

Almajed, Hanan (2023) *Breast cancer awareness among female residents of Kuwait*. PhD thesis.

https://theses.gla.ac.uk/83539/

Copyright and moral rights for this work are retained by the author

A copy can be downloaded for personal non-commercial research or study, without prior permission or charge

This work cannot be reproduced or quoted extensively from without first obtaining permission from the author

The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the author

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given

Enlighten: Theses <u>https://theses.gla.ac.uk/</u> research-enlighten@glasgow.ac.uk

# Breast cancer awareness among female residents of Kuwait

Dr. Hanan Almajed M.B.B.CH, MPH (EPBS)

Submitted in fulfilment of the requirements for the Degree of Doctor of Philosophy

College of Medical, Veterinary and Life Sciences Institute of Health and Wellbeing University of Glasgow

June 2022

#### Abstract

### Background and aim

Breast cancer is the most common cancer among females and the second leading cause of death worldwide. Incidence in developed countries is slightly higher than developing countries; yet mortality rate in developing countries is higher than developed ones. A main reason for this is late presentation of the disease, which is common in Gulf Coorporation Council countries (GCC), and in Kuwait especially. Evidence regarding the reasons behind late presentation is insufficient. This thesis aimed to provide a comprehensive insight into breast cancer awareness and its screening methods among females in Kuwait.

### Method

A multi-method approach was adopted to address the research objectives and gain a deeper understanding in a robust way. Three interlinked studies were carried out. A systematic review of literature attempted to understand the awareness, beliefs and attitudes towards breast cancer and breast cancer screening behavior in GCC countries region. The second epidemiological study was conducted to evaluate the level of knowledge and awareness about breast cancer non-lump symptoms, risks, and screening programs in the general population of females in Kuwait. The research was done using an internationally validated tool, the Breast Cancer Awareness Measure (BCAM). Participants were women who attended primary healthcare centres in the five districts of Kuwait and selected by systematic random sampling. Analysis included multivariable logistic regression analysis to quantify the relationship between the domains of the BCAM and breast cancer awareness. The qualitative study sought to explore and identify the best approaches to improve breast cancer awareness in Kuwait. Key stakeholders involved in breast cancer and breast screening awareness were selected because of their role. Individual in-depth interviews were built around video elicitation, where key stakeholders viewed a series of international breast cancer campaign videos. Reaction to the videos and a topic guide that included ten open-ended questions allowed the exploration of their views of breast cancer awareness in Kuwait. An Inductive thematic analysis was applied to the interview data.

#### Results

A total of 53 studies were eligible for inclusion in the systematic review. A narrative synthesis approach resulted in five main themes, each with subthemes. The synthesis of included studies concluded that awareness about breast cancer and its screening method was low compared to developed countries. Similarly, findings from the cross-sectional BCAM survey shown a lack of knowledge about breast cancer and breast screening methods. In the qualitative study, 14 participants were interviewed. The analysis identified eight themes and sub-themes. Participants discussed the reasons responsible for the low awareness of breast cancer and low uptake of mammography. Fear was a major resisting factor to screening, others mentioned social stigma and taboo and feeling shy, reflecting the cultural norm. Participants also explored different approaches to improve breast cancer awareness among the population of Kuwait.

### Conclusion

Findings from all three studies confirmed the low awareness about breast cancer and its screening methods among female residents of Kuwait. Areas of improvement were discussed and shared by interviewees. A number of recommendations for future awareness raising campaigns have been made. Improvement lies in the form of targeting campaigns for both healthcare professionals and females. Introducing factual females' health programmes in early school was recommended by most stakeholders.

# Contents

Chapter 1 Introduction	15
1.1 Introduction	15
1.2 Breast cancer in Kuwait	17
1.3 Methodological Approach	20
Chapter 2 Background and Breast Cancer Overview	22
2.1. Introduction	22
2.2. Global Breast Cancer Burden	23
2.3. Mortality	23
2.4. Breast Cancer in the Middle East and GCC countries	24
2.5. Risk Factors Associated with Breast Cancer	25
2.6. Breast cancer prevention	27
2.6.1. Introduction	27
2.6.2. Awareness	28
2.6.3. Screening practices	29
i. Breast Self-Examination (BSE)	29
ii. Mammography	30
2.7. Perception of Breast Cancer	32
2.7.1. Stigma and Social Taboo	34
2.7.2. Male perception about female breast cancer	36
2.7.3. Stigma	37
2.8. The role of healthcare professional	37
2.9. Improving awareness	38
2.10. Summary	39
Chapter 3 Kuwait Healthcare System	40
3.1. Introduction	
3.2. Healthcare Organisation	
3.2.1. Role of Kuwait's ministry of health	40
3.2.2. Healthcare system governance	41
3.2.3. Health Service Provisions	43
3.2.4. Health Information System (HIS)	44
3.2.5. Healthcare indicators	45
3.2.5.1. Mortality	
3.2.5.2. Trends in cause-specific mortality	46
3.2.6. Non-communicable diseases and risk factors	47
3.2.7. Healthcare Education and Workforce	49
3.2.8. Health regions	50
3.2.8.1. Health region one	51
3.2.8.2. Health region two	51
3.2.8.3. Health region three	51
3.2.8.4. Health region four	51
3.2.8.5. Health region five	52
3.2.8.6. Health region six	
Chapter 4 Methodological rationale	
4.1. Introduction	53
4.2. Philosophical assumptions	
4.3. Mixed-Methods and Multi-Methods	55
4.3.1. Advantages of multi-method research	56

Chapter 5 Understanding awareness, beliefs and attitudes towards breast cancer and breast cancer screening behaviour in the Gulf region. A systematic review62

and breas	se cancer serecting behaviour in the out region. A systematic revie	W 02
5.1.	Introduction	
5.2.	Aim, research question and objectives	. 62
5.3.	PROSPERO registration	
5.4.	Method	
5.4.1.	Searching for papers	
5.4.2.	Inclusion and exclusion criteria	
5.4.3.	Screening process	
5.4.4.	Quality appraisal	
5.4.5.	Approach to analysis	
5.5.	Results	
5.5.1.	Overview	
5.5.2.	Main themes	
5.6.	Discussion	
5.6.1.	Religion	
5.6.2.	Men's control over women	
5.6.3.	Breast cancer misconception	
5.6.4.	Fear	
5.7.	Strengths and limitations	
5.8.	Summary	
Chapter 6	Breast cancer knowledge and awareness among female residents o	f
Kuwait. A	a quantitative study	127
6.1.	Introduction	127
6.2.	Study Objectives	127
6.3.	Study design and setting	128
6.3.1.	Study population	
6.3.2.	Methods and data collection	
6.3.2.1	. The content of the BCAM	130
6.3.2.2		
6.3.2.3		
6.3.3.	Improving response rate	
6.3.4.	Sample size and sampling method	
6.3.5.	Ethical considerations	
6.3.6.	Data management	
6.3.7.	Statistical analysis	
6.4.	Results	
6.4.1.	Descriptive results	
6.4.2.	Sociodemographic characteristics	
6.4.3.	Exposure to breast cancer information	1/1
6.4.3. 6.4.4.		144
	Recognition of breast cancer signs and/or symptoms and skills in	1 45
	n to detecting breast changes	
6.4.5.	Knowledge of Kuwait National Screening Program	
6.4.6.	Anticipated delay in contacting the doctor	
6.4.7.	Barriers to seeking medical help	
6.4.8.	Knowledge of age-related lifetime risk of breast cancer	
6.4.9.	Knowledge of risk factors	150
6.5.	Awareness of non-lump symptoms and its association with other	
	of interest	
6.5.1.	Awareness and its association with sociodemographic factors	
6.5.2.	Awareness and its association with confidence, skills and behavio	
in relat	ion to detecting breast cancer changes	153

6.5.3. Awareness and its association with the knowledge of the screening Awareness and its association with the barriers to screening ..... 155 6.5.4. 6.5.5. Awareness and its association with the knowledge of age-related and Awareness and its association with the knowledge of risk factors, 158 6.5.6. 6.6. Logistic regression analysis of awareness of non-lump symptoms 6.6.1. Model 1 Univariate analysis ......161 6.6.2. 6.6.3. 6.6.4. 6.7. 6.7.1. Strengths of the study ...... 177 6.7.2. Limitations of the study ...... 177 6.8. Chapter 7 How to improve breast cancer awareness - a qualitative study... 18080 7.1. 7.2. 7.3. 7.3.1. Sampling methodology/Identification of participants and consent 182 7.3.2. 7.3.3. 7.3.4. 7.3.5. 7.3.6. 7.3.7. 7.3.8. 7.3.9. 7.4. 7.5. 7.5.1. 7.5.2. Themes and subthemes ...... 190 7.5.2.1. Theme 2: Low Levels of Awareness ...... 196 7.5.2.2. 7.5.2.3. 7.5.2.4. 7.5.2.5. 7.5.2.6. 7.5.2.7. Theme 7: Reluctance to use emotional content to raise awareness 215 7.5.2.8. 7.6. 7.6.1. 7.7. Strengths and Limitations......235 7.7.1. 7.7.2. 7.7.3. 7.8. Chapter Eight: Synthesis of findings, discussion, and future recommendations 237 8.1.

8.2. Synthesis of the findings	237
8.3. Synthesis of the findings	
8.3.1. Awareness on breast cancer	249
8.3.2. Factors associated with awareness	250
8.3.2.1. Beliefs and Attitudes	251
8.3.2.2. Screening for Breast Cancer	
8.4. Strengths and Limitation	
Researcher's reflection statement	256
8.5. Recommendation of how to improve breast cancer awareness .	257
8.6. Conclusion and summary	
Appendix 1: Ethical Approval- Kuwait Ministry of Health (Arabic version).	263
Appendix 2: Ethical Approval- University of Glasgow	268
Appendix 3: Consent Form (Quantitative Study)	
Appendix 4: Consent Form (Qualitative Study)	271
Appendix 5: Participants Information Sheet (Quantitative study)	
Appendix 6: Participants Information Sheet (Qualitative Study)	273
Appendix 7: Systematic Review Search Strategy	275
Appendix 8: Data Extraction Form	
Appendix 9: Quality Appraisal Tool (Quantitative Study)	283
Appendix 10: Quality Appraisal Tool (Qualitative Study)	284
Appendix 11: Quality Appraisal Tool (Mixed Method Study)	285
Appendix 12: Data coding Dictionary (Quantitative Study)	287
Appendix 13: Validated Modified BCAM (Quantitative Study)	297
Appendix 14: Interview Topic Guide Questions (Qualitative Study)	303
Appendix 15: URLs	305
Bibliography	306

List of Tables

Table 3.1: Child Mortality rate in Kuwait compared to GCC countries and WHO
Eastern Mediterranean Region (Source: WHO, 2015)46
Table 3.2: Rate of some risk factors associated with NCDs in Kuwait as compared
to other WHO EMR (Source: WHO, 2015)49
Table 3.3: Health care workforce comparisons: Density per 10,000 population for
the listed professions
Table 4.1: Paradigms and their applicability in research studies (Adapted from
Creswell 2003)
Table 5.1: Inclusion and exclusion criteria
Table 5.2: Summary of the included papers
Table 5.3: Summary of articles examining beliefs about breast cancer
Table 5.4: Summary of articles examining barriers to screening methods80
Table 5.5: Summary of articles examining awareness of breast cancer
Table 5.6: Summary of articles examining screening methods
Table 5.7: Summary of articles examining men's view about female breast
cancer
Table 6.1: Description of sociodemographic characteristics of the study
population (N=400)
population
Table 6.3: Frequencies of study participants recognizing or not breast cancer
signs and/or symptoms
Table 6.4: Skills in relation to detecting breast changes among the study
population
Table 6.5: Knowledge of Kuwait National Screening Program among the study
population148
Table 6.6: Barriers to seeking medical help among the study population
Table 6.7: Risk factors for breast cancer as perceived by the study population
Table 6.8: Awareness and its association with sociodemographic factors
Table 6.9: Awareness and its association with confidence, skills and behaviour in
relation to detecting breast cancer changes
Table 6.10: Awareness & Knowledge of the National Screening Program in Kuwait
Table 6.11: Awareness and its association with the barriers to screening156
Table 6.12: Awareness and its association with the knowledge of age-related and
lifetime risk158
Table 6.13: Awareness and its association with the knowledge of risk factors.159
Table 6.14: Univariate/ Multivariable Logistic Regression Analysing the
relationship between the awareness of non-lump symptoms (dependent variable)
and the variables of interest
Table 7.1: Participants' Demographics    187
Table 7.2: Summary of participants replies to breast cancer video adverts188
Table 7.3: Themes and subthemes identified in the analysis
Table: 8.1 Summary of the findings from the three studies

List of Figures

Figure 3.1: A chart depicting the average national life expectancy a	it birth in
GCC countries (Source: WHO, 2015)	
Figure 3.2: The contribution of different causes of death to mortali	ty rates in
Kuwait (%), WHO, 2016	
Figure 5.1: PRISMA Flow Chart	

### Dedication

After a long and tough road, I finally grant this achievement to my family, who always believed in me and have been beside me in every step along the way.

