognized intern, resident, and fellowship training site for the Arab Board. Tawam Hospital started its services in September 1979; radiotherapy became available for the first time in the UAE. In February 1983, oncologists in the UAE and the Ministry of Health recommended the Tawam Hospital in Abu Dhabi emirate as the cancer referral hospital in the country (Tadmouri & Al-Sharhan, 2004). Within Tawam Hospital, the cancer registry is considered to be an integral part of the hospital's cancer program which serves the needs of the hospital administration, the hospital's cancer committee, other hospital staff and researchers. Tawam cancer registry plays an important role in measuring cancer care delivery and supports quality improvement studies at the hospital. Tawam cancer registry systematically collects, electronically stores, summarizes and disseminates information about cancer patients who are diagnosed and/or treated at the hospital. The data collected by the registry describe both the patient and the disease and includes patient demographics, tumor information, staging information, cancer treatment and follow up.  In 2012, Tawam Hospital signed a service level agreement with the Ministry of Health UAE to perform cancer data abstraction services required to operate the National Cancer Registry. Moreover, Tawam Hospital has taken a leap to establish Abu Dhabi Central Cancer Registry (ADCCR) as main hub for cancer data collection from all hospitals in the emirate of Abu Dhabi to submit cancer data to Central Cancer Registry Abu Dhabi. It is anticipated that the

structure will be fully operated and the process will start running effectively from 2013 onwards. Tawam Hospital cancer registry is the only hospital based registry in the country which collects, process, analyses and disseminates data on newly diagnosed cancer on patients diagnosed or treated at Tawam Hospital. Tawam hospital data remains the main source of cancer statistic

The study was carried out in three phases.

**Phase I (descriptive)**

**Study design**

The first phase is a descriptive epidemiological study aimed at describing breast cancer trends and patterns of presentation in the UAE. There is insufficient data on breast cancer incidence and mortality rates and the national cancer registry is still under development and will provide data on cancer epidemiology in the future. Hence, data used in this study were extracted from Tawam Hospital cancer registry. Data included age at diagnosis, clinical and pathological stage, TNM staging, grade and differentiation, date of initial treatment, first and consecutive course of treatment, last date of contact and vital status.

**Study population**

Our study looked at clinical presentation and survival analyses of all cases of breast cancer occurring between January 1, 2008 and December 31, 2012 and which were registered in Abu Dhabi Central Cancer Registry database (HAAD). A retrospective review of data was undertaken by the cancer registry staff. Information on patients' age, date of initial diagnosis, date of treatment initiation, TNM staging, last contact date, and vital status were obtained.

**Data collection tools and process**

The staff of Tawam Hospital cancer registry use a predefined tool for an annual breast cancer data audit. Data were requested for five years (2008-2012). The data was received in Excel format. The total number of cases was 1,611 breast cancer diagnosed or treated in Tawam Hospital during the period of 5 years. For quality check, the principal investigator reviewed a random sample of 150 medical records of breast cancer patients independently. No inconsistencies were noted.

**Data management**

All information obtained from Abu Dhabi Central Cancer Registry was inputted into personal computer by the principal investigator. Data were analyzed with the Statistical Package for the Social Science (SPSS) version 20. Frequency checks were done randomly to minimize the likelihood of errors in data entry. Consultation with department biostatistician was made throughout the conduction of the study and especially during the process of data analysis. Both descriptive and analytical statistics were used. Frequency tables, charts and diagrams were used to describe the data obtained from cancer registry. Survival curves were also used.

**Phase II (qualitative)**

**Study design**

The second phase is a qualitative study conducted among breast cancer survivors treated in Tawam Hospital. Thematic/template analysis was used with the help of a proposed thematic framework to explore women's reasons for delay in seeking medical advice for self-detected breast cancer symptoms, and their help seeking trajectories. With the use of the semi-structured interview guide and the flexibility of the interviewing process, large quantities of rich data were expected to be collected. Template analysis is a relatively recent development in qualitative data analysis. This emerged from more structured approaches such as grounded theory and interpretative phenomenological analysis (Waring & Wainwright, 2008) with the difference that it involves the use of a priori defined set of codes. Template Analysis appears to have emerged from the USA during the 1990s and academics familiar with the Grounded Theory approach to data analysis may see similarities in the techniques used. It is now used in the UK in health and sociology related fields. Template analysis starts with some predefined codes intended to help guide analysis (King, 2004). In this study, a priori codes from the thematic framework were adopted. The process involved in-depth confidential person-to-person interviews. This was the preferred method for acquiring data as it involved questions that may be perceived to be 'sensitive' (Kvale, 1996). In depth interviews help explore very sensitive, embarrassing, controversial or "personal" topics such as breast cancer, it also assist the researcher to understand differences within target segments and gain detailed, in-depth individual understanding of the phenomenon. In-depth interviews are preferred over focused

group interviews because they eliminate any potential for interpersonal bias. They are also convenient when trying to study hard to recruit participants.

**Study population**

Women who were first diagnosed as stage IIB and III based on the AJCC classification were selected to participate in the study. To reduce recall bias, only women who were diagnosed recently (i.e. in 2010 and 2011) were selected for the study. Participants were either UAE nationals or non-national women of Arabic origin presenting between January 1, 2010 and December 31, 2011 at Tawam Hospital, Al-Ain, United Arab Emirates.

**Data collection tools and process**

Interview guide was adopted to steer the conversations however, interviews were semi-structured to allow for emerging concepts and to generate rich data. The interview guide (appendix 4) traces the journey of the patient from discovery of symptom(s) of breast disease to their present state of health. A list of all eligible participants was generated from Tawam hospital patient records. Purposive sampling of breast cancer survivors was conducted to gain a diverse range of perspectives and to ensure the inclusion of women from different age groups, ethnicity and educational status. Sampling was continued until data saturation was attained. These women were chosen from the breast center, radiotherapy, oncology clinic, local breast cancer support groups and from Tawam Hospital database.

Recruitment was carried out via telephone calls after extracting potential participants' phone numbers from the Tawam Hospital database. Two further attempts were made to contact non-responders to the initial phone call. Following agreement to participate, the participants had several follow-up phone

conversations with the interviewer to improve interviewer-participant rapport and to help retain interest and participation in the research. Women who agreed to be interviewed were asked to choose a convenient venue of their choice for the interview. Conducting the interviews in the participants' homes was initially considered but later found to be not feasible, as an additional layer of approval from the husband or head of family was required. The interviews were therefore conducted in a local hospital convenient to the participant. This was perceived to be a non-threatening environment for the interviews with the participants. All interviews were conducted in Arabic or English. The duration of interviews ranged from 60 to 120 minutes.

**Data management**

The transcriptions generated from the in-depth interviews (qualitative study) were coded and manually analyzed. No qualitative data software was used. All transcribed data were read by the principal investigator several times to obtain familiarity with the information provided. The data was analyzed using the thematic/template framework analysis method (Ritchie & Lewis, 2003). A priori defined themes and emerging key points were identified from the thematic framework adopted (Figure 14). An approach involving first cycle coding and second cycle coding was used to identify emerging codes (Unger-Saldana, 2009). Coded responses and the views and ideas of all participants were then grouped and classified according to the priori defined themes (see figure 13) which were obtained from the developed conceptual framework for this study. The researchers have used deductive reasoning to move from the developed conceptual framework, which was substantiated with

literature, to the hypotheses. The developed model has provided a framework to guide the research from theory to hypotheses. In this study, psychosocial and cultural issues were expected to arise in the data. It was hypothesized that the lack of awareness about breast cancer and the cultural and psychosocial beliefs were thought to play a major role in delayed presentation to treatment and act as barriers for screening and early detection. The constructs used in the conceptual framework were used to act as priori themes and they were tentative and equally subject to redefinition or removal as any other theme.

Theoretical
concepts
Major themes

Level (3)
Data is sort and sifted
to explore relationships
& trends in themes

Level (2)
Sections of text described &
organized according to the themes
& sub-themes

Level (1)
priori broad codes which identify themes were
generated & expected to strongly be relevant in
the analysis
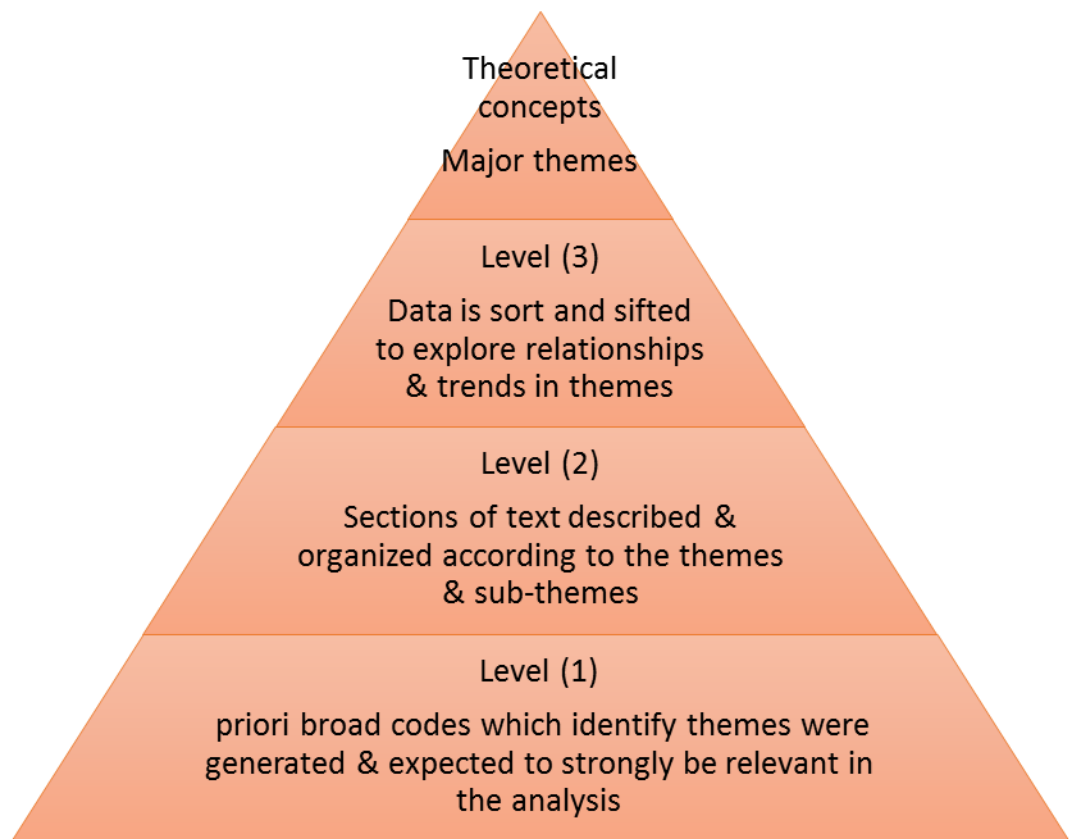
Figure 13: Phase II data analysis process

**Phase III (cross-sectional survey)**

**Study design**

The third phase was a descriptive community based survey/cross sectional conducted among women living in the city of Al Ain. The aim was to assess the breast cancer screening knowledge, attitude and practice among women at screening age who visit community and religious centers in the city of Al Ain, UAE. An interviewer administered questionnaire was developed using the cancer awareness measure and was used in this study. This study will help compare different population groups (national and non-national Arab women) at a single point in time. Results will also be used to compare with similar studies completed in the past.

**Study population**

The sample for the survey was selected from community cultural and religious centers in Al Ain. These centers are designed as places for women to socialize and provide an organized form of religious gatherings. Four centers were randomly selected out of 12 centers. The centers' management was approached and study days were selected. Each center was visited once. All women aged 40 years and above attending the center during the study day were approached and invited to participate. Women who agreed to participate were interviewed in order to answer the questionnaire.

**Data collection tools and process**

A modified Arabic version of the Cancer Awareness Measure (CAM) version 2.1 (Cancer research-UK, 2008) was used. The CAM validity was evaluated by Stubbings et al. (2009), cognitive interviewing of participants in the

validation process indicated that the CAM was being interpreted as intended with high internal and test–retest reliability. However, to accommodate cultural differences in the UAE setting, a few questions were added regarding breast lump interpretation (appendix 5). The questionnaire was divided into three sections: the first section covered socio-demographic characteristics (age, nationality, education level, age at menarche, breastfeeding practice, use of contraception methods and exercise), the second section was on general breast cancer knowledge, risk factors and warning signs, and seven general questions about breast cancer were included. A correct answer was scored as 1, a false answer or 'don't know' was scored as 0. The maximum attainable score is 16. The third section covered the knowledge, practice and attitude to regular BSE, CBE and mammography. Questionnaires were marked based on the Cancer Awareness Measure (CAM) version 2.1 answer sheet (Appendix 6).

**Data management**

Data were analyzed with the Statistical Package for the Social Science (SPSS) version 20. Frequency checks were done randomly to minimize the likelihood of errors in data entry. Consultation with department biostatistician was made throughout the conduction of the study and especially during the process of data analysis. Both descriptive and analytical statistics were used. Frequency tables, charts and diagrams were used to describe the data obtained in phase.