To God, and all my people and those dear to my heart I say:

Thank you for your support, endearing encouragements, and unconditional love with which without I would have not been able to be where I stand right now.

### Acknowledgement

To all my supervisors: Sara Macdonald, Barbara Nicholl and Katie Robb for their invaluable support.

Special thank you for my primary supervisor, Prof. Sara Macdonald who believed in me and encouraged me all the way through. She was not only a supervisor but a mentor, and a guide, someone who I can go to whenever I needed to. She stood by me when I was homesick and always tried to calm me down and provide me with much the necessary emotional support that kept me going.

I would also like to thank the review team, particularly Prof. Kate O'Donnell whose experience in the primary care department is undeniable, thank you for your valuable feedback and support and your willingness to help at any time. I would also like to extend another grateful thanks goes to Dr. Stephanie Chambers Lecturer in Sociology of Health and Well-being for the support.

A special appreciation goes to my supervisor in Kuwait Dr. Amani Albasmi, the head of cancer registry who facilitated all my work conducted in Kuwait. In addition, I would like to thank all the staff in the primary health care department.

I would like to thank E.M. Al-Khasawneh for allowing me to use the Omani modified version of BCAM.

Last but not least, a special thanks goes to my family, especially my children for having to put up with my absence when they needed me the most. To my mother, I will forever be in owe to you for everything you did to me and to my children, and for having to take up the burden of looking after them and provide them with all the love they need when I wasn't there. Your continuous support, is what made me who I am.

### Author's declaration

I, Hanan Almajed I declare that I'm the sole author of this thesis and responsible for conducting all the work involved. The research took place at the General Practice and Primary Care, University of Glasgow. It was under the supervision of Prof. Sara Macdonald, Dr. Barbara Nicholl and Dr. Kate Robb. I declare that all the material presented in this thesis is my own work unless specifically stated otherwise.

Hanan Almajed

June/ 2022

### Abbreviations

- ACS: American Cancer Society
- ASR: Age-Standardized Rate
- BCAM: Breast Cancer Awareness Measure
- BN: Barbara Nicolle
- **Bn: Billion**
- BRCA1 & BRCA2: Breast Cancer Genes
- BSE: Breast Self-Examination
- **CAN:** Cancer Awareness Nation
- CBE: Clinical Breast Exam
- CD: Communicable Disease
- CDC: Centre for Disease Prevention & Control
- COVID-19: Corona Virus Disease-19
- CVD: Cardiovascular Disease
- DALY: Disability-Adjusted Life Years
- DES: Diethylstilbesterol
- EAD: Emirates of Abu Dhabi
- EHR: Electronic Healthcare Record
- ENT: Ear, Nose & Throat
- FBG: Fasting Blood Glucose
- GCC: Gulf Cooperation Council.
- **GDP:** Gross Domestic Product
- **GP:** General Practitioner
- HBM: Health Belief Model
- HIS: Health Information System
- HM: Hanan Almajed
- HRT: Hormone Replacement Therapy
- **IBM:** International Business Machines
- ICD: International Classification of Disease
- **ID: Identification Document**
- IT: Information Technology
- KAP: Knowledge, Attitude & Practice
- K.D: Kuwaiti Dinar
- KM: Kilometre
- KSA: Kingdom of Saudi Arabia

LE: Life Expectancy

MENA: The Middle East & North Africa

MoH: Ministry of Health

MRI: Magnetic Resonance Imaging

NCD: Non-Communicable Disease

NIH: National Institute of Health

NGO: Non-Governmental Organization

OCP: Oral Contraceptive Pills

OECD: The Organization for Economic Cooperation & Development

OR: Odds Ration

PAFN: Public Authority for Food & Nutrition

PHC: Public Healthcare

PHCCs: Primary Healthcare Centres

PhD: Doctor of Philosophy

PRISMA: Preferred Reporting Items for Systematic Review and Meta-Analysis

PROSPERO: International Prospective Register of Systematic Review

**RS: Regular Screener** 

SD: Standard Deviation

SEA: South East Asia

SM: Sara Macdonald

SPSS: Statistical Package for the Social Sciences

SMS: Short Message Service

UAE: United Arab Emirates

UK: United Kingdom

USA: United State of America

WHO: World Health Organization

WW: Well Women

# **Chapter 1 Introduction**

### 1.1 Introduction

Before starting my thesis, a few things need to be clarified for the readers. This thesis is focused on Kuwait, where the researcher is from. Gulf Cooperation Council (GCC) countries comprised of Kuwait, Bahrain, Qatar, United Arab Emirates (UAE), Oman and Saudi Arabia and they are located in the Gulf region. GCC countries share similar culture with each other. Due to limited literature specifically, from Kuwait, comparison made with other GCC countries in particular. Arab countries include all the Arab speaking countries including GCC. Arabs also share some similarities with GCC countries. GCC/ Gulf and Arab countries were used interchangeably for comparison reasons.

Breast cancer is the most common cancer worldwide, with an estimated 2.3 million new cases in 2020, accounting for 11.7% of all cancer cases worldwide, and is the fifth cause of death from cancer overall (6.9%) (Sung et al. (2021). It was also the most common cancer among females in 2020 and ranked as the first cause of death from cancer in females worldwide (685 000) (Sung et al. (2021).

Incidence rates are 88% higher in developed than in less developed countries (55.9 vs 29.7 per 100,000 respectively), however, mortality rates are 17% higher in less developed countries (15 vs 12.8 per 100,000 respectively) (Sung et al., 2021).

In the United Kingdom (UK), breast cancer was the most common cancer in 2013 and the third most common cause of cancer death in 2014, accounting for 15% of all new cancer cases and for 7% of all cancer deaths in the UK (Breast Cancer Research UK, 2019). It is estimated that 53,700 new cases of breast cancer were diagnosed in the UK in 2013. Although breast cancer incidence has increased over the last decade, specifically in females, death rates have fallen by around a fifth due to improved survival, with a 10-year survival rate now of 78% (Breast Cancer Research UK, 2019).

Age at diagnosis varies substantially between developed and Arab countries; in the United States of America (USA) and Europe, the median age at presentation is around 63 years and up to 50% of patients are older than 63 (Sergio Rodri<sup>'</sup>guez-Cuevas, 2001). In the UK, 46% of the cases are diagnosed in females aged 65 and above (Breast Cancer Research UK, 2019); however, in Arab countries, almost 50% of cases are diagnosed below 50 and the median age at diagnosis is 49.8 years (El Saghir et al., 2007a). Similarly, stage of the disease differs considerably, unlike in developed countries, breast cancer is more commonly diagnosed in advanced and metastatic stages in developing countries (El Saghir et al., 2007a). For instance in the UK, almost 85% of breast cancer cases are diagnosed at an early stage (stages I or II) and this may be partly due to awareness of the screening program (Breast Cancer Research UK, 2019, Walters et al., 2013) whereas stage at diagnosis varies between Arab countries, with the majority of the cases being diagnosed at advanced stages, potentially reflecting their low awareness about the screening program (El Saghir et al., 2007b).

Breast cancer was the most common cancer diagnosed among females between 1992 and 2002 in the GCC countries (21.8% from 20,547 cancer cases) (Al-Zahran, 2009) and between 1998 and 2007, incidence increased by 20% (Al-Madouj et al., 2011). In Kuwait, breast cancer is the leading malignancy in females, accounting for 34.3% of all female cancers (Al-Madouj et al., 2011). Kuwait had the second highest age standardised rate (ASR) per 100 000 population (44.3) in 1998, the highest mean age at diagnosis (50.4 (standard deviation12.4)), and Kuwait was classified as a high incidence country compared to other Gulf countries (Al-Zahran, 2009)

Several factors are deemed responsible for regional variations in breast cancer morbidity and mortality. Higher incidence in developed countries have been attributed to lifestyle factors: they are less likely to breast-feed, more likely to give birth at an older age, to have fewer children, and to use oral contraceptives and hormone replacement therapy (HRT). In addition, obesity, alcohol consumption, and physical inactivity might also contribute to this increased risk (Youlden et al., 2012). Incidence in the Arab region including the GCC countries are rising and will continue to rise if no proper intervention is implemented (Hashim et al., 2018a). Although mortality rate in Arab and GCC countries is lower than in Western Europe, but it is comparable to the global average. Assumptions for the reason behind the differences in incidence and mortality rate were attributed to the better reporting and the high prevalence of some risk factors like obesity in the developed countries (Hashim, 2018).

Mortality on the other hand is associated with stage at diagnosis which is attributed to awareness about the disease and participation in screening.

Mortality is also affected by the availability and quality of healthcare provided (Agarwal et al., 2009), which is influenced in many ways by the structure of healthcare systems.

# 1.2 Breast cancer in Kuwait

The total population of Kuwait is around 4.5 million of which 34% are Kuwaiti citizens and 66% are non-Kuwaiti. The majority of non-Kuwaiti nationals are migrants from India, Egypt, Bangladesh and Philippines, motivated by the presence of job opportunities in the country. The majority of the non-Kuwaiti population work in domestic and unskilled occupations (PASI, 2022). Expatriates exert a burden on the healthcare system due to their large number, creating a drop in the quality of healthcare provided (Arrival, 2022). In addition, resources are focused on curative medicine and expanding hospital services rather than strengthening and promoting preventive medicine which aims to prevent chronic illnesses and reduce the burden of disease.

A breast cancer-screening program was launched in Kuwait in April 2014 (Alkhawari et al., 2021). It is the gold standard preventive measure in detecting early breast cancer. A study conducted in Kuwait examined the outcome of the national breast screening program in 14,773 females aged 40 years and older between 2014-2019 and showed that the uptake of screening among the target population was only 7.8% (Alkhawari et al., 2021). Despite the service being provided at no charge for the local Kuwaitis. However, the study found that females were not familiar with the program (Saeed et al., 2014b) and some were reluctant to undergo screening due to fear of illness (Saeed et al., 2014a).

The Kuwait cancer registry reported that breast cancer had increased by threefold for the last 33 years (A. Elbasmi, 2010), with the commonest range of age at diagnosis being between 45-49 years (Alkhawari et al., 2021). Females aged above 40 are encouraged to benefit from the screening program by undergoing mammography every 2 years.

Despite good levels of education and the presence of health facilities in Kuwait, there is limited knowledge and awareness about breast cancer and breast screening methods. One study that explored breast cancer awareness and screening behaviours in 421 Kuwaiti females (specifically in ever married teachers), showed that 67.5% of the participants reported they had some knowledge about breast cancer, and 85.7% did not know what mammography was (Alharbi et al., 2019). It was also shown that females older than 40 years, married females, those who had used contraceptive pills (OCP), and those with a history of child death were more likely to acquire a satisfactory level of knowledge of breast cancer. On the other hand, poor awareness and knowledge have been associated with delay in symptomatic presentation of cancer, a more advanced cancer stage at presentation (Macleod et al., 2009, Forbes et al., 2014) and thus in poor prognosis and poor cancer survival.