The chi-square test was used to test for statistical significance when comparing two or more proportions and the t test was used to compare two means. Two-tailed probabilities were calculated and values of less than 0.05 were considered significant. Multivariate analysis was then carried out by logistic regression in which screening (History of CBE and/or Mammogram) was

considered as the dependent variable and variables known to be barriers or promoters for screening were used as independent covariates.

**Ethical considerations**

**Obtaining consent**

The principles behind consent include: a) the primary investigator being knowledgeable about the consenting process and is responsible for obtaining informed consent from the participants. b) Participants should not feel forced to participate. c) The investigator needs to make sure that participants understand that taking part is completely voluntary and that they may withdraw at any time without having to provide a reason for doing so. d) Participants must also understand that whether or not they participate in the research study will not affect their normal standard of healthcare or their benefits. However, due to the culture and participants' concerns regarding confidentiality despite being provided good explanation of protecting confidentiality, they may be reluctant to sign the consent form and may give only verbal consent. All the three phases of this research received ethical approval from Al Ain District Ethical Committee.

**Ethics approval**

All three phases of this study received ethical approval from Al Ain Medical District Human Research Ethics Committee before the commencement of data collection (Appendix1, 2, 3).

**Emotional distress**

Emotional distress may arise during the interviews with breast cancer survivors. Interviewees may feel emotionally distressed while

talking about sensitive issues and life and death matters. To handle this, the patients' coordinator from the breast cancer center in Tawam Hospital whom the participants know personally and who has a good relationship with patients attended all the interviews to help with these issues as they arose. Participants' were offered the option to withdraw from the study at any point if they wishe.

# Chapter five

# RESULTS

**Phase I (descriptive)**

**Characteristics of the sample**

There were 1,611 cases registered in Abu Dhabi Central Cancer Registry in the period between January 1, 2008 and December 31, 2012. The mean age of all cases was 48.2 years (SD±11.8). There were 8 men (0.5%) in the sample. The study sample comprised of 21.4% (n=344) UAE nationals and 78.6% (n=1267) non UAE nationals. See table (7).

| Age group (years) | Nationality UAE national | Non UAE national | Total |
|---|---|---|---|
| Total | 344 (21.4%) | 1267 (78.65) | 1611 (100%) |
| 15-30 | 20 (1.2%) | 61 (3.8%) | 81 (5%) |
| 31-40 | 66 (4.1%) | 292 (18.1%) | 358 (22.2%) |
| 41-50 | 105 (6.5%) | 445 (27.6%) | 550 (34.1%) |
| 51-60 | 93 (5.8%) | 290 (18%) | 383 (23.8) |
| 61-70 | 36 (2.2%) | 137 (8.5%) | 173 (10.7%) |
| >71 | 24 (1.5%) | 42 (2.6%) | 66 (4.1%) |

Table 6: Distribution of breast cancer cases by nationality and age group

Data analysis showed 61.3% (989) of cases are less than 50 years of age at diagnosis. Most cases fall between the ages of 41-50 34.1% (550) of total, see figure (14). Socio-demographic characteristics other than nationality were not available for analysis.
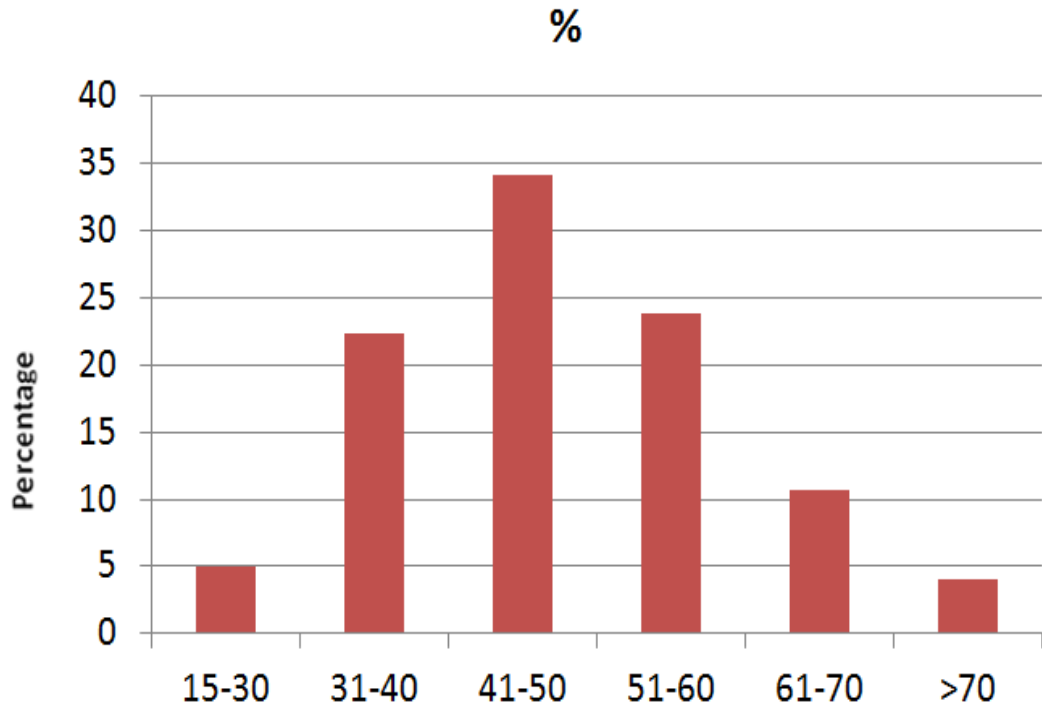
Figure 14: Frequency distribution of breast cancer cases by age group on first diagnosis

**Tumor characteristics**

**Staging**

American Joint Committee on Cancer guidelines (AJCC) was used for staging of breast cancer. The majority of cases were diagnosed at stage 2A 19.9% (320). Advanced breast cancer at stage 4 constituted 7.8% (125) of all cases. See figure (15).
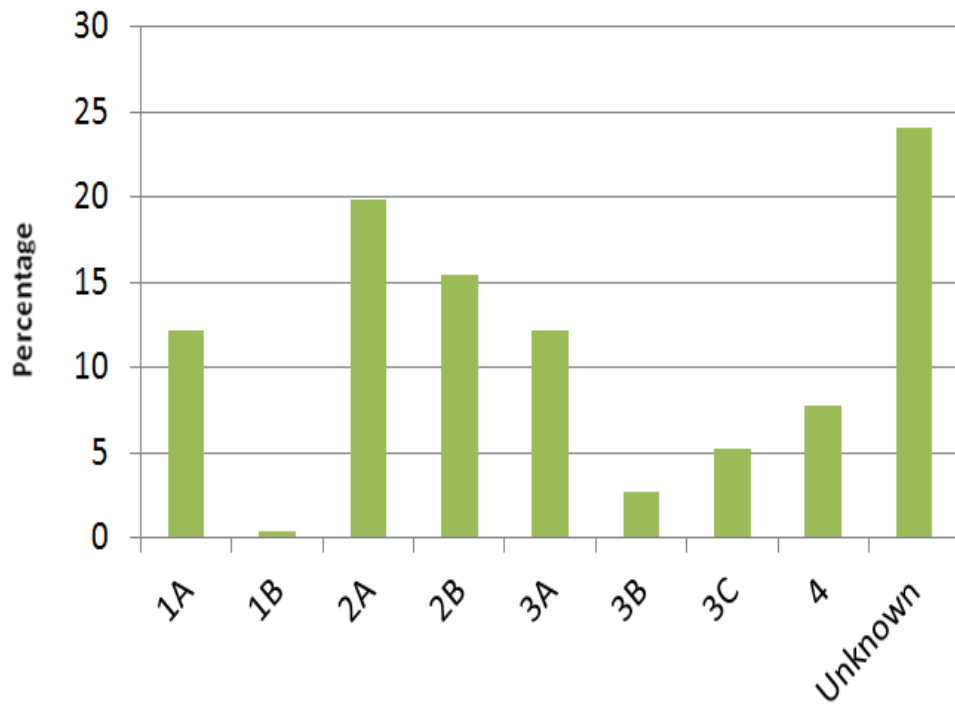
Figure 15: Frequency distribution of breast cancer cases by clinical staging of tumor on first diagnosis

In 52% (836) of cases the site of the tumor at presentation (laterality) was the left breast, the right breast 46.8% (754) cases and bilateral involvement in 1.4% (19) cases, see figure (16).
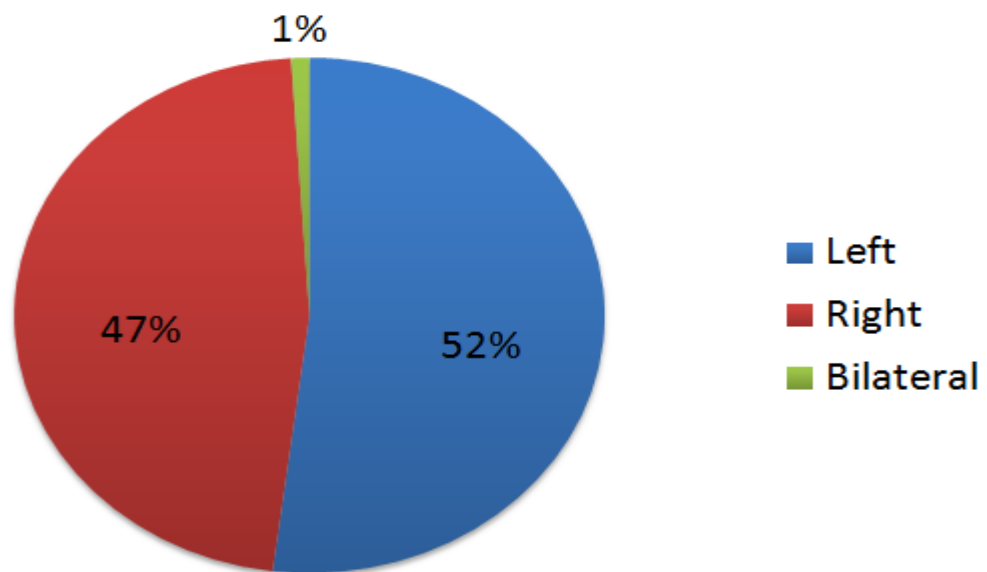


Figure 16: Frequency distribution of breast cancer cases by site of the tumor on first diagnosis

**Grade/ Differentiation**

The majority of cases had grade III/poor differentiated breast cancer

n=692 (43%). See figure (17).
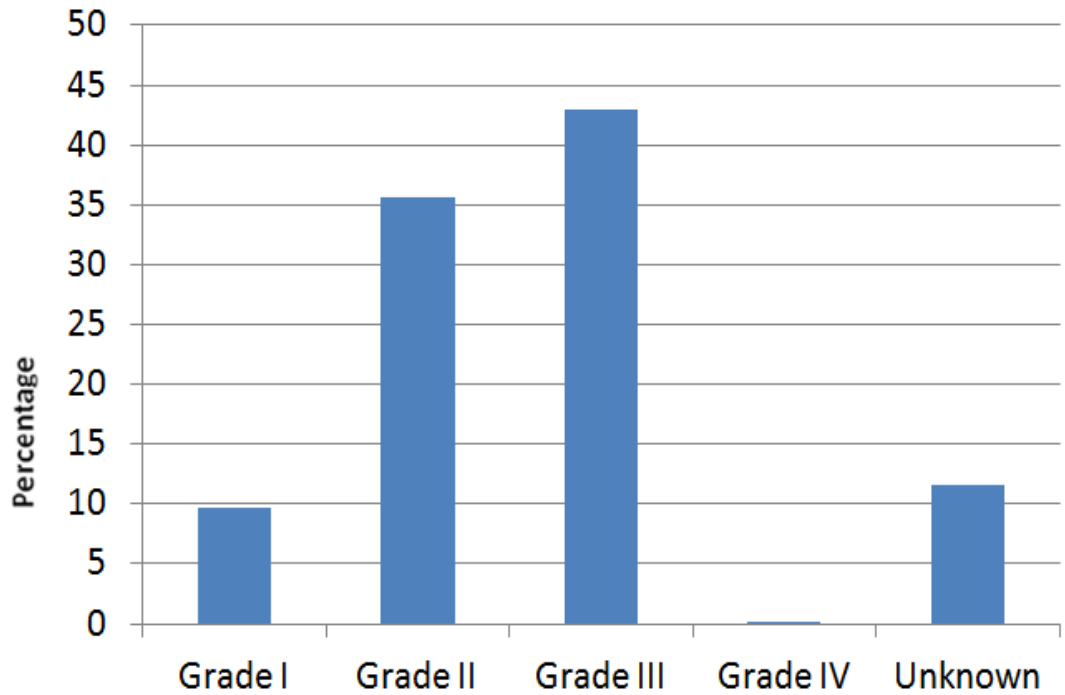


Figure 17: Frequency distribution of breast cancer cases by grade &
differentiation on first diagnosis

Mammography or clinical examination reports revealed lump size at

presentation to be 26.5% (341) less than or 2cm, and majority fell between 2-5cm

52% (669), and 1.4% (18) more than 5cm, 20.1% (324) of cases had missing

information on tumor size. See figure (18).
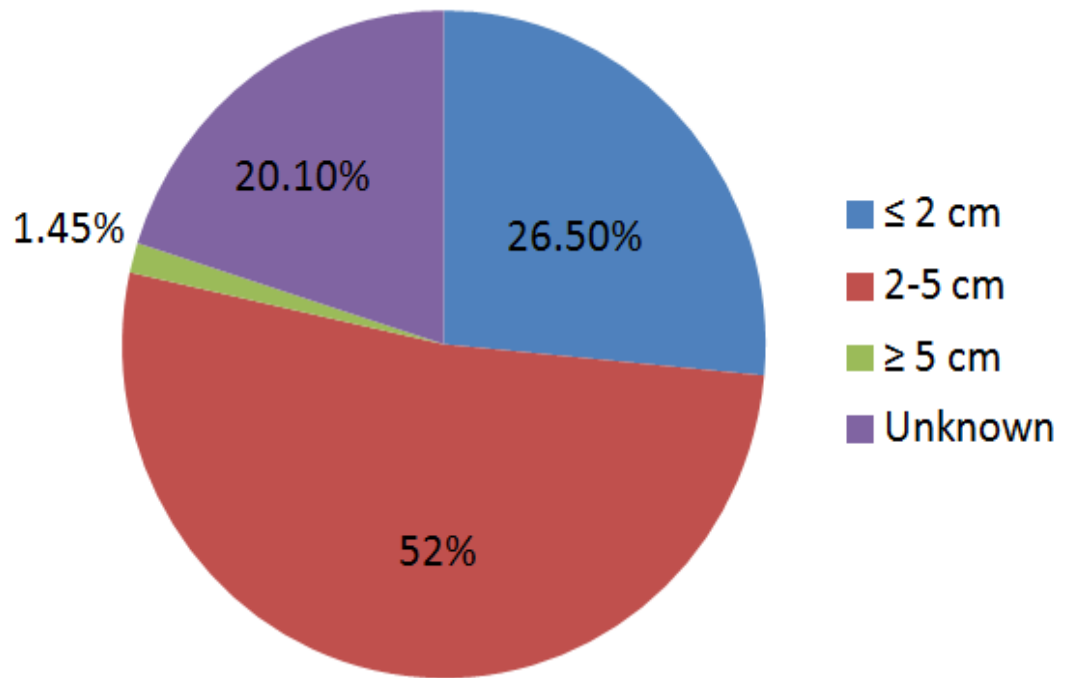
Figure 18: Frequency distribution of breast cancer tumor size on first diagnosis

Axillary lymph node involvement from all pathological reports revealed 92% (1482) involvement in the analyzed sample. Data on contralateral and supra-calvicular lymph node involvement were not available for analysis.

**Treatment**

Of all cases, 83% (1337) had surgical intervention in Tawam Hospital and 74.4% (1198) had surgery and other adjuvant treatment in the hospital. The rest 17% (274) either had the surgical intervention before they were referred for further management or they went abroad for treatment after diagnosis. Data on type and extent of surgical intervention and neo-adjuvant chemotherapy was not available for analysis.

Table (8), shows pathological factors by patient status at the end of the 5 year (2008-2012). 96.7% (1558) cases were alive and 3.3% (53) died.

| Tumor characteristics | Alive | | Dead | | Total | |
|---|---|---|---|---|---|---|
| | N | % | N | % | N | % |
| **Side** | | | | | | |
| Left | 805 | 96.6 | 8 | .4 | 33 | 100.0 |
| Right | 729 | 96.9 | 3 | .1 | 52 | 100.0 |
| Bilateral | 10 | 90.9 | 1 | .1 | 1 | 100.0 |
| Total | 1544 | 96.7 | 2 | .3 | 596 | 100.0 |
| **Tumor grade** | | | | | | |
| Poorly-differentiated | 664 | 96.1 | 7 | .9 | 91 | 100.0 |
| Moderately-differentiated | 556 | 97.4 | 5 | .6 | 71 | 100.0 |
| Well-differentiated | 155 | 98.7 | 2 | .3 | 57 | 100.0 |
| Total | 1375 | 96.9 | 4 | .1 | 419 | 100.0 |
| **Lymph node** | | | | | | |
| Negative Lymph node | 48 | 98 | 1 | 2 | 9 | 100.0 |
| 1-3 Lymph node | 297 | 96.1 | 12 | .9 | 09 | 100.0 |
| 4-9 Lymph node | 167 | 9.4 | 1 | .6 | 68 | 100.0 |
| More than 10 Lymph node | 78 | 97.5 | 2 | .5 | 0 | 100.0 |
| Total | 590 | 7.4 | 6 | .6 | 06 | 100.0 |
| **Tumor size** | | | | | | |
| ≤2 cm | 246 | 96 | 0 | 4 | 56 | 100.0 |
| 2-5 cm | 488 | 97.2 | 14 | 8 | 02 | 100.0 |
| ≥5 cm | 200 | 96.2 | 8 | .8 | 08 | 100.0 |
| Total | 934 | 96.7 | 32 | .3 | 66 | 100.0 |

Table 7: Patients' Characteristics at diagnosis by the patient status at the end of follow-up

**Time interval in months between first diagnosis and first treatment**

Most cases received treatment within one month from initial diagnosis 54.6% (880). 75.5% (1216) received treatment within 3 months and 23.5% (379) received treatment after 4 months from initial diagnosis. Delay mean was 1.2 months from diagnosis. See figure (19).
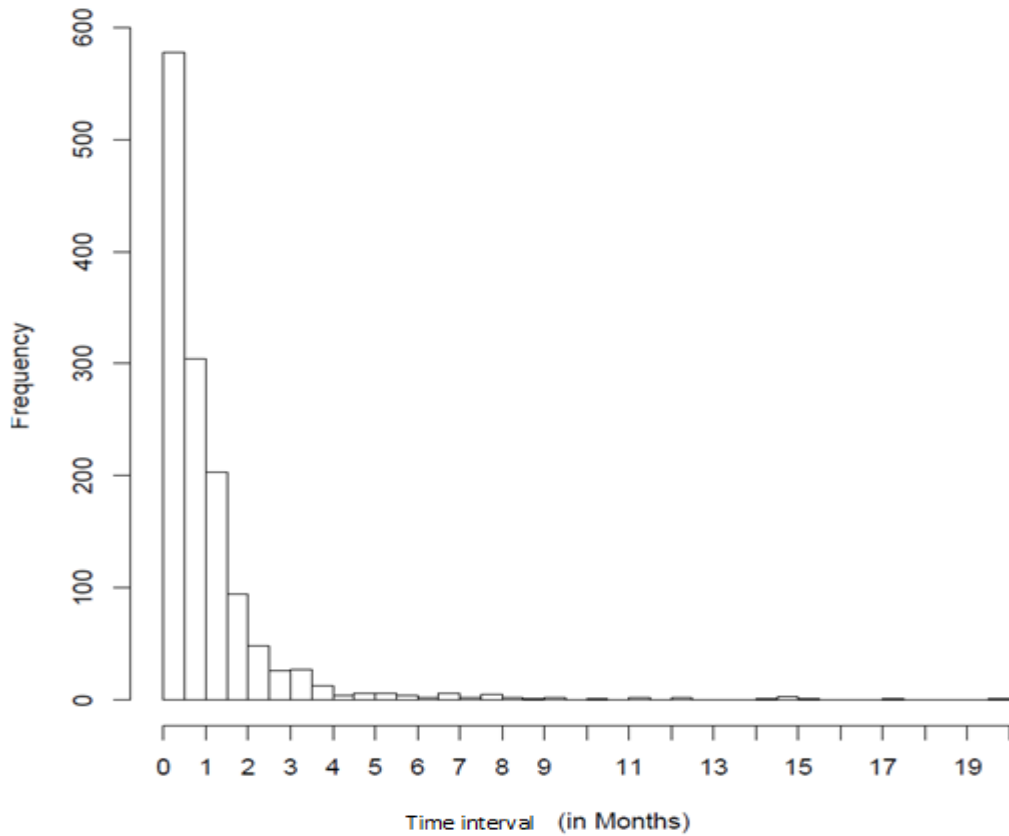
Figure 19: Cases distribution by time interval in months between first diagnosis and first treatment

**Kaplan-Meier survival analysis**

The Kaplan-Meier estimate is one of the best options to measure the fraction of subjects living for a certain amount of time after treatment. In this study, survival analysis showed 3.3% (53) cancer related deaths among the total 1,611 cases in the study. Mean survival time was 18.2 months (SD 14.29). Cumulative survival for all subjects was 96.7% after 5 years.

The hazard ratio (The hazard ratio is an expression of the hazard or chance of events occurring in the treatment arm as a ratio of the hazard of the events occurring in the control arm) between those who had a delay of three months and more and those who had delay less than three months was equal to 2.36 with 95% confidence interval of (1.045-5.35). The p value corresponding to this hazard ratio

was equal to 0.039, which is significant at the alpha level 5%. This result has been confirmed in a descriptive way using the Kaplan-Meier plot, see figure (20).