Breast cancer screening modalities including breast self-examination (BSE), clinical breast exam (CBE) and mammogram, have shown to decrease morbidity and mortality from breast cancer, especially if combined with a superior proper management/ treatment programme. Early detection practice continues to be a reason for breast cancer control despite the insufficient knowledge about the contribution of each method in decreasing mortality and morbidity rate (Albeshan et al., 2018). In the GCC countries, low participation rates in breast cancer screening have led to the delay between the onset of symptoms and the diagnosis. The reasons behind it could be the insufficient knowledge and awareness about breast cancer and the importance of the screening methods. Other key factors like cultural beliefs, fear and stigma had also affected the participation in screening along with the early presentation (Hwang et al., 2017). Due to lack of information in the GCC countries, it is very important to have a good understanding about their beliefs and attitudes toward breast cancer and breast screening behavior (Albeshan et al., 2018); this is discussed further in Chapter 5 Understanding awareness, beliefs and attitudes towards breast cancer and breast cancer screening behaviour in the Gulf region.

In comparison to non-GCC countries, Cancer Research UK reported that three quarters of females invited, participated in screening in the UK (UK, 2018), thus indicating that most were willing to undertake screening. In addition, almost half of the respondents mentioned that they would notice a change in their breasts, 23% noted checking their breasts at least once a month, and 73% said that they would seek medical help within one week of noticing a breast change (Forbes et al., 2011).In United State of America (USA), focus group discussions took place with 44 American Indian participants aged 25-39 females to examine their breast cancer screening perceptions (Filippi et al., 2013). The results showed that

participants had a satisfactory knowledge about the symptoms and risk factors but lacked the knowledge about screening details and their risk of getting the disease. The reported studies show differences in the level of breast cancer awareness and breast screening knowledge. Globally, the level of breast cancer awareness in general is unacceptable and rising especially in developing countries, and as a result the burden of the breast cancer disease is increasing (Wang et al., 2021).

The absence of a standard measure of awareness to be used in all the studies, makes it difficult to compare them. With the presence of insufficient information about breast cancer in Kuwait, there is a need for the following studies to take place to highlight the gaps present in breast cancer awareness among the Kuwaiti population, which could ultimately help in shaping strategies and recommendations for better awareness and improved breast cancer outcomes.

### Aim and objectives

The overall aim of this PhD was to provide a comprehensive insight into breast cancer awareness and its screening methods among females in Kuwait.

This aim was addressed through three specific objectives:

- To provide an understanding about the awareness of, and beliefs and attitudes towards breast cancer and breast cancer screening behaviour in the GCC countries (Systematic review Chapter 5 Understanding awareness, beliefs and attitudes towards breast cancer and breast cancer screening behaviour in the Gulf region)
- 2. To assess breast cancer knowledge and awareness among female residents of Kuwait (Epidemiological study, Chapter 6 Breast cancer knowledge and awareness among female residents of Kuwait. A quantitative study)
- To identify the best approaches to improve breast cancer awareness (Qualitative study, Chapter 7 How to improve breast cancer awareness - A qualitative study)

Each objective was approached and answered using a different research method and are presented in separate chapters of this thesis. The rationale for the approaches used will be discussed in the following section.

# 1.3 Methodological Approach

In order to meet the objectives a multi-method approach was adopted. The thesis is composed of three studies.

- A systematic review which sought to synthesise the evidence available on breast cancer awareness and breast cancer screening in GCC countries.
- A cross-sectional study of Kuwaiti women that examined knowledge and awareness of breast cancer using an already validated tool, the Breast Cancer Awareness Measure (BCAM).
- A qualitative study that explored the perspectives of healthcare professionals on strategies to increase breast cancer awareness among Kuwaiti women.

This is discussed in more details in Chapter 4 Methodological rationale. A summary of the chapters included in this thesis is provided below.

The thesis comprised eight comprehensive chapters about breast cancer in Kuwait. This first introductory chapter provides an overview about breast cancer in Kuwait and situates Kuwait in an international context; whilst introducing the main research objectives and methods.

Chapter 2 consists of the background to the key areas investigated in this thesis, including: the epidemiology of breast cancer, methods used in breast cancer prevention including breast self-examination and population-based screening via mammography; it introduces the issues of stigma and taboo in relation to perceptions of breast cancer in the Gulf region.

Chapter 3 provides an overview of the Kuwaiti Healthcare System.

Chapter 4 Methodological rationale - discusses the methods used in writing this thesis, with emphasis on the rationale for the adoption of a multi-method approach.

Chapter 5 Understanding awareness, beliefs and attitudes towards breast cancer and breast cancer screening behaviour in the Gulf region provides results of a systematic review of literature that centres on the awareness, beliefs, and attitudes towards breast cancer and breast cancer screening behaviour in the GCC countries. Chapter 6 Breast cancer knowledge and awareness among female residents of Kuwait. A quantitative study details the results of the BCAM survey carried out in healthcare clinics in Kuwait.

Chapter 7 How to improve breast cancer awareness - A qualitative study presents the professional perspectives of breast cancer in Kuwait and explores possible strategies that might help raise awareness about breast cancer and the screening programme in Kuwaiti women.

Chapter 8 synthesise the data and the results from all three studies and recommends measures to optimise awareness about breast cancer and breast cancer screening in Kuwait.

In order to appreciate the context of breast cancer awareness and screening in Kuwait, an overview of breast cancer follows in the next chapter.

# Chapter 2 Background and Breast Cancer Overview

### 2.1. Introduction

Breast cancer is one of the most prevalent types of cancer globally. According to the United Nation Global statistics, breast cancer is the most common malignancy among females and among the top three leading causes of death in females along with cardiovascular diseases, infectious and parasitic diseases. Although breast cancer occurs in men, it is mostly rare. Most breast cancers originate in the duct system of the breast, but it can also occur in other tissues in the breast. It may spread to the lymph nodes; i.e. the axillary lymph nodes, and this can lead to metastasis of the cancer and its spreading in other parts of the body (NHS, 2019). Treatment of breast cancer usually includes surgically removing the mass, lumpectomy, or removing part or the whole breast (NHS, 2019). Other treatment includes chemotherapy, which may take place before or after surgery, depending on the spreading ability of the tumour. Radiation therapy and hormone therapy are also utilized depending on stage and tumour growth, (NHS, 2019).

Early detection of the tumour growth is very important as early detection improves outcomes and survival. Survival rate for patients with stage I/II would be for 98% and 90% respectively 5 years after diagnosis (UK, 2020). Therefore, governments and healthcare organizations in GCC countries have been intensifying the efforts to encourage females over the age of 40 and above to perform mammography screening for their breasts. However, in other parts of the world as in USA, mammography screening is recommended for females aged 50+ years (CDC, 2020).

Globally, the month of October has been dedicated as breast cancer awareness month and campaigns that encourage females to be 'breast aware' and participate in breast cancer screening take place every year. Regular self-examination and mammography facilitate early diagnosis, and thus have a higher survival rate and more chances of accessing successful treatment (NHS, 2019). Apart from the health and medical implications of breast cancer treatment, breast cancer has a detrimental impact on females' overall wellbeing. For example, undergoing breast surgery to remove the tumour and especially experiencing total mastectomy can lead females to have a negative body image (Kocan and Gursoy, 2016). In these cases, the females need the utmost support to cope with the disease and the negative perception they might have of themselves (Kocan and Gursoy, 2016). A lot of females choose to undergo breast reconstruction surgery as to keep a normal body image (Fang et al., 2013). Given the significant burden of disease, it is vital that evidence about the best ways to approach campaigns related to breast cancer awareness is gathered.

# 2.2. Global Breast Cancer Burden

The global cancer project (2008) found that compared to the 89.7 per 100,000 females in Western Europe, only 19.3 per 100,000 females in Eastern Africa were diagnosed with breast cancer (Ghoncheh et al., 2016). More recently Cancer Facts and Figures (2019) reported that the highest incident rates are usually recorded in the United States and Western Europe, while the lowest is shown in Africa and Asia. Historical trends show that the incidence of breast cancer rose between the 1980s-1990s possibly reflecting the increases in access to mammography screening, and it stayed stable but increased again in the second half of the 1990s, which the authors propose might be explained by an increase in use of menopausal hormones. Overall, it remains stable but might differ according to age and race (ACS, 2019).

## 2.3. Mortality

Estimates suggest that of all worldwide cancer deaths in 2020, 684,996 cases were due to breast cancer (Sung et al., 2021), making it the second highest cause of cancer death and the leading cancer-related death among females with a global mortality rate of 12.9% (Ghoncheh et al., 2016). Despite more breast cancer diagnoses in developed countries, it was reported that 50% of breast cancer cases and 62% of deaths happened in less developed countries (Vieira et al., 2017). In developing countries breast cancers are typically diagnosed at more advanced stages when metastasis has already occurred and therefore, they have poor prognosis and survival rates. In developed countries, such as England or Australia, diagnosis at stage III or IV is rare. In Eastern Europe 60% of females are diagnosed by stage II or III, while in Kenya and Uganda diagnosis is in the late stages with a higher mortality rate, where statistics shows that 69% of patients diagnosed in the late stages end up dying up to five years after treatment (ASC, 2019).

Such figures highlight the importance of early detection which can lower mortality and improve outcomes. Moreover, improvements in treatment and healthcare facilities together with earlier diagnosis led to improved survival and outcomes. Global trends highlight the discrepancy between developed and developing countries; although the incidence rate is higher in the developed countries, mortality is higher in developing countries. Advancing early detection globally will have a positive impact on breast cancer outcomes.

# 2.4. Breast Cancer in the Middle East and GCC countries

As the focus of this thesis is Kuwait it is important to outline breast cancer incidence and outcomes in Middle East and GCC countries. Breast cancer is the most common cancer in Arab females, and makes up around 17.7-19% of all female cancers in 2018 in the Arab states (Fearon et al., 2020). However, the typical age profile differs from that in the global North. Around 50% of the cases in GCC countries occur in females under 50 years (Hashim et al., 2018b).

Age-adjusted standardized incidence rates of breast cancer have increased in several Arab countries in recent years (Zahedi et al., 2020). In addition, according to the Gulf Centre for Cancer Registration which collates data from the Gulf countries, breast cancer is common in GCC countries, with Bahrain reporting the highest incidence, with 46.4 per 100,000 females followed by Kuwait with 44.4. The International Agency for Research in Cancer showed that breast cancer is the most common cancer in Kuwait and accounts for 22.7% of cancer in females (Organization, 2021). Breast cancer has the highest incidence and mortality rate, with 53.4 and 17.6 per 100,000, respectively. Although incidence rates are on the rise in the middle east, they are still less than those of developed nations. In 2016 breast cancer incidence among females in the Arab region was 28/100,000, globally 46/100,00 and 148/100,00 in western countries (Hashim et al., 2018a), and the rates are on the rise specially with the awareness campaigns that encourage screening and early detection, and the facilities provide better treatment.

### 2.5. Risk Factors Associated with Breast Cancer

According to Centre for Disease Prevention and Control (CDC) risk factors can be divided into two groups, those you can control (also known as modifiable risk factors) and those you cannot. Modifiable risk factors include physical inactivity, diet and weight, hormonal intake, alcohol consumption and reproductive history. Physical activity and leading a healthy lifestyle can decrease the risk of many diseases, including breast cancer by around 12-21% (National Cancer Institute, 2020). The American Cancer Society (ACS) suggests engaging in physical activities in order to maintain good health, most likely since it maintains a good hormonal and energy balance, and not doing regular physical activity increases the risk profoundly (ACS, 2019). Additionally, having a healthy and normal weight is recommended, especially after menopause (ACS, 2019). Following menopause fat tissue is a source of oestrogen. Thus, being overweight leads to more oestrogen production, which increases the risk of breast cancer, since oestrogen is the hormone responsible for the growth of breast cells (ACS, 2019). Sustaining a healthy diet will also help with maintaining a healthy weight, so it is recommended to limit the intake of fat and increase intake of vegetables and fruits.