**Kaplan−Meier Curves according to Delay**
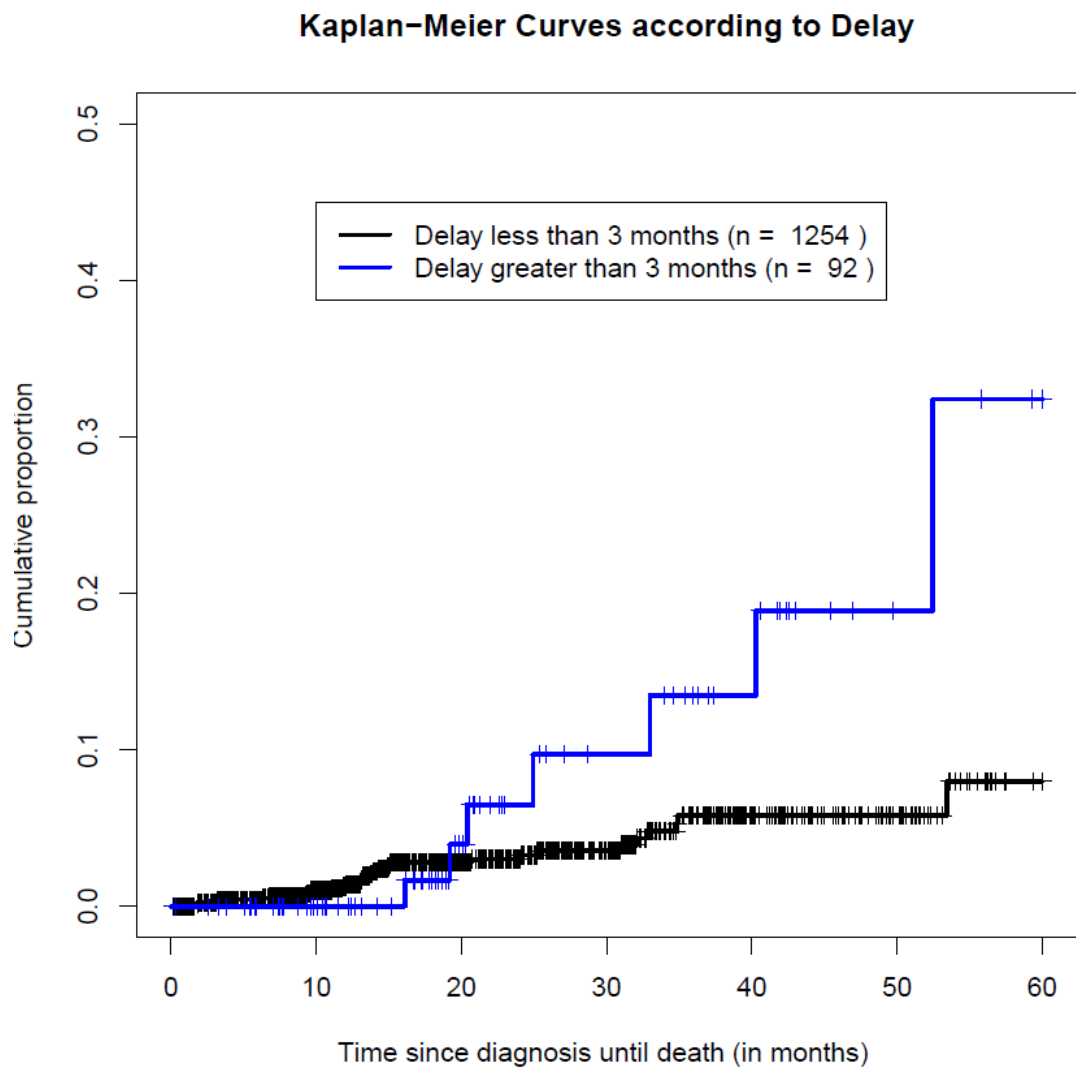


Figure 20: Kaplan – Meier curves according to delay

For other potential confounders such as age, lymph node involvement and tumor size, no significant effect was found. The p values were 0.325, 0.719 and 0.19 for age at diagnosis, lymph nodes involvement and tumor size, respectively. Kaplan-Meier curves for these variables confirm the results; see figures (21, 22).
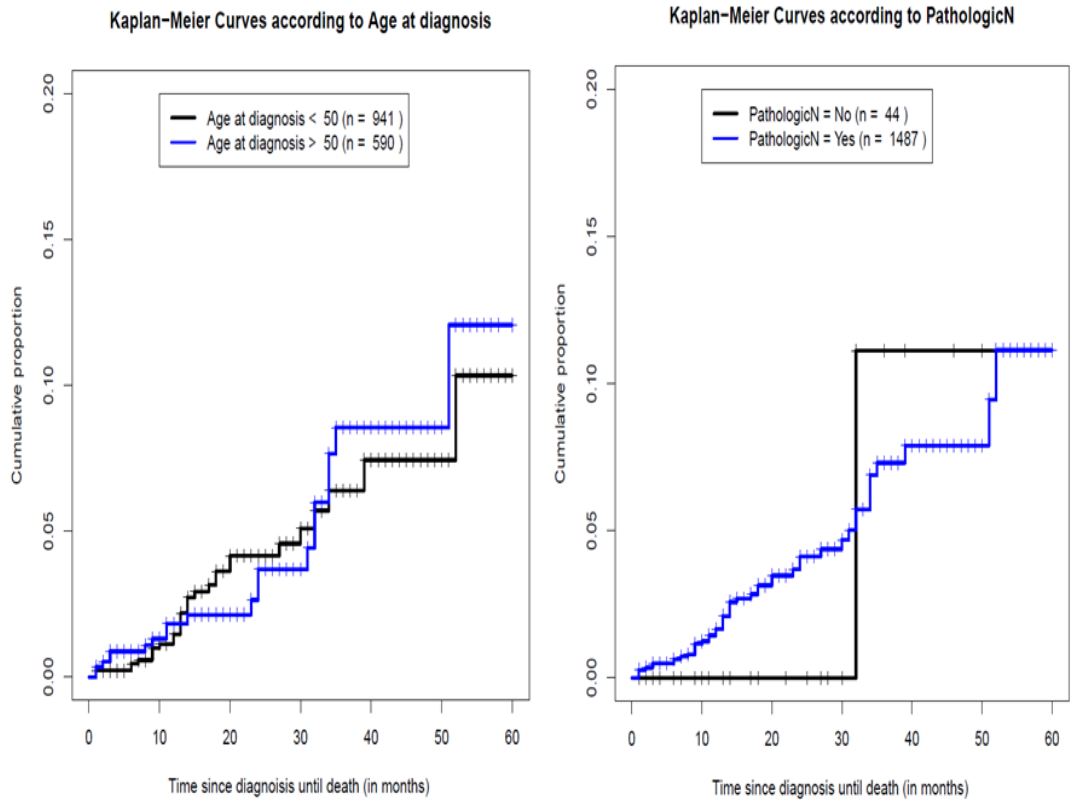
Figure 21: Kaplan-Meier curves according to lymph nodes involved and age at diagnosis

Figure 22: Kaplan-Meier curves according to tumor size

**Phase II (qualitative)**

**Sample characteristics**

A total of 19 women were interviewed. Twelve women were UAE nationals and seven were non Emiratis of Arabic origin. These seven non-nationals were from Iraq (2), Egypt (1), Jordan (1), Tunisia (2) and (1) Palestine. Their socio-demographic characteristics are as shown in figure (23) and table (9). They ranged in age from 35-70 years, with a mean age of 48.6 years (SD 11.29). Eighteen women indicated that they had previously heard of breast cancer and three women had a positive family history of breast cancer (i.e., breast cancer in a close relative). The education level of participants ranged from illiteracy to university level. The time interval between symptom discovery and seeking medical help ranged from three months to two years (table 10). The principal investigator and the study participants were in agreement regarding the suitability and effectiveness of the interview process. The participants felt that their privacy and confidentiality were protected. They could freely discuss personal experiences on sensitive issues such as the influence of culture on behavior and on their personal relationship with their spouse and family members.
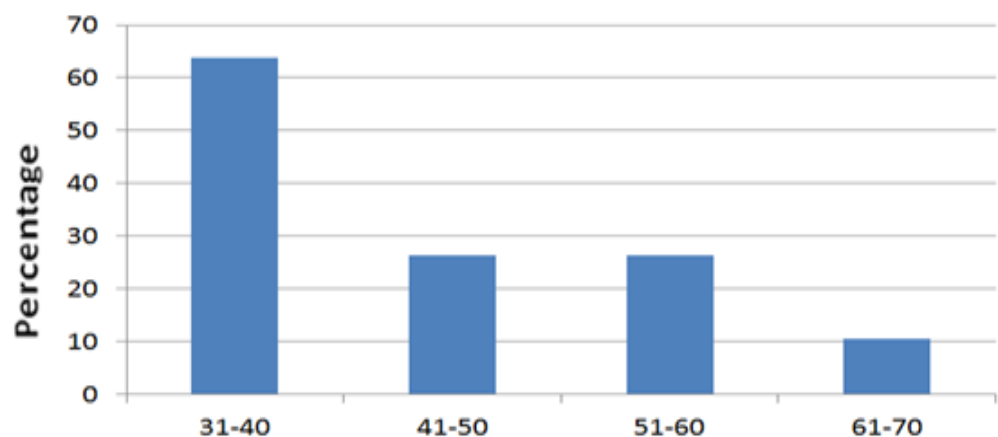


Figure 23: Age distribution

| Variable | N (%) |
|---|---|
| **Marital status** <br> Married <br> Single/divorced/widow | 14 (73.7) <br> 5 (26.3) |
| **Gravity** <br> Multi <br> Nulli | 17 (89.5) <br> 2 (10.5) |
| **Education** <br> No formal education <br> Formal education | 5 (26.3) <br> 14 (73.7) |
| **Occupation** <br> Unemployed <br> Employed | 8 (42) <br> 11 (58) |
| **Ethnicity** <br> UAE national <br> Other Arab national | 12 (63) <br> 7 (37) |
| **Religion** <br> Muslim | 19 (100) |
| **Disease stage at presentation** <br> IIB <br> III | 10 (52.6) <br> 9 (47.3) |
| **Family history** <br> Positive <br> Negative | 3 (15.8) <br> 16 (84.2) |

Table 8: Socio-demographic characteristics of the study participants

| The interval between symptom discovery and diagnosis in (months) | Association between the time interval between symptom discovery and diagnosis, %, age & stage | | |
|---|---|---|---|
| | N (%) | Age | St age |
| 3-5 months | 9 (47.3) | 40 | IIB |
| | | 36 | IIB |
| | | 65 | III |
| | | 55 | IIB |
| | | 45 | III |
| | | 47 | IIB |
| | | 60 | IIB |
| | | 36 | IIB |
| | | 36 | III |
| 6-10 months | 1 (5.2) | 45 | III |
| 11-12 months | 2 (10.5) | 40 | III |
| | | 67 | III |
| 13-18 months | 1 (5.2) | 48 | IIB |
| 19-24 months | 1 (5.2) | 60 | III |
| More than 24 months | 5 (26.3) | 68 | III |
| | | 50 | III |
| | | 55 | III |
| | | 36 | IIB |
| | | 36 | III |

Table 9: Extent of delay

The three main themes identified through thematic analysis process were 1) symptom recognition and appraisal, 2) role of community and social network and 3) healthcare delivery system. These are presented with illustrative quotes in the following sub-sections:

**Symptom recognition**

**Visibility of symptom**

Breast cancer symptoms vary from lumps to skin changes and nipple bleeding. Despite the visibility and the classical presentation of breast cancer

symptoms, five of the interviewed women interpreted the warning signs incorrectly.

*"Around two years ago…. I noticed a lump… like a small peanut…..I only felt it when I touched my breast, I am not currently breastfeeding but I thought it was something related to an old breast milk as I breast fed all my children, frozen old milk or something….''*

**Persistence of symptom**

The persistence of the symptom was sometimes the reason to draw the woman's attention to the presence of disease, and this motivated them to seek evaluation and treatment.

*"I was breastfeeding and I noticed my breast is getting hard with a lump, I thought it is from milk accumulation, I ignored it and continued breastfeeding for a while ……but then the lump was not going away; my breast was getting larger and larger every time I look….…..only then I realized that something might be going wrong with me ….''*

**Risk perception**

Women did not view themselves as at risk for breast cancer. They did not have personal perceptions of susceptibility and education level did not appear to influence their behavior in regards to measures for early detection of breast cancer.

*Interviewer: "Have you had mammography before?''*

*"Never, never because I am ….years old and married, I have 5 children; I do not take any medicine except the glucophage tablet for my diabetes……. I am very very healthy, so I did not go for the screening….I mean why should I ?... I used to do pap smear ……many times, I was concerned about cervical cancer but breast*

*cancer…. never suspected it. I was telling myself why should I go for checking if I am not feeling anything''*

**Attribution**

Women attributed signs of breast cancer to other diseases or to an event that happened prior to the symptom discovery. One of the women interviewed thought the breast lump was due to a fall she had prior to discovering it. This attribution greatly contributed to long delay until a symptom of an advanced disease appeared.

*"Well… around a year and a half ago I noticed a lump in my breast… I was thinking it is from a fall I had previously…. All the doctors were upset from me… they were saying where have you been hiding with this huge bleeding breast, you should have come earlier….I said to them I was treating myself by myself…..I thought it was a trauma related symptoms…I was putting ointments and taking pain killers to cope with it…''*

**Misconceptions**

Women had misconceptions about the breast cancer and its treatment.

*"I was afraid from the surgery and the disease…. Previously we had a misunderstanding that if you go for surgery the disease will get spread… because they touch it…. This is lack of awareness… people used to refuse surgeries because of this myth… I used to be thinking this way…. But thank God I did the surgery"*

*"I heard that breast cancer comes after a certain age more than 50 years and it does not come to women who breastfeed. But I had while I was breastfeeding, so I realized it has nothing to do with breastfeeding"*

**Symptom appraisal**

**Breast cancer knowledge**

Four women did not know about the breast cancer relevant symptoms and signs, screening procedures and treatment options.

*'' I heard of cancer before…blood cancer, brain cancer, lung cancer……. but I never thought it can come in the breast…I was surprised when they informed me''*

*"I felt the lump long time ago….around two years ago, I never expected it could be cancer…. I was even going to my heart doctor frequently but never thought of mentioning it to him, until I saw some blood coming out of my nipple, then I asked him "*

*"I didn't complain of anything,….I didn't even have pain…it was only that small lump which never bothered me…."*

*"I never expected it, to be honest, because I was active…I worked two jobs…I work outside…and at home, I like the house chores and…I mean…I was a home body, like they say….I liked to work.  So I was active and had no symptoms.  I didn't have pain, nor stinging or any…..let's say….symptoms regarding the breasts.  Not in the breasts or the nipples or excretion of fluids…I didn't have any of those problems at all…"*

**Knowledge of health services**

A lack of knowledge about healthcare services available for breast cancer screening and treatment was verbalized by one woman interviewed.

*''I was feeling my breasts regularly, I felt a small lump…but I did not know where to go….. I asked my neighbor and she didn't know as well….. She advised*

*me to read holy Quran and apply olive oil to it…. I did that for a couple of years….''*

**Attitude regarding seeking help**

A few (3) women thought that in order to have cancer, they had to experience serious symptoms, such as pain, vomiting or bleeding. They did not consider painless lumps to be a serious condition that would require immediate attention.

*'' I don't go to the doctor to ask for unnecessary tests, you do not go to a doctor if you are ok; you have to be in extreme pain or complaining of something to go and see a doctor…..''*

*"Around two years ago. It was from inside nothing was showing outside, I thought it is something related to breast milk, frozen or something…"*

*"I was concerned about cervical cancer but breast cancer never suspected it. I was telling myself why should I go for mammogram if I am not feeling anything, I only suspected it when I felt I was losing weight and became pale…"*

**Community and social network**

**Breast cancer stigmatized**

A woman expressed the difficulties with day to day activities and how she experienced suffering and worry even before experiencing cancer. Many felt that they fulfill multiple roles in regards to their families and to society. They felt pressurized because they are expected to be role models in their society and cancer is thought to affect this role and the attitude of society members to them once they experience disease.

*"Our old ladies used to say stress …. you know the relationships and troubles which happen in life… all this stress is one of the contributing factors to cancer*

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*especially in the middle east … because women in the middle east suffer in silence over a lot of things … for example, I knew women who have family, who have children … then the husband goes and he marries another woman.. She reaches the depth of despair that my husband is married to another woman... the husband comes home for one night... Do you see the children going astray, the boys are not being controlled … they have no control because he has another family or two families... The wives get stressed, they go crazy and they end up with some form of illness and usually breast cancer, this is what I have actually observed ....''*

The women expressed concerns about stigma and prejudice towards the whole family because of such a disease as breast cancer. Women with breast cancer therefore often prefer to stay at home and suffer in silence because they do not want their families to pay the price of having a mother, a sister, or an aunt with breast cancer.

*"When there is a family history of breast cancer, the older women keep it quiet the whole family keep it quiet because we are worried about our daughters prospects for getting married... we are worried about our younger sisters getting married, and we are worried about getting a bad name in our family or people staying away from us … because people are afraid of '-catching-' the disease, we keep quiet and we do not say that we have cancer through the generations of this family … we are all afraid psychometrically to come forward and frightened to come forward to say I have a lump .. Because we are worried about our image and our families... we are worried if our husbands would still want us... we are worried about whether we are still able to produce children…worries and worries….. This is what makes us hide''*

**Silence around women's issues**

Most of the women shared the view that cancer was not a popular topic to talk about in society or even within the family. It was not encouraged to talk about cancer openly in society or even discuss it within the family. It is a sensitive topic surrounded by shame and silence.

*''Before I never heard of breast cancer not even cancer, nobody was allowed to talk about it, you just look at their eyes and you will see the fear and vagueness…you will just know...''*

Another aspect which emerged in the interviews is the way society views breast cancer survivors. Members of UAE society do not want to talk about cancer survivors, not because they are ashamed of them, but because of the inadvertent bad publicity. Most of the participants disclosed that nobody around them knew about their cancer diagnosis and they would prefer to keep quiet and not share this news with anybody because they do not know how people around them would react to the information. Others were convinced that they will be treated badly and that their families will suffer with them as well.

*"Because here in our culture people look to you differently if you have cancer, I didn't tell anybody….I did not want them to look at me this way…. My whole family will be affected''*

Some were isolated from society because people do not want to visit them as they are afraid of the evil eye (in Arabic culture the evil eye is a symbol for envy and jealousy from a sick person regarding the health of a healthy person. this is believed to bring bad luck and disease) or thinking the disease is contagious. These misconceptions and a lack of general awareness about the nature and cause of cancer made most of the women keep their disease hidden and some do not

seek medical attention even when they have relevant signs or symptoms of breast cancer.

*"People will say do not visit auntie (me)…. she has cancer because you do not want to catch it, the bad eye will fall on you do not go and visit her …''*

Another informant talked about a painful experience she had as a result of people knowing what she was suffering from during her treatment.

*"I just finished chemical therapy and I went to visit somebody in her house, she had some other guest, four women. While sitting with them, my head cover moved a little and some of the bald patches on my head were revealed. They looked at me and laughed and started whispering to each other's, I could not take it, I left immediately and went home, I was crying all night long. I told my sisters that I did not want to see that look from people and that's why I isolated myself away from them and since then I don't visit anybody….''*

Some participants expressed the idea that the society considers them guilty and having cancer is a payback for sins and mistakes during their life.

*Informant (7): "My husband and family said to me….oh you must have done something in your life and it came back on you…. what did you do?  This is to pay for your sins''*

**Fear of being abandoned by husband**

An informant talked about the relationship she had with her husband after she was diagnosed and how he was living with her under the same roof but not as a married couple.

*"My husband completely changed, I have been married for 10 years; I was diagnosed a few years ago and since then he was pretty much on his own. It is*

*because of cancer….I suppose he tried to support me in whatever way he could… But I would never let him see me down; I will never let him see that he broke me''*

Another woman talked about the intimate relationship between her and her husband.

*"The change was mainly sexually, we never sleep together after I was diagnosed, we just live in the same house and we tolerate each other. I did the full breast reconstruction and I was happy ….he wasn't ….actually he never saw them….you see the husbands supporting their wives in TV only, in romantic movies but not in real life…this is the truth''*

**Healthcare system**

**Acceptability**

A woman delayed for 8 months because she did not want a male physician to examine her. This religious and cultural restriction on contact between the sexes contributed to the delay in seeking help.

*"I felt a lump in my breast, I went to the health center in my village and they only had one doctor… a male doctor…of course I went back home without checking and I forgot about it… few years later… the breast cancer campaign came to our village and I was diagnosed and referred to the hospital"*

**Diagnosis error**

Two women experienced delays because of inaction by healthcare providers. Errors in diagnosis can cause false reassurance regarding the seriousness of breast symptoms or signs.

*"I went to the hospital, they said there is nothing to worry about and the lump is from milk production. So I did not check further, the tumor was smaller… Three*

*years later, the tumor became very big, I went to another hospital and they said*

*you have cancer…''*

**Referral process**

Some delays were made by healthcare providers after diagnosis, particularly in waiting to be referred to a regional oncology center for commencement of treatment.

*"I went at the beginning of the year and they did for me the x-ray which squeezes*

*the breast. They said I have cancer and that they will refer me to Tawam*

*Hospital… I waited for their call but nobody called me for 6 or 7 months…"*

**Phase III (cross-sectional)**

**Statistical analysis**

**Results**

A total of 305 eligible women were approached, of whom 247 women agreed to participate and completed the research questionnaire in March, 2013 (response rate 81%). UAE nationals constituted 43.3% (107) and the remainders were citizens of other Arab countries. The majority were married 88.7% (219) and 94.3% (233) were literate. Their mean age was (46.1) years ± SD 4.95. See Table (11).

| Category | Sub-category | Total (n) | Breast Self-Examination n (%) | Clinical Breast Examination n (%) | Mammography n (%) |
|---|---|---|---|---|---|
| | Total | 247 | 127 (51.4) | 122 (49.4) | 111 (45.1) |
| *Nationality* | UAE national | 107 | 56 (52.3) | 59 (55.1) | 53 (50%) |
| | Non-UAE national | 140 | 71 (50.7) | 63 (45) | 58 (41.4) |
| *Age* | 40-49 yrs | 200 | 101 (50.5) | 95 (47.5) | 81 (40.7) |
| | ≥50 yrs | 47 | 26 (55.3) | 27 (57.4) | 30 (63.8) |
| *Education* | No formal education (illiterate) | 14 | 8 (57.1) | 9 (64.3) | 11 (78.6) |
| | School level | 115 | 55 (48.2) | 58 (50.9) | 52 (46) |
| | College/university level | 118 | 64 (54.2) | 54 (45.8) | 47 (39.8) |

Table 11: Socio-demographic variables of women who attend breast cancer screening (BSE, CBE, and mammography)

The screening uptake in our study group was BSE (51.4%), CBE (49.4%), and Mammography (45.1%). In this study, 22% stated that they were not sure if breast cancer was contagious, 38% believed that only women got breast cancer, 43% reported that breast cancer is the commonest type of cancer in women, and 26% believed that breastfeeding was protective against breast cancer. 17.5% thought that mammogram was done only when having symptomatic breast complaints. In our study, 16% of women were not sure when to go for mammography. 5% had good general knowledge of breast cancer while 14.6% had very poor knowledge of breast cancer. UAE national women scored better than non-UAE national women (means 7.14-6.99) (See table 12). Generally, younger women (40-49) years of age had better scores regarding knowledge than older women (>49) years of age as expected. Level of education was positively associated with better knowledge scores (p=<0.001).

| Category | Sub-category | Frequency n (%) | General knowledge score Mean (SD) |
|---|---|---|---|
| Nationality | UAE nationals | 107 (43.3) | 7.14 (2.87) |
| | Non-UAE nationals | 140 (56.7) | 6.99 (3.29) |
| Age group | 40-49 | 200 (81) | 7.12 (3.18) |
| | >49 | 47 (19) | 6.78 (2.83) |
| Highest Level of education | No formal education | 14 (5.6) | 5.57 (2.53) |
| | School level | 115 (46.5) | 6.56 (2.97) |
| | College or University | 118 (47.9) | 7.71 (3.18) |

Table 12: General Knowledge score by different variables

To determine predictors of screening, multivariate logistic regression analysis was performed (table 13). The predictors of BSE, CBE and mammography are in table 3. Having higher knowledge score and being counseled by a healthcare provider regarding breast health were the strongest predictors of screening uptake. A negative association was noted between screening uptake and nationality (non-UAE nationals), non-UAE nationals had poorer mammography uptake compared to UAE nationals, but the association was not significant (p=0.758). UAE- nationals reported being given breast health counseling (52.8%) more than non-UAE nationals (47.2%) p=0.002. 85 (62.5%) of women who reported not having had mammogram had never been given breast health counseling (P=<0.001). Women who reported not regularly performing BSE, CBE or Mammography were asked to choose a reason for that. Reasons with women responses are outlined in table (14).

| Variable/ predictor | BSE | | CBE | | Mammogram | |
|---|---|---|---|---|---|---|
| | OR (95%CI) | P | OR (95%CI) | P | OR (95%CI) | P |
| Age | 0.96 (0.90-1.02) | 0.241 | 0.94 (0.88-1.00) | 0.062 | 1.14 (1.07-1.22) | 0.001 |
| Education | | | | | | |
| School level* | 2.59 (0.59-11.24) | 0.204 | 2.61 (0.60-11.22) | 0.196 | 0.18 (0.37-0.91) | 0.039 |
| University level* | 1.79 (0.39-8.13) | 0.448 | 3.52 (0.78-15.90) | 0.101 | 0.13 (0.02-0.72) | 0.019 |
| Knowledge score | 0.81 (0.73-0.90) | 0.001 | 0.83 (0.75-0.92) | 0.001 | 1.20 (1.09-1.33) | 0.001 |
| Breast health counseling | 4.30 (2.36-7.85) | 0.001 | 3.95 (2.21-7.05) | 0.001 | 0.38 (0.21-0.69) | 0.001 |

*As compared to illiterate education group

Table 13: Predictors of Screening

| Screening method | Reason | no. | Nationality | | Education | | |
|---|---|---|---|---|---|---|---|
| | | | UAE-National n (%) | Non UAE-National n (%) | Illiterate n (%) | School n (%) | University n (%) |
| BSE | I would like to do it but I do not know how | 33 | 12 (23.5) | 21 (30.4) | 4 (66.7) | 20 (33.3) | 9 (16.7) |
| | I know about it but I am afraid to do it or have no time to do it | 46 | 17 (33.3) | 29 (42) | 1 (16.7) | 15 (25) | 30 (55.6) |
| | Never heard of it | 41 | 22 (43.1) | 19 (27.5) | 1 (16.7) | 25 (41.7) | 15 (27.8) |
| Total | | 120 | 51 (42.5) | 69 (57.5) | 6 (5) | 60 (50) | 54 (45) |
| CBE | Not for my age group | 52 | 18 (36.7) | 34 (44.7) | 2 (40) | 27 (47.4) | 23 (36.5) |
| | I know about it but I am afraid to do it or have no time to do it | 17 | 8 (16.3) | 9 (11.8) | 0 (0) | 5 (8.8) | 12 (19) |
| | Never heard of it | 52 | 23 (46.9) | 33 (43.4) | 3 (60) | 25 (43.9) | 28 (44.4) |
| Total | | 125 | 49 (39.2) | 76 (60.8) | 5 (4) | 57 (45.6) | 63 (50.4) |
| Mammography | Not for my age group | 46 | 14 (25.9 | 32 (39) | 2 (66.7) | 21 (33.9) | 23 (32.4) |
| | I know about it but I am afraid to do it or have no time to do it | 30 | 14 (25.9) | 16 (19.5) | 0 (0) | 13 (21) | 17 (23.9) |
| | Never heard of it | 60 | 26 (48.1) | 34 (41.5) | 1 (33.3) | 28 (45.2) | 31 (43.7) |
| Total | | 136 | 54 (39.7) | 82 (60.3) | 3 (2.2) | 62 (45.6) | 71 (52.2) |

Table 14: Reasons for not performing regular BSE, CBE, and mammography

Chapter six
# DISCUSSION

**Phase I (descriptive)**

The study analyzed 1,611 breast cancer cases registered at Tawam Hospital cancer registry. The cases were diagnosed between 2008 and 2012. The sample does not represent the whole UAE, but it captures a good proportion of breast cancer patients referred to Tawam Hospital. Many data were missing as many patients are managed abroad. UAE nationals were found to be 21.4% (344) of all cases. The majority of cases 34.1% (550) fell between the ages of 41-50 years old, and 61.3% (989) were ≤ 50 years old. These results are similar to those derived from the literature of neighboring countries.

The literature from developed countries indicated that breast cancer risk increases with increased age at diagnosis (Fakhro et al., 1999). However, the age at diagnosis of breast cancer in the Arab world was reported to be a decade earlier than in western countries (Najjar and Easson, 2010). In this study the average age at diagnosis was 48.1 years old, which is similar to other countries in the region. This data suggest that there may be clear social, economic and population differences in the age of presentation of breast cancer between Arab and Western populations. This also has important implications for screening and cancer management strategies in these countries, including the ideal age at which to begin screening. Adoption of Western guidelines without critical amendment in planning breast cancer programs might waste resources without achieving desired outcomes. Determination of the true frequency and age of onset of breast cancer in Arab women should be an important research priority. Moreover, the optimal screening modality would also need to be explored.

Screening mammography is less sensitive in younger women, mainly due to increased breast density that can obscure the radiological features of early breast cancer. However, magnetic resonance imaging (MRI) has proved to clarify ambiguous lesion on mammograms. In fact, strategies that combined MRI plus mammography with or without ultrasound and clinical breast examination reported sensitivities of 93-100% (Lord et al., 2007) and could be investigated in a randomized fashion as a screening modality in young Arab women.