HRT is also associated with an increased risk of breast cancer (ACS, 2019) as is the use of OCP (ACS, 2019). Alcohol consumption, specifically the daily consumption of alcohol also increases breast cancer risk by 10% (WHO, 2021). Further, a female's reproductive history is also associated with breast cancer risk, including getting pregnant after the age of 30, not completely breast feeding and not having a full-term pregnancy (ASC, 2019). Breast feeding is seen as beneficial since it reduces the females' menstrual cycle, and the longer one breast feeds, the better. The ACS suggests that for every 12-months breast feeding, the risk decreases by 4% (ACS, 2019). Furthermore, smoking has also been shown to increase the risk of breast cancer but not as prominently as the factors outlined previously, and no relationship has been observed between second-hand smoking and getting breast cancer (ACS, 2019).

Some factors, outside of personal control increase the risk of breast cancer including age and sex, genetics, family and personal history, breast density, bone mineral density and several environmental factors (Cancer Research UK, 2020).

Females in their 40s up until 80s are at higher risk for developing cancer. Inherited genetic mutations also play a role in developing breast cancer specifically those in BRCA1 and BRCA2 genes which increase breast cancer susceptibility (ACS, 2019). Although these mutations are rare (less than 1%), in the general population, they are more common in groups of a specific ethnicity. There are also some other inherited disorders that might raise the risk such as Cowden and Li-Fraumeni. Females with late menopause or early menstruation also have an elevated risk. Statistics show an increase by about 5% for each year of getting menstrual cycle earlier, and around 3% for each year of getting menopause later (ACS, 2019). This may be explained by exposure to reproductive hormones for a longer period. It is also important to note that getting pregnant at an earlier age than 35 is linked to less risk of breast cancer (ACS, 2019). Females with a family history of breast cancer, especially those with a first-degree relative (parent/sibling) are at an increased risk of 2-3 times (ACS, 2019). There is also a small possibility of developing breast cancer in the opposite breast if the females have a history of the disease (ACS, 2019).

Having a history of benign breast disorders also increases the risk of breast cancer since they are strongly linked with breast cancer risk (ACS, 2019). Females with greater breast density, as those with 26%-50% or greater than 50% of the average breast size are 1.6 to 2.3 times more at risk than females who have lower breast density (ACS, 2019). Areas where breast tissue is dense might not be screened well by mammography and detection may be compromised; it is recommended that females with high breast density use alternative screening methods, such as ultrasound, MRI, or digital breast tomosynthesis.

Environmental factors considered risk factors for developing breast cancer include previous exposure to radiation, Diethylstilbesterol (DES) intake, and night shift work. Elevated breast cancer risk exists for those who received high-dose radiation therapy to the chest for treatment of other diseases. This risk starts eight years after treatment and continues to exist for more than 30 years. It is also high in survivors of atomic bombs (ACS, 2019). DES intake was given as a treatment to some women, during the 1940s through the 1960s to decrease the risk of miscarriage. Studies have shown that DES increases the risk by 30% (ACS, 2019). Moreover, nurses who work the night shift or working as flight attendants have higher risk of breast cancer, related to the disturbance in the circadian rhythm (ACS, 2019). Melatonin, which is a hormone related to sleep regulations, is produced less in night shift workers in specific, since these workers are exposed to light during the night. It has been proved that it can inhibit tumour growth or the developments of news ones, which can therefore increase the risk of breast cancer (ACS, 2019).

It was especially important to look at the different ways to reduce and prevent breast cancer. Essential aspects of breast cancer prevention will be presented in Section 2.6. of this chapter.

# 2.6. Breast cancer prevention

### 2.6.1.Introduction

Efforts have shifted worldwide towards strengthening and promoting preventive medicine instead of curative medicine with the aim of preventing chronic illnesses and reducing the burden of disease (World Health Organization, 2006). For example, a breast cancer-screening program has been recently launched in Kuwait. This is a one-step strategy in implementing a preventive measure in the country. Females aged above 40 are encouraged to benefit from the screening program by undergoing mammography every 2 years. The service is provided at no charge for the local Kuwaitis. However, not all the females are familiar with the program (Saeed, et al., 2014) and some are reluctant to undergo screening in fear of illness.

Much research around the world has focussed on prevention strategies for breast cancer. Overall, estimates show that more than half of all breast cancers could be prevented through healthy behaviours and chemoprevention (Colditz & Bohlke, 2014) in addition to early detection and screening characterized by the awareness of females at early age. Research suggests that the importance of timing for prevention is concluded by the risk accumulation through premenopausal years and the burden of disease diagnosed among females aged <50 years (Colditz & Bohlke, 2014).

### 2.6.2. Awareness

In the UK, breast cancer awareness and knowledge have been assessed and findings have been consistent across studies. Awareness of breast cancer symptoms and risk factors were overall unsatisfactory (Adlard & Hume, 2003; Grunfeld, et al., 2002; Forbes, et al., 2011). Females had a limited knowledge of their risk of developing cancer, and of the risk factors and symptoms associated with it. More importantly, older women had poorer knowledge, which may explain why they sought help less promptly (Grunfeld, et al., 2002).

In addition, a large population-based survey of females aged 30 and above in East London found that breast cancer awareness was low overall; only 18% of respondents could identify five or more non-lump symptoms of breast cancer, only 14% knew that older age was a risk factor for breast cancer and 52% answered that they knew about the National Health System Breast Screening Program (Forbes, et al., 2011). In addition, almost half of the respondents mentioned that they would notice a change in their breasts, 23% noted checking their breasts at least once a month, and 73% said that they would seek medical help within one week of noticing a breast change (Forbes, et al., 2011).

The one study that explored breast cancer awareness and screening behaviours in Kuwaiti females, showed that many of the participants had some knowledge about breast cancer, and majority did not know what mammography was (Alharbi, et al., 2012). Poor awareness and knowledge have been associated with delay in symptomatic presentation of cancer, a more advanced cancer stage at presentation (Macleod, et al., 2009; Forbes, et al., 2014) and consequently in poorer prognoses and survival.

Cancer Research UK reported that three quarters of females invited for screening in UK participate in screening (UK, 2020), meaning that most females were receptive to screening, however, channels of breast cancer screening advertisement were not reaching a high proportion of the females.

One study carried out in Italy examined whether having a positive family breast cancer history is associated with health behaviours/screening practices found that contrary to expectation, females with a family history of breast cancer did not report healthier behaviours more often than those without a family history (Marco Bertoni, 2019). The study suggested that having a family history of cancer is not sufficient to change females' behaviours about physical activity, weight control and diet, smoking, and drinking, but it does influence their breast cancer screening behaviour (Marco Bertoni, 2019).

These results suggest the need to increase females' information and/or understanding that healthier lifestyles contribute to cancer prevention (Marco Bertoni, 2019). Awareness is not only about knowing how to lead healthy lifestyle and decrease the risk factors associated with developing tumours, but it also includes regular check-up and follow-up on overall health to be able to detect any lumps at early stages.

### 2.6.3. Screening practices

### i. Breast Self-Examination (BSE)

Females in the Middle East face a significant risk of high mortality rate from breast cancer, due to the delay in the diagnosis and the advanced stages of the disease at the time of diagnosis (Alharbi, et al., 2012). One of the methods used in GCC countries to detect early breast cancer is the BSE. Knowing that the most common symptom of breast cancer is a painless lump, females were advised to practice BSE for early detection especially as it may influence treatment, prognosis and survival rates in females with breast cancer. BSE is a simple inexpensive, non-invasive, procedure which involves little time and physical energy, and does not depend on professional help (Al-Naggar, et al., 2011). However, there is a difference in BSE encouragement between GCC countries and UK or USA where evidence is equivocal. In UK, although BSE is not recommended, doctors still advise females to be aware of their breasts so that if any changes occur, they can report it immediately. In GCC countries, BSE is considered one of the screening methods and females are encouraged to practice it.

One of the causes of increased incidence in breast cancer observed in Kuwait/GCC, aside from the change of lifestyle, is the improvement of early screening and diagnosis in some Arab countries (Hashim, et al., 2016). Awareness and practice of BSE is an important method of prevention of breast cancer or its early detection. Despite this, the literature still reports limited level of knowledge and understanding of BSE (Alshareef, et al., 2014). Particularly in developing

countries most females reported that they had not performed any breast exams before. The main barrier reported for not practicing BSE include lack of knowledge about BSE or not knowing how to actually perform BSE, other barriers included not having the symptoms to feel the urge to do an examination or being scared of finding something wrong (Al-Naggar, et al., 2011).

Furthermore, some studies aimed at scrutinizing the association of BSE and other screening methods and its effect in reducing the mortality rates concluded that in "technically advanced countries where adequate treatment is given, no screening modality is likely to be sufficiently beneficial to outweigh the harms of screening, especially false positives and over-diagnosis." (Miller & C.J., 2011) and that the benefits of early screening may outweigh the harm particularly for females ages less than 50 years old. No matter how effective the BSE actually is in decreasing the mortality rate, it remains a main tool for spreading awareness for the importance of breast cancer screening, especially among high-risk females.

### ii. Mammography

Screening to detect life-threatening disease at its early stages and thus having more chances to be curable is a fundamental measure to reduce mortality rates. Cancer- screening programs that are effective, could increase the incidence of cancer detected at an early stage and thus provide a better treatment which in return increases the chance for survival. The most common screening test for breast cancer is Mammography.

"Mammography is an imaging modality that uses low energy x-rays specifically for imaging of breast tissue. Mammography practice utilizes standardized views of the breasts to for the assessment of breast lesions. It is also used as a screening tool for the detection of early breast cancer in asymptomatic women. Each breast is examined separately and compressed against the film to obtain maximum visualization of masses or calcifications. Early detection of breast cancer allows early treatment and increased rates of survival" (WHO, n.d.). In fact case-control study design is increasingly used, showing reductions in the risk of breast cancer death varying between 32% and 48% in the evaluation of organized mammography screening programs (Otto, et al., 2012). An article by Otto et al, reported the results of the case-control study conducted in the Southwest region of the Netherlands to assess the effectiveness of mammography screening in reducing the risk of breast cancer mortality among females who had received at least one invitation to mammography screening. The findings provided robust evidence on the beneficial effect of screening in reducing the risk of breast cancer mortality among females who were invited and participated in national mammography screening program (Otto, et al., 2012).

In a similar study by Puliti and colleagues showed that service screening reduced the probability of breast cancer death with 45% among females invited for screening in 17 areas in central and northern Italy (Puliti, et al., 2008). Moreover, an evaluation of the National Health Service (NHS) breast cancer screening program in the East Anglian region UK showed a 48% reduction in the risk of breast cancer death (Allgood, et al., 2008) comparable with the estimate of 41% reduction for Breast Screen South Australia.

Modelling techniques have shown that both screening and advancement in treatment contributed to the fall observed in breast cancer mortality rate. However, studies are not able to isolate the contribution effect of treatment in mortality reduction. On the other hand, analysis of the mortality cases and their detection stage, and having gone through surgery showed that the method of detection and not the difference in therapy is an important prognostic factor for breast cancer, even after adjusting for known tumour characteristics (Paci, et al., 2005)

Although it may seem that there is no harm that would outweigh the benefits of screening for breast cancer, yet the debate over its advantages and disadvantages has always been going on. The main harm is usually related to finding false positives and what such a finding can bring about from anxiety and extra testing procedure for a healthy female. Primary care teams have an important part to play in encouraging females to attend for screening and in providing information, advice, and reassurance at all stages of the screening process (Marmot et al., 2013). Reasons for poor uptake of screening are not completely clear. However, some reasons are outlined below in section 3.7.

As much as regular screening is important for females all over the world, its availability and presence depend on the level of awareness existent in a certain region or community.

# 2.7. Perception of Breast Cancer

Studies about breast cancer, statistics, causes and effects in the Arab region are very scarce compared to those in the western countries. Research conducted in UAE, Saudi Arabia and Qatar, showed a lack of awareness about breast cancer, its symptoms and the importance of screening, especially with females from older generations and from low socio-economic status (Elobaid et al., 2014). In addition to the lack of awareness, a great fear of regular screening is caused by many cultural factors, misconceptions and misinformation about the illness.