In 2008, Abu Dhabi Community Profile indicated that breast cancer patients in UAE visit physicians in later stages of the disease. Our finding showed 53.4% of breast cancer cases had tumor size of $\geq$ 2cms, and 52% of cases had tumor size 2-5 cm at presentation. This confirms the assumption that women present with palpable breast lumps of $\geq$ 2cms. Only 12.2% were diagnosed at stage 1A and 92% of cases had axillary lymph nodes involvement at diagnosis with 8.3% of cases having distant metastasis. Larger tumors at presentation and advanced stages with lymph nodes involvement and distant metastasis have implications on treatment options available for Arab women. For example, breast conserving surgery is generally appreciated by young patients, but with larger tumors. Negative surgical margins might not be achievable and sometimes left with the option of mastectomy. Because of this reason, rates of mastectomy are high in the Arab countries (refer to table 4). Mastectomy is a source of anxiety and fear for many women. This fear might act as a barrier for screening and early detection. Aggressive chemotherapy with all its side effects and complications is often necessary. Treatments need to follow standard protocols to avoid inappropriate management and non-compliance. Reconstructive breast service should be offered to all women. A comprehensive plan that includes training in

the different disciplines is required for healthcare providers to recommend screening for younger women and not to dismiss the suspicion of malignancy in younger women. The establishment of specialized breast units, provision of equipment's and adequate financial support is required to care for these patients properly.

A delay of more than 3 months was closely associated with increased tumor size and advancement in the disease stages (Kothari & Fentiman, 2003). Rossi et al. (1990) found a consistent and direct relationship between delay and tumor size, nodal involvement, presence of metastases, and histologic grade of disease at diagnosis. The 5-years survival of women who had surgical treatment after a total delay of less than two weeks was 90% compared with 80% of those who had a total delay of more than two weeks and this effect of delay on survival was observed to be significant in younger women (15-39 years old) (Smith et al., 2013). In our study a delay of more than 3 months between initial diagnosis and first course of treatment had significantly decreased survival time (p=0.039). This delay was calculated as the difference between the initial diagnosis and the start of first course of treatment. In this case, it was not known whether the delay was from the patient after receiving the initial diagnosis or from healthcare providers/system if referral or commencement of treatment consumed time more than 3 months.

**Phase II (qualitative)**

**Lack of knowledge and risk perception**

Knowledge and perception of breast cancer contributes to women's participation in screening activities (Amin et al., 2009). A woman needs to know all relevant information about breast cancer including risk factors, signs, personal and population risk and who is most affected and why before attempting to make a decision whether to seek medical advice or not. The lack of this knowledge may contribute to the delay. As illustrated in the health seeking model, after the discovery of the symptom, the woman has an internal dialogue trying to evaluate the seriousness of this symptom, and without the knowledge and perception of risk, the decision might not be favorable. In this study, the demonstrated lack of knowledge of breast cancer reported by the study participants was translated by the low adherence to breast cancer screening guidelines. In this study, participants verbalized their feeling that breast cancer did not impose a serious threat prior to being diagnosed with it. This misunderstanding may reflect the prioritization of breast cancer screening. The screening concept itself is strange, and mammography is not socially accepted in the community (Baron-Epel, 2010). Cognitive factors play a major role in the perception of risk and prevention behaviors (Noroozi & Tahmasebi, 2011). Champion (1999) as cited in (Noroozi & Tahmasebi, 2011), modified the Health Believe Model in an attempt to understand women's beliefs and perception of risk with regard to CBE and mammography. Champion (1993) suggested that preventive health behaviors are based on four factors: (a) susceptibility: perceived personal vulnerability to or subjective risk of a health condition, (b) seriousness: perceived personal harm of the condition, (c) benefits: perceived positive attributes of an action, and (d) barriers: perceived

negative aspects of an action. These four factors define the women's attitude toward health prevention actions and prioritization in her life. Health motivation and self-efficacy were then found to be influential in the health prevention behavior.

**The role of healthcare providers**

The healthcare providers' role in increasing the awareness of these symptoms and encouraging women with such symptoms to seek clinical help is an important activity. Not perceiving painless breast lumps as a threat to life and therefore delaying seeking help reflects the lack of knowledge in regards to breast cancer. Despite the advancement in breast cancer treatment, the establishment of screening services in the emirate of Abu Dhabi, and the availability of health coverage, there is still a considerable lack of awareness about breast health, regular screening, and breast cancer signs/symptoms and predisposing factors (Bener at al., 2001; Taher et al., 2008). Public health education has a strong impact on women's perception and knowledge of breast cancer (Johnson & Dickson-Swift, 2008). Earlier studies have reported that physicians' recommendations were the single strongest predicator of breast cancer screening (Friedman et al., 1999; Thomas & Fick, 1995). Participants in this study reported the lack of advanced directions from healthcare providers, especially physicians. Neither the participants have been referred by a healthcare provider for breast cancer screening, nor did they receive recommendation or information on breast cancer screening guidelines. Even after diagnosis, many participants verbalized the uncertainty and lack of confidence about their level of breast cancer

knowledge. Some participants, who lost their breast after surgical treatment, did not know what they should do after treatment finished and whether they should follow any screening guidelines for the remaining breast.

The participants in this study verbalized their awareness about where to get information about breast cancer if they wanted, but the way this information was presented was not appealing to them. They also discussed the complexity of the data presented to them in an overwhelming and confusing manner. A number of women were not aware about the breast health services and programs offered to them and their cost. Female nurses play a major role in the productivity of public health education programs, especially in a culturally gender sensitive community (Hussain & Ansari, 1996). Many studies in the Middle East have been conducted to measure the knowledge level of healthcare providers about breast cancer and screening guidelines, and some of them concluded that the inadequate knowledge (Alkhasoneh, 2007; Jaradeen, 2010). In this study, many participants did not have trust in the healthcare professionals and they sought advice from different sources for the symptoms they experienced, including friends and family members. Other participants did not want to consult a healthcare provider because they believed they should only see a physician when the symptom is serious, such as feeling pain, bleeding, or experiencing fatigue. Screening was a novel concept in this community. Although painless lump is the most common presenting symptom of breast cancer, many participants in this study believed that a painless lump does not qualify for a doctor visit. This might be related to the weak relationship between women and their healthcare providers. There is a need to assess the counseling practices offered to women by their healthcare providers.

Muslims' and Arabs' lifestyles are based on the traditional Islamic value system detailed in the Holy Quran and exemplified in the lifestyle of Prophet Muhammad (Peace Be Upon Him). Due to the diverse population in the UAE, many healthcare workers are of non-Arab and Non-Muslim origin. Unintentionally, this might lead to violation of customs and beliefs which can prevent the establishment of relationship that allow health care providers to explore different issues related to the Arabic and Islamic culture. Cultural competence is an important concept when attempting to resolve obstacles in this relationship. Hammoud et al (2005) suggested two levels of cultural competence. The first level involves the basic understanding of certain beliefs and customs that can greatly influence the lives of patients within certain cultures. This opens doors to relationship with patients in an attempt to proceed to the next level which is the exploration of individual concepts of health and illness. Another obstacle faced by women in the UAE is the language barrier. As many healthcare providers do not speak Arabic, this might be an issue when administering public health education. Cultural and language barriers may keep Arab women from seeking healthcare or cancer related services.

Healthcare provider gender is a very important factor in attracting women to participate in screening activities and in presenting earlier for treatment. Arabic and Muslim women prefer female healthcare providers. Muslim women might refuse treatment no matter how urgent is the situation if the provider is a male (Hammoud et al., 2005). In this study, a participant delayed seeking medical help for eight months because of the unavailability of a female healthcare provider at the nearby health center.

The current public health program is deficient either in communication important health messages or in reaching enough women.

**Cultural, religious and societal influences**

"A culture is a configuration of learned behaviors and results of behavior whose component elements are shared and transmitted by the members of a particular society" (Linton, 1945, p. 32). There are three major socialization blocks in Arab/Muslim culture that could impact the delivery of healthcare significantly. These are the family system, the role of the individual relative to social organization and the assignment of primary gender roles (Hammoud et al., 2005). The family system in the Arab world is considered one of the strongest. The oldest male of the family is considered the guardian. All issues in the family need his approval. In this study, conducting interviews with the participants needed the approval from the head of the family. Most rejections to the women participating were due to the disapproval by the head of the family. The interview venue was then changed to the non-threatening environment of the hospital as it was thought to be more convenient for the participants to freely discuss their experiences. The traditional role of women in Arabic and Islamic culture is an important factor in the help seeking process. The pervasive societal expectations of the community are high. Women are seen as caregivers, obedient and role models for their daughters and younger female members of the family. The Arab tradition emphasizes that collective welfare outweighs individual wellbeing. Women's traditional role allows them to think of their own needs only after considering all other family members' needs. Some women suggested feeling inferior to men in the community and being less powerful, as their role in the family obliges them to please their husbands and obey them.

Like other studies (Baron-Epel, 2004; Remmenick, 2006), this study found that fear of losing this traditional role was found to be a barrier for early presentation with breast cancer symptom. Fear about the community's reaction in regards to women with breast cancer, and failing to meet community expectations about health and disease strongly influence the decision making process more than the fear of death from impending disease (Azaiza & Cohen, 2008). Many participants in this study preferred to keep their disease as a secret; they did not want their surrounding community to talk about them. Therefore this fear holds the women back from seeking medical advice and imposes silence.

Abuidris et al. (2013) discussed social stigma surrounding breast cancer. This might be due to the fact that the breast is attached to the sexual and reproductive system. In Islamic culture, women are inhibited from asking questions about physical and related changes. Women were raised to understand that part of being a grownup woman is to keep silent about women's health issues (Hamid et al., 2010). Women prefer to hide the disease from their families and friends, trying to escape accusations and the feeling of guilt and shame. In our study, most participants preferred to keep their disease hidden. One participant's family and husband accused her of committing major sins in her life and that was why God was punishing her with breast cancer.

The religion of Islam shapes Muslims' lives. It defines different aspects such as marriage, relationships, health and illness and death. Healthcare providers could be confronted by the theme of faith or destiny "Qader" in Islamic culture. Muslims consider this belief a defining idea

about events which are beyond the individual control.  Muslims believe that no matter what you do, everything in your life is defined and written and no one or any action can change it. From a non-Muslims healthcare providers' perspective, Qader is considered fatalistic. In this study, many participants believed that having breast cancer was their destiny "Qader" and it does not matter if they knew or practiced screening, their Qader would not have changed. This belief puts additional pressure on healthcare providers on designing and providing focused education programs that carefully incorporate religious messages in an attempt to persuade women to participate in breast cancer screening activities. This study shows that cultural and societal beliefs have a great effect on women's attitudes and behaviors towards symptom recognition, appraisal, screening and presentation for medical treatment.

**Traditional Islamic medicine**

Traditional Islamic medicine originates from the life of Prophet Muhammad (Peace Be Upon Him). Many Muslims may employ "prophetic medicine" as part of their normal life and disease cure.  Prophet Muhammad's lifestyle and recommendations were used as a basis for the prophetic, recorded in the hadith (reports) and certain verses of the Qur'an.  Pork, alcohol, and other intoxicants are prohibited and the regular consumption of fruits and vegetables, dates, yogurt and milk is encouraged with emphasis on the avoidance of overeating. These are the main aspects of this prophetic medicine.  The use of honey, olive oil and black seed (nigella sativa) products are particularly widespread as preventative medicines and treatments for a variety of diseases including cancer. Other healing methods are cautery and hijama (pressure cups to remove spoiled blood). Many participants in this study verbalized using one of

these methods, most commonly herbal drinks of black seed and honey. One participant reported the use of camel milk and urine for curing cancer and others discussed the use of cautery in the treatment of gastrointestinal cancers. Most participants believed in traditional Islamic medicine but preferred to inform their oncologists before using it.

Another well-known concept in traditional Islamic medicine is the "evil eye". The evil eye is believed to be the jealous look of others upon the good fortune of another without saying "Mashaa allah" or God's will to prevent it from harming another. The evil eye may initiate an adverse event for another, including harm to their health, business or family. All Muslims follow the assumption that God is the ultimate healer,  the divine word, expressed in the Qur'an, has the power to heal the body, mind, and soul, many Muslims recite the Qur'an over the site of pain, offering special petitions, and exorcism of evil jinn. All participants in this study employed spiritual remedies to heal their disease, mainly by reciting Qur'an or visiting Mutawaa "Islamic leader" to recite the Qur'an on them.

**Role of spouse**

The husband's relationship with a woman diagnosed with breast cancer is a very sensitive issue. This study provided an opportunity for women with breast cancer to openly talk about their feelings, behavior and relationships. In Islamic religion and culture, men are allowed more than one wife, and this fact puts fear and pressure from being disfigured by surgery and losing a husband and support for their children.

Dahlui et al. (2013) reported that marriage was a predictor of regular practice of BSE, CBE & mammogram. They also reported that women who had supportive husbands are nearly two times more likely to attend CBE and more

likely to perform BSE. In this study, none of the participants reported the attendance or support of their spouse during diagnosis or treatment. Two participants reported being abandoned by their husbands after diagnosis. Women with supportive husband and families tend to be diagnosed at an earlier stage. In this study, some participants discussed the role of their husband in their lives after diagnosis. Some reported their spouses being better at being instrumentally supportive than emotionally so. Similar to the findings of Fergus and Grey (2009), a major challenge faced by women is the altered sexuality caused by the stress of the illness and side effects of treatment. Participants revealed their struggle with how to retain intimacy and feelings of closeness without their usual sexual routines. Including husbands in the education programs and encouraging them to attend with their wives the CBE and mammography is essential for successful breast cancer screening promotion (Osborne et al., 2005; Umberson, 1992).

**Phase III (cross-sectional)**

Our results are consistent with those of a Saudi Arabian study (Amin et al., 2009) in which screening services were noted to be underutilized and mainly used for the diagnosis or follow up of existing breast lesions. Screening services are widely available in the UAE, with the advantage of screening coverage by health insurance and availability of free screening offered by some facilities for non-nationals with limited coverage from health insurance. Unfortunately, women are not referred for screening in these facilities. In this study, 81%, 41.3% and 82.6% of women who practiced BSE, CBE and mammography respectively stated that it was recommended by their healthcare provider. In general, Arab women regard physicians' offices, clinics and other healthcare facilities as places to go only when one feels ill or when symptoms appear. Moreover, 37.9% of women

gained their breast cancer knowledge from their healthcare provider. 18.2% of women believed that a mammogram is only done when preceded with a serious breast complaint such as pain or inflammation. Consequently this perception can serve as a barrier for health promotion efforts to achieve high participation rate. This has implications on the effectiveness and success of current screening programs. Our findings showed a significant improvement in the screening uptake, BSE (51.4%), CBE (49.4), Mammography (45.1%) of women in the city of Al Ain compared with findings of a similar study conducted in (2001) by Bener et al., in Al Ain city, which showed uptake of (12.7%), (13.8%), (10.3%) for BSE,CBE and mammography, respectively. Even in Qatari women (Bener et al., 2009), the screening uptake was lower compared to our findings, 24.9%, 23.3% and 22.5% for BSE, CBE and mammography, respectively. In the general uptake of screening (CBE and/ or mammography), a study of Saudi women (Radi, 2013) reported screening uptake of 20.5% compared to 58% in this study. One of the major barriers to screening is the lack of knowledge about the benefits of early detection (Pearlman et al., 2008). Studies have also implied that with improved knowledge, screening uptake will increase (Fletcher at al., 1993; Davis et al., 1996). In our study, responses to the general breast cancer knowledge questions suggested inadequate knowledge. This finding supports previous study findings (Bener et al., 2001).

**Breast Self-Examination (BSE)**

In this study, 51.4% reported practicing BSE. BSE was practiced among UAE nationals more frequently than non-UAE nationals, at 55.1% and 45% respectively. In contrast to the study conducted previously (Bener et al., 2001), older women (≥49 years of age) were found to practice BSE more frequently than

younger age group (40-49 years of age). In our study, 81.6% of women practicing BSE were given instructions by a healthcare provider compared to 38% in the previous study (Bener at al., 2001). This might be due to the increased early detection and awareness activities conducted by the local health authorities during the past decade (Taher et al., 2008). Thus, offering information to women on how to perform BSE improves screening practices (Smith et al., 2010). In the 1980s in the United Kingdom it was found that after introducing the national screening program, rates of advanced breast cancer reduced dramatically (Stockton et al., 1997). In the UAE, the efforts of Abu Dhabi Health Authority are improving and resources are directed toward better implementation of screening activities. The improved rate of BSE practice in this study population indicates the success of the educational and awareness programs. However, still the rates are low compared to developed countries. In a total of 120 women who do not regularly perform BSE, 41 (34.1%) of them had never heard of BSE, and 33 (27.5%) expressed willingness and interest to perform BSE if they were instructed on how to perform it. However, 46 (38.3%) claimed good knowledge of BSE performance but not actually performing it due to fear of discovering a lump or lack of time. See table (14).

**Clinical Breast Exam (CBE) and/or Mammography**

In this study, 58% reported having a history of CBE or a mammography in the past few years. This percentage is low compared to the other countries, for example 72% of the target population in Canada reported to have had a mammogram in the past two years (Statistics Canada, 2009). In the UK more than 80% of women aged 50-69 are reported to have had mammography in the previous three years (WHO, 2008). However, comparing the UAE experience to a

neighboring country, Qatari women reported low participation rate in breast cancer screening activities, 23.3% and 22.5% for CBE and Mammography respectively despite having adequate levels of knowledge level (Bener et al., 2009). Our findings showed that 80% and 83% of women who reported having a history of CBE and/or Mammography respectively indicated that these screening techniques were recommended by their healthcare provider. Improvement in the uptake of CBE has been linked to the increased awareness about the importance of attending regular CBE (Dundar et al., 2006). Education level in our study was positively correlated with knowledge score, however, participation in mammography was negatively associated with education level, OR 0.18 and 0.13 for school level and university level respectively compared to illiterate women. Although the level of knowledge of breast cancer was higher in more educated women, they were not very keen on practicing mammography. 23 (32.4%) of women who hold a university degree and do not perform regular mammography believed that it is not for their age group. 56 (44.8%) of women who never had conducted CBE and 60 (44.1%) of women who never had mammography expressed lack of knowledge about existence of these screening techniques. Healthcare providers play an important role as enablers and facilitators for effective utilization of screening techniques. Not receiving a recommendation by healthcare provider to perform screening has been found to be a barrier for participation in screening (Azaiza & Cohen, 2006). In this study, some women who never had CBE or mammography had a misunderstanding that they were not in the target group for screening and they believed it is for older women (41.6% and 33.8% in CBE and mammography respectively). In this study, older women

(≥49 years of age) were more likely to go for mammography p=<0.001 (OR 1.14, CI 1.07-1.22).

Another misconception noted was the belief that mammography should be performed once and not on a regular bi-annual basis. It is also worth noting that the quality of reassurance by the physician who tells the patient that there is no significant finding may have a certain impact on the extent of concern retained by the rescreened women. In fact, a benefit of breast screening programs and high participation rates may be derived from reassurance for those women in whom no evidence of breast cancer is found.

**Breast lump interpretation**

A question in the general knowledge section of the questionnaire was introduced regarding the breast lump finding interpretation. Women were asked if they would seek medical attention if they noticed a lump in their breast. Nearly a third of the women interpreted the breast lump incorrectly and expressed less worries about the nature of the lump and indicated no intention to seek medical attention as they perceived the lump would be due to normal hormonal changes which affects women at menopausal age or is related to breastfeeding. Correct interpretation of the finding of a breast lump was positively associated with extent of general knowledge p=<0.001 (OR 1.26 CI 1.12-1.41). Women easily fall in misconceptions and myths about breast lumps. This study results highlight the importance of misconceptions about breast lumps in contributing to longer delay. 56.9% of respondents misunderstood screening as seeking medical attention only when symptomatic. Common barriers towards screening included fear of pain and embarrassment fear of radiation causing cancer, and perceived inadequate facilities. Women would change their minds if they became symptomatic or if

their doctors, family or friends encouraged them. Holding a misconception about breast lumps was strongly associated with prolonged patient delay. Increased level of knowledge was present in women who did not interpret breast lump as threatening or an alarming sign of breast cancer.

**Screening and over-diagnosis**

Multiple cancer screening tests have been advocated for the general population. However, clinicians and patients are not always well-informed of screening burdens. The ability of mammography to diagnose small, early stage breast cancers, which have favorable prognosis, is well documented (Moody-Ayers et al., 2000). Over-diagnosis or over-detection is a term used when a mammogram detects cancer that would have neither caused death nor presented clinically during the woman's lifetime (Welch & Black, 2010). Although survival is better in screened versus non-screened women, a number of biases may explain this finding. According to the National Cancer Institute (2013) at least four biases need to be considered when interpreting mammography screening benefits:

"Lead-time bias: Survival time for a cancer found mammographically includes the time between detection and the time when the cancer would have been detected because of clinical symptoms, but this time is not included in the survival time of cancers found because of symptoms".

"Length bias: Mammography detects a cancer while it is preclinical, and preclinical durations vary. Cancers with longer preclinical durations are, by definition, present during more opportunities for discovery and therefore are

more likely to be detected by screening; these cancers tend to be slow growing and to have better prognoses, irrespective of screening".

"Over diagnosis bias: An extreme form of length bias; screening may find cancers that are very slow growing and would never have become manifest clinically in the woman's lifetime".

"Healthy volunteer bias: The screened population may be the healthiest and/or the most health-conscious women in the general population".

Recently, many scientists debated the benefits of screening and the issue of over diagnosis and subsequent overtreatment. The reduced breast cancer related mortality attributable to screening was balanced against the cost of screening in terms of physical and psychological harm to women and the financial impact on health services. An expert panel review of the value of breast cancer screening in the UK published in 2012 (Independent UK Panel on Breast Cancer Screening, 2012) reported some limitations related to the available evidence. The panel estimated that almost a fifth of breast cancers discovered through screening resembles over-diagnoses. However, the report provided evidence of a 20% relative reduction in deaths from breast cancer in women invited for breast cancer screening. On the other hand, Baum (2013) criticized the UK panel review. He claimed that the report lacked quality of life considerations. Because the clinical trials used in the UK panel review were unable to detect any impact on all-cause mortality, only cause-specific mortality was measured. Burton et al (2012) suggested that with the advances in the systemic treatment of breast cancer

(chemotherapy and hormonal therapy), the window for the impact of screening narrows substantially and as over-diagnosis rates increase then the importance of the relatively rare lethal toxicities of treatment increase. Baum (2013) also indicated that any estimates of benefits and harms based on trials reported 20 to 25 years ago, as described in the UK panel review report, are irrelevant to the modern practice of medicine.

There are analyses to other cancer screening programs. For example, the value and effectiveness of prostate cancer screening has been debated recently. The uptake of routine Prostate Specific Antigen (PSA) testing in the UK is not high, although the incidence of prostate cancer has increased by 4% per annum especially in the 1990s (Melia et al., 2004). There are conflicting opinions regarding the magnitude of the screening benefit in different populations, the extent of over-diagnosis and over-treatment of low risk disease, the optimum treatment for localized disease and the costs of implementing procedures (Lane et al., 2010). Pashayan et al. (2009) indicated potential stage migration of prostate cancer if screening was introduced in the UK. The potential over-diagnosis was modeled to be around 20% (Pashayan et al., 2009).

Over-diagnosis is of particular concern in lung cancer screening also, because new imaging technologies can detect very small lung nodules. Although these nodules are considered to be abnormal, their clinical significance remains uncertain. Furthermore, persons most likely to be screened for lung cancer (i.g., heavy or long-term cigarette smokers) often have clinically significant cardiac or pulmonary comorbid conditions, which increases the risk of serious adverse events, including death, during diagnostic evaluation and treatment. Identification

of over-diagnosed cancers through screening would unnecessarily put these persons at potentially serious risk (Marcus et al., 2006).

In a multimodal cancer screening program, Croswell et al. (2009) determined the cumulative risk for an individual of a false-positive screening result and the resulting risk of a diagnostic procedure. They analyzed data from an ongoing cancer screening trial. Four cancers were screened for: Prostate, Lung, Colorectal, and Ovarian (PLCO). Fourteen screening examinations for each sex were possible during the 3-year screening period. They concluded that "for an individual in a multimodal cancer screening trial, the risk of a false-positive finding was about 50% or greater by the 14th test. Physicians should educate patients about the likelihood of false positives and resulting diagnostic interventions when counseling about cancer screening" (Croswell et al., 2009).

Screening for breast cancer and prostate cancer appears to detect more cancers that are potentially clinically insignificant (Esserman et al., 2009). Esophagus and ductal carcinoma of the breast are examples for which the detection and removal of lesions have not led to lower incidence of invasive cancer. In contrast, colon and cervical cancer are examples of effective screening programs in which early detection and removal of precancerous lesions have reduced incidence as well as late-stage disease (Howlader et al., 2012 as cited in Esserman et al., 2013) (See table 15).

**Table. Change in Incidence and Mortality of Cancers Over Time From 1975 to 2010 as Reported in Surveillance, Epidemiology and End Results**

| Change[a] | Incidence Per 100 000 1975 | Incidence Per 100 000 2010[b] | % Change | Mortality Per 100 000 1975 | Mortality Per 100 000 2010[b] | % Change |
|---|---|---|---|---|---|---|
| **Example 1** | | | | | | |
| Breast[c] | 105.07 | 126.02 | 20 | 31.45 | 21.92 | −30 |
| Prostate | 94 | 145.12 | 54 | 30.97 | 21.81 | −30 |
| Lung and bronchus[d] | 52.26 | 56.68 | 8 | 42.56 | 47.42 | 11 |
| **Example 2** | | | | | | |
| Colon | 41.35 | 28.72 | −31 | 28.09 | 15.51 | −45 |
| Cervical | 14.79 | 6.71 | −55 | 5.55 | 2.26 | −59 |
| **Example 3** | | | | | | |
| Thyroid | 4.85 | 13.83 | 185 | 0.55 | 0.51 | −7 |
| Melanoma | 7.89 | 23.57 | 199 | 2.07 | 2.74 | 32 |

Table 10: Change in Incidence and Mortality of Cancers over Time from 1975 to 2010 as Reported in Surveillance, Epidemiology and End Results (Howlader et al., 2012 as cited in Esserman et al., 2013)

However, recommendations for breast cancer screening have not changed in any major way. The UK panel review stated that "The Panel agrees that over-diagnosis is important but it is impossible to say, for an individual woman with cancer detected at screening, if her cancer represents over-diagnosis. It is therefore difficult to estimate the magnitude of over-diagnosis". Breast cancer screening may yield individual level benefits, however community long term mortality benefits still need to be investigated.