Research studies have presented evidence that there are still many misconceptions, stigma and taboo surrounding breast cancer in the middle east and gulf region societies, which greatly affects the way members of the community view regular screening practices.

Females' perception of breast cancer has an effect on their pursual of screening and choice of treatment in case of positive diagnosis with breast cancer. Many females miss regular screening for breast cancer because of the negative perception associated with the sickness. In a study about breast cancer presentation and delays in the UAE, many females' testimonies reflected misconceptions and ignorance about the disease (Elobaid, 2016). Some females thought that they should only present for medical checks if they are bleeding or if they feel pain. Others felt the lumps but thought that since they are breast feeding, they would not be afflicted by the disease. Some even have not heard of the fact that cancer can affect the breasts. Certain females felt the symptoms and had the intention of seeking help but were uninformed of where to go and whom to tell (Elobaid, 2016).

Females often perceived themselves as minor to any treatment decisions, and occasionally underwent treatment against their expressed wishes (Obeidat and Lally, 2014). When it comes to treatment impacts several studies labelled the described breast cancer treatments as losses. For example, females described losing their hair, a breast, a normal life, fertility, independence, autonomy, physical attractiveness, and arm function (Obeidat and Lally, 2014, Fearon et al., 2020). These losses, especially hair loss and mastectomy, were perceived by respondents as negatively influencing their quality of life, physical well-being, body image and relationship with their husbands, if married (Fearon et al., 2020).

For some females, losing a breast was as equally shocking as learning of their diagnosis (Jassim and Whitford, 2014a) Arab females have been reported to describe breast cancer as a battle not just against sickness itself, but also against the stigmatisation they experienced which influence their perception about the sickness (Fearon et al., 2020).

It is important to note that the level of awareness and education are associated with perceptions about breast cancer and screening. The latter underscores the role of health education and spreading awareness about breast cancer especially among the feminine social networks and in the Arab society in general as being pivotal. This necessity is highlighted in a study conducted in the Saudi Arabia. The study showed how open Saudi females are regarding screening for breast cancer. In comparison to developed countries, the Middle East in general has low levels of females undergoing screening for breast cancer, especially mammography (Nouf Almutairi, 2019). A study conducted in Saudi Arabia in King Abdullah bin Abdulaziz University Hospital of 228 women of ages between 25 and 50 showed a higher acceptance of having mammography screening (Nouf Almutairi, 2019) It revealed that most participants were educated in university. However, there is no correlation between age and having history of breast cancer with their views regarding mammograms, but it rather showed that the higher the education these women had, the better beliefs they had regarding screening by mammograms, since they were better informed and aware about the disease and ways to prevent it (Nouf Almutairi, 2019). Also, females who were married and with higher incomes adhered more, mostly because of having the means to follow up on their health. The awareness in level is better than before between Saudi females, and the more they are educated about it, the more positive their perspective is towards screening for breast cancer using mammography. This shows how education plays a main role and should be taken more seriously in order to increase the percentage of females who will undergo screening.

Another study conducted on Kuwaiti females, shows that only 43% of females had a robust knowledge about breast cancer risk factors, symptoms, and types of screenings. However, around 59.9% of the females lacked knowledge about mammography, the proper age to start the screening and the frequency of screens per year (Saeed, 2014). Only 9.4% of the females were informed about the sideeffects of mammography. More than half of the females had fears and concerns regarding the x-ray procedure, and the painful compression and discomfort subjected to the breasts during a mammography, moreover the awkwardness and stress they would feel during the procedure for exposing their breasts (Saeed, 2014).

As to men's views, a study done in Qatar showed a general acceptance and encouraging attitude from men about females' self-examination and regular examination on the condition that it is done by a female physician and not a man. In fact, many have pressed on this idea, preferring screenings to be proceeded by other females and they would only revert to a man if it were a matter of life or death. In addition to that, men had a basic to general knowledge about breast examinations but lacked knowledge about the details of the procedure and the various types of examinations present, since only a few had further knowledge about the types of screening and the specifics about its procedures.

Ignorance and lack of knowledge are present in particular amongst females with low level of education and females from older generations could greatly affect their perception about the disease and thus lead to them fearing it or having misconceptions which would have serious consequences on their health because they are diagnosed at a late stage. However, the younger generation or females who have a high level of education and awareness about breast cancer, have greater acceptance of undergoing regular screening and thus preventing fatal consequences (Alhurishi et al., 2011).

### 2.7.1. Stigma and Social Taboo

The diagnosis for breast cancer is largely affected by social beliefs and cultural values. Some societies are more conservative than others, especially when it comes to the reputation of its females. We find this conservative mentality in the Middle Eastern region and Gulf area (Donnelly, 2017). Not only because breast cancer involves a sexual part of a female but also the word cancer is considered a taboo to be spoken about, that most of the time it is referenced as "that illness". Many cases of breast cancer in women have been delayed because of this cultural factor (Elobaid, 2014).

The perception and beliefs that the females' body is private and should be conserved and that breast cancer leads to death, adding to that the fear of the negative reactions of society in case of being diagnosed with the disease have great impact on the views of Arab men and females about breast cancer and the percentage of Arab females who undergo breast screening.

In the Arab societies the role of females was primarily viewed as being a daughter, a wife or a mother. However, a diagnosis of breast cancer threatens these identities and roles (Almegewly, et al., 2019). The principal priority for many Arab women was to protect and promote their family's wellbeing. There is suggestion that females initially conceal their diagnosis to protect others from distress and sadness, especially their children (Jassim and Whitford, 2014a). This switching of roles led to increasing disease burden. Disease burden is:

"The impact of health problem on a given population and can be measured using a variety of indicators such as mortality, morbidity or financial cost. This allows the burden of disease to be compared between different areas, for examples regions, towns or electoral wards. It also makes it possible to predict future health needs." (Knowledge and Education, 2017)

Moreover, when it comes to treatment the combination of the effects of mastectomy and the side effects of chemotherapy, such as loss of hair, decreased libido, and early menopause constitute a serious threat to a female's body image and femininity. A study on the psychosocial impacts of breast cancer on Omani women reported that many females were reluctant to inform their friends about the diagnosis and they preferred to only share the news with close family members. Another major concern observed in this study was "cancer stigma," which led to feelings of unattractiveness, self-consciousness, and solitude (Al-Azri, et al., 2014). Some of the participants believed that society viewed them with pity, which in turn caused limited interaction and isolation from people and the community. Negative attitudes, stereotypes, and discrimination toward cancer patients are common in some societies where they were referred to as "victims" unable to make any contributions to the community and some people even avoid working with them (Al-Azri, et al., 2014).

### 2.7.2. Male perception about female breast cancer

As to male views, in Qatar, a lot of male participants in research acknowledged the importance of screening but they also claimed that females are naturally shy about breast examinations out of modesty and mainly because breasts are a sensitive sexual part in the females' body. Adding to that, the men still valued their traditions mentioning that women need to ask for permission from the males in their family to go to the hospitals for check-ups (Donnelly, 2017).

What further proves the men's point of view is the female perspective in the study done in the UAE; one of the cases that was interviewed have reported that she had felt a lump, and went for an examination but when she found that there was only a male doctor, she turned back home, which delayed her diagnosis for another eight months when she went for a check-up as a breast cancer campaign was being held in her village (Elobaid, et al., 2016). Some participants were aware that the topic of breast cancer and cancer in general is very sensitive when it comes to Arab societies. Many men referred to breast cancer as "that disease" refusing even to call it by its name, which reflects the taboo surrounding breast cancer and other types of cancer. A participant of the study explained this taboo as the following:

"They used to name it 'that disease.' They don't like to speak about this disease and until now they don't like to talk about it; people are usually disturbed of these issues and even of the name of the disease. And that's why it is a problem to go and do the examinations or to say that someone is infected with this disease. . . It is shameful to ask about this disease and more specifically about women's disease . . . People don't like to name it; they call it: that disease. They don't pronounce the name cancer. They say: such or such is infected with this disease without pronouncing its name." (Donnelly, 2017, p.14).

The participants also clarified that in the Arab culture, discussing topics concerning sexuality and sexual parts of the body is considered taboo (Donnelly, 2017).

#### 2.7.3.Stigma

In UAE, females with breast cancer have faced many societal barriers, namely the dread of social marginalization and the worry of being abandoned by their partners, and these same barriers prevented them from seeking early help. A female mentioned that her husband blamed her for having the disease claiming that she must have committed a sin to get it. Others stated that family members avoided them because they believed that they were under an evil eye, a religious belief that illnesses inflict the victim which mostly comes from being envied by people. Some people also distance themselves of breast cancer patients believing that it is contagious. Others believed that if they recite the Quran, the disease will disappear. Moreover, breast cancer patients were even afraid to tell anyone that they are suffering from breast cancer to protect the reputation of their families and the future of their daughters. Many also were subject of ridicule from their social environment (Elobaid, 2014).

# 2.8. The role of healthcare professional

Since breast cancer has been known to be the most common cancer in females and poses a noteworthy issue in both developed and developing countries, another group of people should be considered. It should be pointed out general practitioners (GPs) and healthcare providers have an important role regarding early detection of breast cancer.

Research done in UAE mentioned two females being wrongly diagnosed which gave them misinformation about the types of symptoms they should consider serious (Elobaid, 2014). One participant testified that she went to the hospital to check for a small lump, and that she was told it was from milk production. Three years later, her lump got bigger and with another examination they diagnosed her with breast cancer. Another case mentioned that she took a mammogram and was told she had cancer and that they would later call her to refer her to a hospital, however she had never received a call for months leading to a delayed treatment (Elobaid, 2014).

Nevertheless, the healthcare system in the Gulf Region relating to breast cancer is developing slowly, but surely. Another study which focused on how knowledgeable GPs are regarding breast cancer aimed to study the method in which female GPs in primary healthcare centres in Riyadh, Saudi Arabia deal with breast cancer, specifically concerning screening, and diagnoses, along with their knowledge of risk factor of breast cancer, and their beliefs regarding clinical breast examination, breast self-examination and mammography (Saeedi, et al., 2016). In general, satisfactory results were shown with how GPs deal with breast cancer. All participants showed that they were knowledgeable about most of the risk factors and on how essential mammography is to screen for breast cancer, and how it should be recommended yearly for those who were above 40 years old. However, only 19.1% of them requested it for their patients since it was unavailable in some of the centres, or because of the absence of cooperation from patients, along with cultural reasons (Saeedi, et al., 2016).

It is true the role of primary care physicians should be more involved in directing the patients into screening for breast cancer, especially when they are at the recommended age, and follow up with them regarding this, and to follow with the guidelines implemented by the country about managing breast cancer, although some cultural or other barriers might be in the way. More studies should be implemented along Saudi Arabia and the rest of the Gulf Region concerning GPs as a method in encouraging and guiding patients toward early screening and breast examination along with raising awareness and trying to reduce the barriers that might arise, specifically the cultural taboo that might be a primary reason why patients might not follow up (Saeedi, et al., 2016).

#### 2.9. Improving awareness

The Middle East & North Africa (MENA) and Gulf Region, as well as the Arab society in general should work more to erase the stigma surrounding this disease, as well as work more in order to lessen the concern regarding females screening for breast cancer. Studies have shown that the more educated people are, specifically females, the more they have a positive perspective towards the subject of breast cancer, this is also true regarding the socioeconomic status in the UK, the higher it is, the more they are inclined to discuss it and undergo screening (Forbes, 2011). Also as mentioned above, studies have shown that men are aware of the importance of screening for breast cancer, but a lot are still resistant to the idea of male doctors being the ones doing the check-ups (Jassim and Whitford, 2014a). Awareness campaigns are also required since many misconceptions are present regarding breast cancer and methods of screening, which in turn leads many females to be hesitant in seeking help when they notice anything unusual regarding their breasts. It should be noted that including females who are survivors of breast cancer and them educating and sharing their experience can be of an immense help, since their knowledge and familiarity with their journey can help encourage others to view things differently and lead them to remove their prejudice and misconceptions (Alhurishi, et al., 2011).

## 2.10. Summary

Breast cancer is a very common disease in the world and although it can occur in men, it is one of the leading causes of death in females. It has many risk factors, some that can be controlled or modified while others cannot. Early screening and detection are extremely important and can greatly affect survival rate, so yearly mammography and check-up is recommended for females above age 40 (El Saghir, et al., 2007). There is inconsistency between developed and less developed countries in both incidence and mortality rates.

Although incidence rates are higher in developed countries due to more awareness and early screening, mortality rates are higher in developing countries due to diagnosis in the late stages. Treatment consists of having surgery to excise the tumour, chemotherapy and sometimes radiation and hormonal therapy, depending on the type/stage. Compared to western countries, especially the United States and Europe, the MENA and GCC regions still register lower incident rates, but prevalence is increasing. Breast cancer in GCC Countries and specially Kuwait is the number one cancer in females and overall. Providing awareness and encouraging screening is playing a role in increasing early diagnosis for Arab females. Detailed evidence on screening and awareness in Kuwait is lacking, emphasizing the gap in evidence and therefore the need for your research.

This thesis provides a comprehensive insight into breast cancer awareness and its screening methods among females in Kuwait. In order to understand the context of the research setting, the next chapter presents an overview of the Kuwaiti health system.

# Chapter 3 Kuwait Healthcare System

# 3.1. Introduction

Kuwait's Ministry of Health (MoH) is the main governing body that oversees the public healthcare system. It is one of the largest ministries in Kuwait established around 80 years ago. The MoH runs 74 primary health care centres (Hendi B, 2020) including services such as GPs, dentistry, maternity care, nursing care, preventive care, pharmaceuticals, and family medicine. There are six major hospitals which provide secondary healthcare: Al Jahra hospital, Al Amiri hospital, Al Mubarak Al-Kabeer, Al Sabah, Al Fawraniyya, Al Adan and specialized centres. The MoH covers almost 85% of the healthcare expenditure for its people. The government also funds treatment of its citizens abroad with private sector expenditure on healthcare treatment abroad long being a concern for the Kuwait government (\$1.5bn was spent to fund 11,000 medical trips abroad in 2014 (World Health Organization WHO, 2015). Although Kuwait is categorized by the World Bank as a high-income country, its total expenditure on health as a percentage of gross domestic product (GDP) in 2014 was 3.04% which is considered relatively low as compared to the average of 9% and more in advanced economies (World Health Organization WHO, 2015).

In 2015 a Ministerial Decree (No. 233/2015) was issued which set out a mandate to develop a new 'National Strategy for Health and Health Care' in the year 2016. However, due to the high turnover of MoH ministers (the average minister lasts between 9-12 months) it has been challenging to develop and commit long term strategic plans. With the help of the World Health Organization (WHO) the MoH has announced new healthcare strategic priority areas, which are currently being developed into a full strategy. Kuwait has also awarded projects worth \$11billion (bn) in the construction of new infrastructure for healthcare as it seeks to prioritize the transformation of its healthcare sector.

# **3.2. Healthcare Organisation 3.2.1.Role of Kuwait's ministry of health**

The MOH in Kuwait was established in 1936. Being third after the Ministries of Education and the Interior, MoH is one of the prime ministries in Kuwait, providing

the majority of healthcare services to the population. The main role of central MoH is to regulate, control, evaluate, finance, allocate resources, and deliver care services (LSE, 2018). The MoH in Kuwait is unique in that it is the primary funder and provider, as well as sole regulator of healthcare services (WHO, 2017). This arrangement has given MoH responsibilities that are overwhelming and conflicting. Yet, the strength of the Ministry lies in the provision of healthcare and the ability to prioritize reforms for an improved health system. MoH's structure involves twelve functional divisions embracing 42 central departments and offices at the central level. In addition, it is important to highlight that the private healthcare sector in Kuwait is growing, however, at present, it is not sufficiently regulated to prevent adverse outcomes, such as risk selection (LSE, 2018).

#### **3.2.2. Healthcare system governance**

While the health sector is governed at the national level by the MoH, there exist six health regions whereby the health sector is governed at the local level. A health region is a decentralized administrative unit with significant autonomy related to tasks within the following areas: financing, administration, workforce training, health information, management and service delivery (WHO, 2017). It is also responsible for supervising the private healthcare sector (World Health Organization, 2006). Each health region is headed by a Director of Health. The health regions will be discussed in more detail in the section 3.2.8.

The Ministry of Finance and the Supreme Council of Planning and Development are also considered key stakeholders that indirectly influence the health sector in Kuwait. While the Ministry of Finance is responsible for distributing public funds to the MoH and other public bodies undertaking tasks within the healthcare sector, the Supreme Council of Planning and Development develops five-year national plans outlining high-level frameworks which are then distributed across government ministries, including the MoH (LSE, 2018).

Other organizations also have some responsibility for providing healthcare, for example, the Ministry of Defence provides care for its entire staff. The Kuwait Oil Company developed its own hospitals for its employees and the Ministry of Social Affairs provides care targeted at the disabled and elderly (World Health Organization, 2006). In terms of legal framework, the Health Committee within

the General Assembly is responsible for legislation and oversight of the executive branch, which covers the MoH.

Other organizations are less influential in the decision making, yet crucial in the overall health sector skeleton including the Public Authority for Food and Nutrition (PAFN), Healthcare professional associations, Academic institutions, and Private healthcare providers such as Dar Al-Shifa Hospital, Al Salam International Hospital, Al Omooma Hospital, New Mowasat Hospital, Hadi Clinic, and International Health Services (IHS).

Kuwait's national health plan 2010-2014 aimed to increase accessibility of healthcare services across the regions in Kuwait by providing a strong infrastructure of health centres, skilled healthcare professionals and advanced technological advances in the health sector. In addition, the healthcare sector forms a central part of the government's Kuwait's Development Plan 2015-2020. The plan includes the construction and extension of hospitals at a cost of \$1bn. The Ministry of Public Works has also allocated \$4.2bn to build nine additional hospitals, which will boost the number of beds available in public facilities by 3334, while creating an estimated 15,000 new jobs (Group, 2022).

The sector however is not free from major challenges. Around 80% of deaths in Kuwait are due to non-communicable diseases (NCD). Reasons for this might include a weak primary care system (WHO, 2017) where the emphasis on health promotion and prevention is traditionally not found, and a lack of policy reform that prioritizes preventive care. Currently Kuwait is still behind other high-income countries with regard to the monitoring and supervision of the healthcare sector. There are no recognised standards for maintaining privacy and confidentiality of medical records, licensing of healthcare professionals, liability, or suitable payment mechanisms for healthcare services (Almutairi, et al., 2019).

According to a thorough review done by the London School of Economics on the health care sector in Kuwait, the major challenges in governance are outlined by having (LSE, 2018):

- strategic policy making decisions not evidence-based, rather they are politically motivated.
- the Ministry of Health's strategic vision for the system neither communicated nor shared among stakeholders and the public.

- key leaders and policymakers within the Ministry of Health continually changing, which prevents continuity of policies.
- the Ministry of Health's numerous responsibilities fosters inefficiency within the healthcare sector.
- policies within the healthcare sector are developed without consulting key stakeholder groups, therefore their execution is not well planned.
- governance of public health in Kuwait is fragmented and needs to be consolidated.
- the private healthcare sector is not sufficiently regulated to prevent adverse outcomes.

# 3.2.3. Health Service Provisions

It is important to note that for this section the health service provisions referred to are only public services provided by the MoH and its allied centres.

For non-emergency cases, patients must first access care from a family physician or GP within a primary healthcare centre located within the patient's catchment area, as identified by their civil identification document (ID) card free of charge. If further medical treatment is required, the family physician or GP must refer the patient to a secondary hospital, also located within the catchment area. However, non-Kuwaitis are charged one Kuwaiti Dinar (3 USD) for visiting the public primary health centre, and two Kuwaiti Dinars (K.D) 6 USD for visiting public clinics of hospitals and specialized health centre. Alternatively, a patient with private health insurance may directly receive services from a private provider.

There are 74 government-run primary healthcare centres (PHCCs) spread over the country. These provide services for approximately 34,000 inhabitants per catchment area who are registered through the national heath registration system.

Currently the focus of the primary healthcare service is on immunization, preventative care, providing family physician services, dental services, pharmacy, childcare, maternal health care, laboratory services and radiology. The total number of visits to PHCCs in 2013 exceeded 15 million, the majority being for Kuwaitis (WHO, 2013).

Kuwait provides secondary care through six general hospitals that have an emergency department, inpatient and outpatient services. Hospitals in Kuwait cover a full range of medical services including Internal medicine, ENT (Ear, Nose, and throat), general surgery, dental services, dermatology, paediatrics, ophthalmology, orthopaedics, physical medicine, trauma, and psychiatry. Public hospitals accounted for around 72.4% of all discharges (MoH, 2014). These hospitals consume the largest proportion of the health budget, despite moderate bed occupancy and high pressure on primary care services (WHO, 2013).

Tertiary healthcare is the third level in healthcare in Kuwait. It includes 11 specialized hospitals and centres. These centres provide all citizens and residents with specialized healthcare services including obstetric care; specialized chest care; psychiatric care; neurosurgery; cancer care; transplantation and a specialist burns treatment centre. These services are provided free of charge for Kuwaiti citizens.

## 3.2.4. Health Information System (HIS)

The consideration of HIS in Kuwait dates back to 1995 when the MoH launched its first centralized national HIS based on patient information database including both nationals and expats (Almutairi, 2011). This work has been handled by the Department of Information Systems at MoH with the ultimate goal to develop a standardized electronic healthcare record (EHR) system used across primary, secondary and tertiary levels of care in one integrated HIS (Almutairi, 2011). In 2001 the system was successfully implemented in the primary healthcare centres. EHRs set out a list of diseases according to the WHO's International Classification of Diseases (ICD), physicians accessing EHRs have access to a list of chronic conditions the patient suffers from, medications he/she takes (with the ability to retrieve medication over the last six months and last prescription), allergies, and vaccinations (LSE, 2018). Secondary healthcare centres have made use of the EHRs however through outsourcing this responsibility to the private sector. Given the latter the information obtained by the secondary healthcare centres were not linked to those of the PHCCs nor to the MoH Department of Information Systems. Currently, only inpatient discharge summaries are sent to the National Centre for Health Information (Health & Vital Statistics Department) within the MoH (LSE, 2018).

The overall HIS system in Kuwait is considered 'adequate' given the availability of different data sources and presence of information products, however this element of the healthcare sector suffers many challenges. The healthcare workforce is inhibiting advances in healthcare IT due to skill shortages and resistance from workers (LSE, 2018). Despite three hospitals introducing EHRs, patient records (discharge summaries) are frequently completed manually. In addition, healthcare initiatives are not adequately advertised to the public leading to low rates of uptake (LSE, 2018).

Advancing healthcare IT has been an area of focus among the MoH in recent years as evidenced by current and future developments. However, collection of data to inform policy has not been exploited (LSE, 2018). In order to create an integrated electronic communication network to link all sectors and departments of the MOH including clinics, hospitals, and medical centres, one EHR used across primary, secondary and tertiary levels of care shall be is to be developed. This has a potential to create and maintain a central patient database that can be used by all stakeholders for service planning, providing, evaluating, and quality monitoring (Almutairi, 2011).

## 3.2.5. Healthcare indicators

#### 3.2.5.1. Mortality

Life expectancy (LE) at birth for the entire population in Kuwait was 74.7 years in 2015 (WHO, 2015) when broken down by gender, figures show that LE for females is higher than men in Kuwait (75.9 years vs. 73.6 years) (WHO, 2015). Kuwait has been experiencing a growing improvement in its mortality and infant mortality. Although it is positive that both men and women in Kuwait have experienced increases in LE since 2005 (from 72.7 and 74.6 years, respectively), the LE at birth for Kuwaitis is still lower than its neighbouring GCC countries as depicted in Figure 3.1.