**Strengths and limitations**

Similar to many studies of breast cancer with methodological limitations, this study encountered some limitations which need to be considered in the interpretation of results.

**Phase I (descriptive)**

Obtaining breast cancer statistics data for the first phase from the cancer registry posed some difficulties as much assurance needed to be given before the release of data. This could be due to the nature of study as it is the first study based on cancer registry data in UAE describing breast cancer. Five years' data were available for analysis, however, breast cancer is a cancer that has relatively longer survival rate than other types of cancer, and therefore 10 years' data would give a clearer analysis of survival. Heavy data censoring was faced as the data on vital status was not complete. The cancer registry data obtained does not represent all of the UAE. The data included many missing values and incomplete information.

**Phase II (qualitative)**

This is one of the few qualitative studies on breast cancer in the Middle East and describes the reasons for delay in seeking treatment. It explores different aspects of the complex health seeking behavior of UAE national and non-national Arab women in the religiously dominated society of the UAE. It will pave the way for comparisons with the experience in other countries in the Middle East (eg., Saudi Arabia) and other Muslim countries in Asia (eg., Malaysia). The interdisciplinary nature of the research team allowed for different perspective analysis.

Breast cancer delay is a new topic of research in the UAE, there was lack of prior research studies in the Middle East to compare to or build upon for this topic. No developed model or framework for breast cancer help seeking behavior was developed for Arab women. It is possible that, unknowingly, the investigator recruited only women who were more open and willing to talk about their feelings about breast cancer. The study was faced with some rejection from participants regarding the interviews despite giving assurances that their identity will not be disclosed by the research team and only group data will be published without identifiers. This might be due to the complex nature of the study and the sensitivity of the issues discussed. The interview venue needed to be changed so participants could find it more convenient and less threatening to discuss their illness experience. Caution in interpreting the findings regarding these women is required since this was a small sample designed for a qualitative pilot study and might not be representative of the greater target population. Further verification of these findings may be derived through focus group discussions.

**Trustworthiness in phase II/ qualitative study**

During data collection, participants were visited several times in the hospital before, during and after conducting the interviews to establish a good rapport and to allow women to have sufficient confidence in the principal investigator and the interview method to completely discuss their experiences. Some interviews were conducted more than once to allow for more productive discussion and to ensure that what was said by the woman was well understood by the principal researcher. A second quality control check was to use coding of three randomly selected sets of interview information, to be coded separately by a different researcher with extensive experience with women issues and qualitative

research methodology. The second researcher was not involved in the data collection. It was reassuring to note that the codes generated by both researchers were similar. All findings were brought back to participants for verification.

**Phase III (cross-sectional)**

This cross sectional survey is one of the few community based studies on the effect of national screening program and knowledge and practice of breast cancer screening among women in Al Ain city. We used a previously validated questionnaire (CAM 2008). Mammography use and BSE performance were evaluated with self-report, whereas mammography use can be more valid via a medical record review. Overall, community-based programs should be expanded to different women groups to assess the actual rate of screening behaviors and effective factors on them.

Community centers were chosen as they would be more representative of Al Ain community in comparison to recruiting women from primary health centers as in previous studies. The study had sufficient power but faced some limitations. Including time and resources constraints, it was not feasible to select a random sample of women in the Al Ain community. A random sample could be drawn from different households selected randomly. This might have led to socio-demographic differences between the two groups (UAE nationals & non-nationals). Multi-variate logistic regression analysis was therefore used to adjust for these differences. Since this study was not completely based on a random sample, the findings of this study may not be generalized to all women in the UAE. Three types of bias might have been introduced as a result of non-random sampling: (1) selection bias, (2) non response bias and (3) response bias. Selection bias is a systematic tendency to exclude one participant or another from the

sample. In this study, the inability to select a random sample from Al Ain community may have introduced selection bias. Moreover, women attending the community cultural and religious center might differ from those in the community. Not all women can attend these centers due to work or life constraints. Non response bias might also be exemplified in this study with the assumption that non respondent women to the questionnaire might differ from women who were willing to respond. In this study, the response rate was 81% which is considered high and has minimized the non-response bias. Source of response bias could be generated by the interviewer who administered the questionnaire, respondents can easily be lead to hide the truth, by interviewer attitudes, the precise wording of questions, or even position of one question with another. To minimize respondents' bias, the principal investigator administered the questionnaires.

# Chapter seven

# CONCLUSION

Findings from this study confirm the occurrence of breast cancer in younger age groups than in Western countries. It is still the most common type of cancer occurring among females in the UAE. The analysis supports the established guidelines of BSE and CBE but argues the mammography guidelines in the UAE. Although Tawam Hospital cancer registry has gone through major improvement in the terms of data collection and assessment during the past few years, there is still large number of incomplete data of cases counted. For example, hormonal receptors status, treatment, mortality/survival are all incompletely assessed. In future years, breast cancer follow-up will be longer allowing survival to be estimated with greater precision and to allow the estimation of survival beyond the 5 years possible in the future.

The study suggests that delay in help seeking has had several negative effects on disease prognosis. Culture has a great impact on the decision making of affected women to seek help earlier. The lack of awareness about signs and symptoms of breast cancer and routine screening has affected symptom appraisal and consequently correct decision making. Part of this study used a qualitative approach and proposed a help seeking model to explain Arab women help seeking behavior. Arab women in the UAE are surrounded by many influencing factors in regards to their social environment, religion and culture which often place them in a disadvantaged position with inequity in healthcare access and illness. This study provides an understanding of women's help seeking behavior and factors influencing the time interval between presentation of symptoms and signs to treatment. It reveals cultural and religious aspects of breast cancer and the distinct way UAE society reacts

with women who have breast cancer. Lack of knowledge was not the only reason for delay; a complex array of personal, social, and cultural factors appears to influence a woman's decision on how soon to ask for appropriate clinical advice.

National efforts are needed to address specific benefits of early detection and increase the awareness about these benefits. The establishment of a supportive relationship between healthcare providers and women with an expectation of periodic breast screening may reduce the likelihood for delay. Despite the increase in the uptake of screening modalities in our study group, lack of knowledge about breast cancer screening is still evident in this part of the UAE. The positive association between knowledge of breast cancer and screening uptake is clear, but it is always difficult to determine whether breast cancer knowledge preceded cancer screening or whether previous exposure to screening increased knowledge. A follow up case control study may help establish the direction of causality. Most efforts of local health authorities were targeting individual level barriers of screening; more holistic approach to tackle socioeconomic, cultural, and religious factors is needed.  Health promotion priorities should be aimed at clarifying misconceptions and addressing barriers such as fear and embarrassment. In particular, it should be emphasized that screening should be performed even when asymptomatic. More awareness should also be raised towards available subsidies and facilities. Opportunistic screening adopted by the national screening program in the UAE does not completely fulfill the program objectives, so efforts need to be directed toward organized and better utilization of resources. Language and trust barriers between women and healthcare providers need to be minimized for practical and efficient implementation of screening programs. There is an urgent need for coordinated awareness campaigns organized by the local health authority

and healthcare providers. Differences in the provision of breast cancer screening services offered to women in the UAE are thought to be an outcome of the fragmented health system of the UAE. The different health administration authorities often allow for inequities in regards to access level and quality of healthcare and preventive services. Information on breast health from different health providers varies markedly, especially with regard to the screening guidelines. The fragmented healthcare system in the UAE, which involves the unorganized efforts from local health authorities, is a major barrier for the consistency and continuity of breast health awareness and screening programs. Health education is only intense during October, leading to a dramatic increase in the number of mammograms in this month only and dropping to lower levels for the rest of the year. Community outreach programs are deficient, especially for women living in the urban areas. Healthcare professionals lack awareness of screening guidelines and existing screening providers. Despite the wide availability of mammography, Screening is mainly provided by the public sector. Most private health care providers offer mainly diagnostic mammograms. Communication and co working between providers in Abu Dhabi is not optimal leading to missed opportunities for joint initiatives.

This study recommends that the mammography screening guidelines be revised for consideration of younger age presentation with breast cancer. Starting the clinical screening at the age of 35 with different screening modality such as MRI or ultrasonography would be more appropriate for younger women with dense breasts. There as an urgent need for more efforts from stakeholders to develop a national cancer registry with a more comprehensive and full database representing all UAE for future comparison with other countries in the region.

This study also recommends that breast awareness education be integrated into already existing health education programs. In addition, doctors should endeavor to educate women on "breast awareness" during regular physician office visits for other health matters. Establishing and organized outreach programs embedded in the community could be very effective through community educators in which members from different communities in the UAE will be trained as educators to conduct regular activities to raise awareness within their communities. Healthcare providers including physicians, nurses and radiographers need to be offered regular training and awareness workshops which includes culture sensitivity awareness as most healthcare professionals in the UAE are from different cultural and ethnic background.

It is important to encourage health professionals at primary healthcare centers (PHC) to increase rates of clinical breast examination (CBE) and mammogram referrals. Enhancing collaboration of different care givers by encouraging proactive and regular reporting of screening data from all providers in order to monitor screening rates, with regular feedback to providers is also advisable. Using survivors and religious leaders as speakers in awareness activities could increase the response to breast cancer screening initiatives especially when the response rate is relatively low. Breast cancer awareness campaigns need to target younger women as participants in the survey claimed that screening practices are for older women. These campaigns may be having the undesirable effect of giving younger women the perception that they cannot be affected. It is recommended that a health promotion campaign be developed to educate young women about what it is recommended they should be doing and their risks. This study also recommends that women's health education should

occur at an earlier stage in young women's lives. The suggestion of making it compulsory for pre-secondary school girls to learn health information and regular screening for different diseases including breast cancer, cervical cancer and osteoporosis at school or through appropriately targeted information should also be considered.

Despite the fact that breast cancer is the leading cancer in the UAE and the large role culture and psychosocial beliefs play in the health matters of Arab women, few support services exist in the UAE (Taher et al., 2008). Mainly breast cancer support is provided through small support groups that women attend. Small numbers attend these meetings and Emirati women are usually absent. There is no available psycho-oncologist for support. Breast cancer support services provide comfort and support to women diagnosed with cancer and their families. Support services should be provided in different ways, programs be offered to help deal with the stress of treatments, give information to help make good decisions about health care, and provide peer support so that women know they are not alone.

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# APPENDICES

**DISCUSSION GUIDE**

**Introduction (5 min)**

Introduce yourself as a field researcher; explain that as a researcher you are genuinely interested in knowing the main reasons on why some patients do not come at an earlier stage to hospital for diagnosis and treatment. We would like to improve services and their honest opinion would help us a lot. There could be many reasons and many could be personal. This interview aims to discover the actual feelings and issues that the patient experience. This discussion will take one to two hours and would be grateful to switch off all hand phones and lock the door for no interruptions.

Please fill up the forms given.

**Stress that:-**

Interested in personal views and opinions

No right or wrong answer

Explain that audio taping is necessary to do the research analysis and documentation

Take verbal consent for the interview and the audio taping from the participant

Any questions before we start?

1. Can you tell me what breast cancer means to you?

2. Can you describe your experience on how you discovered your initial symptom of breast cancer i.e breast lump, pain etc.?

3. When did you first feel/think that something might be wrong with your health?

4. What was your initial reaction?

5. What did you do upon discovering that symptom? How long did you take before seeing a doctor?

6. Why did you take a long time?

7. Who did you confide in when you first discovered your breast cancer symptom?

8. Why did you confide in this particular person?

9. Have you at any point consulted traditional/ alternative/ religious healer?

10. Can you describe what you went through to arrive at the diagnosis?

11. Probe about clinic visits, biopsy.

12. How was the diagnosis communicated to you?

13. What was your reaction(s) when the doctor told you the diagnosis?

14. How did your life change after the diagnosis (at work and socially)?

15. How did it affect your marital (communication, sexual) relationship, work and social life?

16. Please elaborate and tell us all the different types of treatment that you have had so far for breast cancer (modern medicine, alternative medicine and other types of treatment)?

17. Did they work for you and why is that so?

18. How did you make the decision to have whichever treatment first?

19. Who and what helped you make that decision?

20. Looking back what could have made you make a better decision.

21. As time went by, how did the cancer progress?

22. How did you cope at home, at work and when socializing?

23. Did you face any problems (include emotions; ability to work, financial (was treatment expensive?)

24. And social relationships)?

25. What are the factors that prevent women from coming early to the hospital or refuse hospital treatment? There is no right or wrong answer. Most people might not really know why, but it is okay to share your thoughts. We would really like your honest opinion on this issue.

26. What are your needs in terms of the health care system (delivery of services eg. clinic, doctors, nurses, information etc), financial support, social support and family support?

27. Were the needs met?

28. How these needs can be met?

29. What would you do differently if you knew what you know now?

30. What would you recommend to other women?

31. What would make you have hospital treatment earlier?

32. Probe for financial support, psychological support, social support, more information and health care delivery.

33. Are there any regrets or disappointment for what you have been through?

34. Did anyone in the family have this disease? In the community? Is this an openly talked about subject?

35. Do you think by talking about 'cancer', this can bring bad luck to you or/and your family?

36. What education was given to you in regard to your other breast health and screening?

37. In case I have missed out anything, is there anything else that you would like to share with me regarding your illness?

Thank you for your time.

Appendix 4: Interviews discussion guide