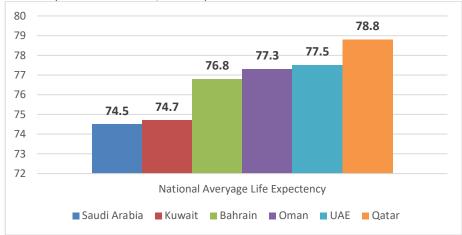


Figure 3.1: A chart depicting the average national life expectancy at birth in GCC countries (Source: WHO, 2015)

Under 5 years mortality rate per 1000 live births are lower in Kuwait than most of the WHO Eastern Mediterranean Region (Afghanistan, Bahrain, Djibouti, Egypt, Iran, Iraq, Jordan and Kuwait) yet compared to its neighbouring GCC countries Kuwait still needs to improve further (see Table 3.1)

# Table 3.1: Child Mortality rate in Kuwait compared to GCC countries and WHO Eastern Mediterranean Region (Source: WHO, 2015)

Under-5s mortality rate per 1000 live births, 2013		
WHO Eastern Mediterranean Region	55.2	
Saudi Arabia	15.5	
Oman	11.4	
Kuwait	9.5	
Qatar	8.2	
United Arab Emirates	8.2	
Bahrain	6.1	

#### 3.2.5.2. Trends in cause-specific mortality

The Global Burden of Diseases Study, established by WHO and the World Bank, has identified a clear global shift since 1991 from deaths predominately due to communicable disease (CD) to deaths mainly due non-Communicable Diseases (NCD) (Mokdad, 2014). Two thirds of the world's deaths are due to NCDs, and this

is no different in the Arab world where in developed countries like Kuwait and other GCC countries, ischemic heart disease and other NCDs are the highest causes of death (Mokdad, 2014).

Cardiovascular disease (CVD) is the leading cause of death in Kuwait, where 41% of deaths are due to CVD. The second most common causes of death are cancer, communicable, maternal, perinatal and nutritional conditions, which includes many of the NCD and risk factors of NCD. Injuries, predominated by road traffic injuries, are the third most common cause, at 13% (see Figure 3.2) (WHO, 2016).

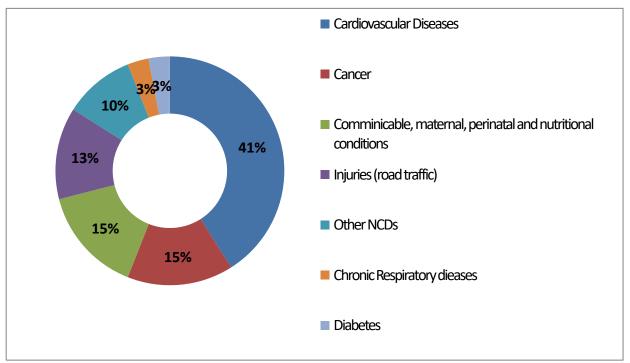


Figure 3.2: The contribution of different causes of death to mortality rates in Kuwait (%), WHO, 2016

### 3.2.6. Non-communicable diseases and risk factors

In 2015, 77.2% of deaths in Kuwait were attributed to NCDs, up from 75.3% in 2005 (LSE, 2018). Chronic diseases such as cardiovascular, diabetes, cancer and respiratory conditions (WHO, 2015) are the leading causes of deaths in Kuwait (see Figure 3.2). Risky health-related behaviours are known to lead to poor health and increased likelihood these diseases that could be prevented. Smoking, poor dietary habits and inadequate physical exercise are the main risk factors associated with the development of NCDs such as diabetes, CVDs, cancer, respiratory diseases and others. Thus, interest to target the risk factors associated

with such diseases is increasing, particularly those related to obesity, physical activity and dietary habits due to increased fast food consumption.

Kuwait has one of the highest percentages of obesity in the world; nearly 40% of the population is obese. With the absence of physical activity, the widespread consumption of fast food, government policies in the past did not help the shift into healthy lifestyle at the national level. Inadequately designed pedestrian walkways and bicycle routes, limited parks and facilities to cater to sporting events, no regulation on the amount of sugar and salt in foods and beverages, in addition to sedentary school environment (physical education is often optional and not viewed as important as other classes), are all areas that the government can tackle to make a change. Certain steps have been taken to achieve this goal such as restricting the amount of salt used in all bread products by the Kuwait Flour Mills and Bakeries Company (initiated by the Public Authority for Food and Nutrition). As well as preparing national marathon and sports events.

Table 3.2 below shows the rate of some risk factors associated with NCDs in Kuwait as compared to other WHO Eastern Mediterranean Region (EMR). As depicted by Table 3.2, raised fasting blood glucose (FBG) and raised blood pressure is higher in Kuwait than in the WHO EMR - this is true for FBG in particular. This could be attributed to the high levels of obesity in Kuwaiti adults, with almost 35% of men and 46% of women are obese. More than 80% of adults in Kuwait and other Arab countries reported eating less than the WHO recommended level of five servings of fruits and vegetables per day. Obesity is alarmingly prevalent in Kuwait and high levels of physical inactivity are reported (Abdul-Rahim et al., 2014). A recent study showed that the contribution of obesity, hypertension, high cholesterol and raised FBG levels to disability-adjusted life years (DALYS) has increased between 1990 and 2013 (Mokdad et al., 2014). The prevalence of smoking is very low amongst Kuwaiti females and alcohol consumption is almost negligible.

	WHO Eastern Mediterranean Region	Kuwait			
Raised fasting blood glucose (%)					
Male	13.4 21				
Female	13.8 18.9				
	Raised blood pressure (%)				
Male	Male 27.5				
Female	26.4	22.6			
Obesity (%)					
Male	14.6	35.5			
Female	23.6	45.9			
Alcohol per capita consumption (liters pure alcohol)					
	0.7	0.1			
Smoking any tobacco product, aged over 15 (%)					
Male	36.2	35			
Female	2.9	4			
Physically inactive (%)					
Male	Not reported 56.9				
Female	male Not reported 72.1				

Table 3.2: Rate of some risk factors associated with NCDs in Kuwait as compared to other WHO EMR (Source: WHO, 2015)

# 3.2.7. Healthcare Education and Workforce

Table 3.3 represents the healthcare workforce in Kuwait as compared to other WHO Eastern Mediterranean region and GCC countries. As the figures show, Kuwait has an average density per 10,000 population for physicians, nurses and dentists, higher than that of WHO EMR and most of its neighbours. However, it has a lower density when it comes to pharmacists.

Region/Country		Physicians	Nursing and Midwifery	Dentistry	Pharmacists
WHO	Eastern	12.7	18.0	1.9	6.5
Mediterranean	Region*				
2007-2013					
Kuwait		19.5	47.3	6.0	4.8
Bahrain		9.4	24.5	2.5	1.6
Oman		15.4	33.5	18.5	3.5
Qatar		19.6	57.0	5.7	9.3
Saudi Arabia		25.7	52.1	4.0	7.0
UAE		15.6	30.6	3.1	3.7

Table 3.3: Health care workforce comparisons: Density per 10,000 population for the listed professions

2007-2013 (Source: WHO, 2014; 2015)

The Kuwaiti healthcare system has physician and nurse ratios comparable to that of the Organization for Economic Cooperation and Development (OECD) uppermiddle income countries. While there is no comparable data for dentists, Kuwait appears to be reasonably well supplied with respect to dentists and also for pharmacists and pharmacy technicians. Moreover, although managerial and technical staffs were predominantly Kuwaiti, the medical, nursing and other support staff were dominated by non-Kuwaitis. To address this, Kuwait's government has implemented a national approach of Kuwaitization mentioned earlier to increase the number of the Kuwaiti medical staff in the health sector and reduce the demand gap among certain healthcare professions (WHO, 2006).

## 3.2.8. Health regions

Kuwait is divided into six health regions/districts namely: Capital, Hawally Ahmadi, Jahra, Farwaniyya and Sabah. Each region acts an "independent decentralized administrative unit" (WHO, 2006).

The regions are responsible for the administration and delivery of all health and support services, as well as strategic direction (WHO, 2006). The regions are also responsible for information technology (IT) support and staff training. Primary

Healthcare (PHC) is delivered through a series of health centres, with general or family health clinics, maternal and childcare clinics, diabetic clinics, dental clinics, and preventive care clinics, school health services, and ambulance services. The following is a brief description of the resources of each health region.

#### 3.2.8.1. Health region one

The first health region, Kuwait City, is the Capital of Kuwait which has an area of 200 km<sup>2</sup> and a population of 534,964. It is home to Kuwait's main financial and business sectors. It was recorded by the World Health Organization as a healthy city in 2014 (Arab Times, 2017; Globe Media Ltd, 2014).

#### 3.2.8.2. Health region two

Hawally health region has an area of 82 km<sup>2</sup> with a total population of 890,000. Middle and young aged citizens dominate this modern city which is characterized by quality services (Kuwait E Gate, 2017).

#### 3.2.8.3. Health region three

Ahmadi Health region is located in the southern part of the country and has an area of 5,120 km<sup>2</sup> and a total population of 809,353. It has a total of 20 PHCCs. It forms an important part of Kuwaiti economy as several Kuwait's oil refineries are located there (Kuwait E Gate, 2017).

#### 3.2.8.4. Health region four

Jahra is located to the northwest of the other governorates and has an area of 11,230 km<sup>2</sup> and a total population of 491,392. It includes the Bubyan Island and is the largest governorate in Kuwait; the region occupies most of Kuwait's arable land.

The central administration of PHC is located in Jahra health region in Saad Al Abdallah (Kuwait E Gate, 2017), which provides only six kinds of services: primary care, pharmacy, dental care, medical devices sterilization services, and specialized clinics for chronic disease such as diabetes.

#### 3.2.8.5. Health region five

Fawraniyya health region has an area of 190 km<sup>2</sup> and the largest population with around 1,077,377 residents. It is Kuwait's main residential area and forms an important part of Kuwait's commercial activities.

## 3.2.8.6. Health region six

Sabah health region has an area of 1.5 km. It is composed of secondary care facility providing general secondary care services and specialized clinical services provided by specialized tertiary health care centres.

# 3.3. Summary

This chapter has provided an overview about the Kuwait Healthcare service to provide context to this study exploring breast cancer in Kuwait. The following chapter 4 will discuss the methodology approach of this thesis.

# Chapter 4 Methodological rationale

This chapter addresses the different methodological approaches used in this thesis. It starts by describing the philosophical assumptions and paradigms applicable for each method and the rationale behind using each of them. Mixed and multi-methods are discussed and why the multi-method approach was chosen for this thesis.

# 4.1. Introduction

Research methods are defined as procedures or approaches one can use to collect data or information about a specific topic (University of Newcastle Library Guides UON, 2020). Several data collection methods are available and should be matched to the research questions and aims. Data are then analysed to provide evidence and arrive at conclusions. Methods include systematic reviews of literature, quantitative research or qualitative research and in some studies, mixed or multiple methods are used. It is important to understand the beliefs or philosophical assumptions considered before applying these methods.

# 4.2. Philosophical assumptions

There are certain beliefs, often referred to as philosophical assumptions that should be taken into consideration before researchers undertake their research. Typically, four sets of beliefs and assumptions are considered, these include epistemology, ontology, methodology and alternative method claims. Collectively those assumptions/ beliefs are employed into research via an underpinning *paradigm*, which are often also labelled as interpretive frameworks or worldviews (Creswell & Plano Clark, 2011).

Paradigms are ways or ideas used to shape our world and explain something. They include concepts, research methods or postulates creating a theoretical framework. They are a *"basic set of beliefs that guides actions"* (Guba, 1990). The most common paradigms being positivism, constructivism, interpretivism and pragmatism. They further can be classified by addressing their ontology (nature of reality), epistemology (knowledge) and methodology (process of conducting research). Positivism is a paradigm used in research philosophy methods. The knowledge obtained relies on facts. This is achieved through observation and measurement. The researcher is required to collect and interpret the data in an objective way. Then the observed data should be quantified leading to statistical analysis (BRM, 2011). Quantitative research relies on the positivism paradigm. Social constructivism, also called "interpretivism", is a belief or paradigm whereby the individual uses the surrounding world to pursue the research. The aim of the research is subjective and depends on the researcher's experiences with the surroundings. For this reason, qualitative research is described as interpretive research. Pragmatism focuses on the outcome of the research and involves multiple data collection as in a mixed-method approach. Further description about paradigms and their applicability in research studies is provided in Table 4.1.

	Quantitative	Qualitative	Mixed method
Philosophical assumptions	Postpositive knowledge claims.	Constructivist advocacy or participatory knowledge claims.	Pragmatic knowledge claims.
Strategy of inquiry	-Experimental design. -Non-experimental design e.g., survey.	-Narratives. -Phenomenology. -Ethnographies. -Grounded theory. -Case studies.	-Sequential. -Concurrent. -Transformative.
Specific research method	<ul> <li>-Predetermined.</li> <li>-Closed, instrument based questions.</li> <li>-Performance, attitude.</li> <li>-Observational and census data.</li> <li>-Statistical analysis.</li> </ul>	-Emerging method. -Open question. -Interview, observation, document, audio- visual data. -Text and image analysis.	-Both predetermined and emerging methods. -Both close and open questions. -Multiple forms of data drawing on all possibilities. -Statistical and text analysis.
Motivations for selection	-Test a theory or explanation. -Identify factors that influence an outcome. -Understand the best predictors of an outcome.	-Understand a concept or phenomenon due to insufficient or new research. -Identify unknown variables.	-Generalize findings to population whilst developing a detailed explanation of the concept or phenomenon.

 Table 4.1:Paradigms and their applicability in research studies (Adapted from Creswell 2003)

Due to the holistic nature of the research question "Breast cancer awareness in Kuwait" the best approach to use was a pragmatic approach, combining systematic review, quantitative and qualitative research methods. The focus was to find out what we already know about breast cancer awareness in GCC countries, to examine the awareness among a cross-section of Kuwaiti females and to explore the suitability of awareness programs in a Kuwaiti context; a multi-method approach was the most appropriate for these aims. Before discussing the methodological considerations of each of the included studies; systematic review, quantitative survey, and qualitative study with key stakeholders; mixed and the multi-method approaches are outlined.

# 4.3. Mixed-Methods and Multi-Methods

Mixed or multi-method research are considered as an important tool in answering research questions where studies in combination can contribute to a better understanding of a research problem compared to research that is based on only one methodological approach (Creswell, 2015). While often few distinctions are made between mixed and multi-methods it is important to outline the differences between these two approaches and to provide the justification for the use of a multi-method approach in this thesis.

The best way to understand mixed-methods is by the definition provided by Creswell (2015), where he stated that it is "an approach to research in the social, behavioural, and health sciences in which the investigator gathers both quantitative (closed-ended) and qualitative inputs (open-ended) data, integrates the two, and then draws interpretations based on the combined strengths of both sets of data to understand research problems." (Creswell, 2015).

Traditionally multi-method was defined as "the use of several studies within the same paradigm: for example, several qualitative studies or quantitative studies but not the two together" Creswell, J.W. (2015). A concise Introduction to Mixed-Methods Research. Thousand Oaks, CA: SAGE Publications. However, for Morse, multi-method research *'consists of two or more studies using different methods, which address the same research question or different parts of the same research question or programmatic goal.'' (Creswell, 2015).* 

Mixed-methods research therefore combines both the qualitative and quantitative research techniques to offer holistic research in which data are integrated and analysed to provide a more in-depth understanding of the subject under study. Although similar to mixed-methods, multi-methods refer to the conduct of several sub-studies that can be viewed as stand-alone enquiries. Often however, the terms are used interchangeably. Multi-method research combines two or more methods

but is not limited to both quantitative and qualitative being present (Stange et al., 2006). However, each approach can stand alone and answer the broad research questions (Pastor, 2004). The multi-method approach provides the means to answer a series of related questions and to examine them from slightly different perspectives. Bazeley has defined multi-method as "... when different approaches or methods are used in parallel or sequence but are not integrated until inferences are being made" (Anguera et al., 2018).

Typically mixed-method studies provide opportunities for triangulation (Duchon, 1988), where the research questions are answered using different methods. The use of different methods therefore strengthens and confirms the results and conclusions. Mixed-methods studies have become increasingly common over the last 20 years particularly in the field of intervention studies, where qualitative studies sit alongside traditional experimental studies to evaluate the 'softer' aspects of interventions. Central to the mixed-method studies is the sequence in which the component parts are carried out, where one typically follows the other. However, mixed-method approaches are often criticised for lacking methodological precision and therefore amount to a 'hodgepodge' mixed-method studies and more recently, multi-method studies, are useful approaches to answer complex research questions (Anguera et al., 2018). Nevertheless, various studies that have shown that there is a misperception between the definition of multimethod and mixed-method (Sale et al., 2002).

Therefore, the distinction between mixed and multi-method is not simply one of terminology, but importantly (and particularly for this PhD) in conceptualisation. Inherent in mixed method is the integration of study findings; both quantitative and qualitative data are gathered and combined in a cohesive manner in order to reach an understanding of the goal of the research. While multi-method may bring findings together, it is not essential to interpret findings collectively, instead different methods are used to discover different objectives of the research goal.

#### 4.3.1. Advantages of multi-method research

Using the multi-method approach in research comprised different scope of methodologies (Mike-Meyer, 2020). By using a different methodology approach, the quality and the strength may increase because different methods allow

different angles to be visible. It has been recommended to be used in research in order to understand a multifaceted topic (Orton et al., 2011). Multi-method approaches therefore have several advantages. Adopting multiple methods in research allows a wider set of research questions such as what, how and why. This, in turn helps to achieve a more comprehensive approach to the phenomenon under study. Multi-method aids our understanding of the subject from several viewpoints and permits a well-rounded knowledge of the subject. Lastly, it facilitates discovery. When research produces unexpected results and discovering new outcomes, it can be considered a major advantage since it can lead to future research. Thus, the multi-method approach is helpful in a number of different ways as the method used in research (Gil-Garcia and Pardo, 2006).

#### The Use of Multiple Method Approach in this PhD

Matching methods with research questions is an important aspect of any research study as this allows research aims and objectives to be met and to reach adequate and cohesive conclusions (Anguera et al., 2018). The aim of this thesis was to address a series of questions about breast cancer and breast cancer screening in Kuwait. As such, a series of studies, which used different methods, to enable a holistic picture to not only assess awareness but also to explore potential solutions was planned. The data obtained from each approach was sufficient on its own and led us to a set of useful conclusions and recommendations. Yet, brought together the findings from the individual studies allowed a synthesis that strengthened the overall results.

Before discussing the purpose of using each study approach, it is helpful to revisit the objectives of the PhD:

- 1. To provide an understanding about the awareness, beliefs and attitudes breast cancer and breast cancer screening behaviour in the Gulf region (Systematic review).
- 2. To assess breast cancer knowledge and awareness among female residents of Kuwait (Quantitative survey study).
- 3. To identify the potential approaches to improve breast cancer awareness (Qualitative study).

The systematic review of the literature was used to explore the current information available in peer reviewed literature about breast cancer and its associated awareness and activities. whereas the quantitative survey explored a different edge whereby the information obtained were used to analyse the breast cancer knowledge among female residents of Kuwait. Finally, the aim of the qualitative interviews was to investigate the views of key stakeholders in the healthcare sector whose remit included managing breast cancer. The interviews used a novel methodology of utilising a series of breast cancer awareness campaigns (in video form) to prompt general discussions of breast cancer in Kuwait and consider suitable methods for breast cancer awareness campaigns in a Kuwaiti context.

By combining all three methods and their findings, a full picture could be concluded about the best ways to improve breast cancer awareness in Kuwait.

#### Study 1 - Systematic Review of the Literature

Systematic reviews bring together all available evidence on the subject under study. They allow not only the compilation of evidence but importantly highlight evidence gaps. The five steps involved in constructing a systematic review start with formulating the research question (UOL, 2022). After formulating the research question: **"Understanding awareness, belief, and attitudes towards breast cancer and breast cancer screening behaviour in the Gulf region",** it was essential to perform a scoping search before proceeding to the next step of the systematic review:

- Scoping search to inform the researcher about the presence of published similar systematic review and in that case the topic has to be changed unless if it was conducted 5 years ago or more and the researcher is seeking to update the information.
- 2. To determine if there is sufficient literature related to the topic to perform the review.
- 3. To be able to specify the research question according to the amount of data available (UOL, 2022).

The next steps range from papers screening, data extraction, quality appraisal, data analysis and then reporting findings (Khan et al., 2003). More detail of each step in the systematic review is described in the systematic review chapter (Chapter 5 Understanding awareness, beliefs and attitudes towards breast cancer and breast cancer screening behaviour in the Gulf region).

#### Study 2 - cross-sectional survey

Given the gaps highlighted in the scoping review around the lack of evidence of breast cancer awareness in Kuwait, the aim of this study was to investigate awareness among Kuwaiti females. Cross-sectional study design is a type of observational study that is not an expensive type of study and can measure associations between the exposures and outcomes of interest however, it cannot be used to follow up participants overtime or examine causation (Wang and Cheng, 2020).

The cross-sectional design also allows the examination of multiple variables at the same time. In planning the quantitative study in this PhD, the researcher was able to examine different variables at the same time, ranging from sociodemographic variables until breast cancer risk factors. The BCAM is an internationally validated measure that can be used to measure the general population awareness about breast cancer and breast screening. Since the researcher comes from an Arabic speaking country and specifically a GCC country (Kuwait), it was more convenient to use the modified Omani version of the BCAM which was further adapted to suit the Kuwaiti culture. The tool comprised eight domains and it is very easy to monitor the awareness of the same population several times and also on different population.

A further advantage of employing a cross-sectional study is the use of a population-based survey. The sample size was calculated according to a specific sample size equation in relation to the total number of female populations in Kuwait at that time. The desired study population were selected from all over the five districts in Kuwait in order to have a representative sample of the females in Kuwait. All the details were provided in Chapter 6 Breast cancer knowledge and awareness among female residents of Kuwait. A quantitative study.

The researcher was able to measure the odd ratio (OR) and to conclude associations between the variables and the outcome but not causal relationship as this is difficult to obtain in cross-sectional study.

#### Study 3 - Qualitative interviews

#### How to improve breast cancer awareness

As well as quantitative examination of awareness the thesis also sought to identify potential awareness raising measures. A qualitative study was planned to allow the issues of awareness to be explored in detail. Initially a series of focus group discussions were planned but owing to challenges during the corona virus disease-19 (COVID-19) pandemic and strict lockdowns in Kuwait, the protocol was altered to include individual interviews (Hoover, 2021). The overall aim was to capture the views of key stakeholders working in the field of breast cancer in Kuwait in clinical and/or public health roles.

Qualitative research gathers information about experiences, feelings, actions and meanings. It allows us to better understand social relations and disentangle challenging subjects (University of Newcastle Library Guides UON, 2020). The focus is on the understanding of how and why things happen. Qualitative techniques or tools typically involve individual interviews and/ or focus groups. Less commonly the documentary analysis examines written accounts. This qualitative study sought to identify optimal ways to address the gaps in breast cancer awareness in Kuwait.

Interviewing participants was face-to-face or one-to-one interaction involved the researcher and the participant being interviewed. The interview is a way to gather in-depth information about the topic being studied. It gives participants the freedom to talk and the interviewer to probe for additional information (CFR, 2021). Fewer number of participants is required to achieve this type of a study compared to a quantitative study. Conducting a qualitative study is considered to be more expensive than other types of studies and if the researcher or the interviewer did not have the proper skills when interviewing participants, the study could fail to answer the research question in mind (Hoover, 2021).

For that reason, the researcher undertook a special training courses in conducting qualitative studies. (Qualitative Research 1, Qualitative Research 2 and Introduction to Qualitative interviewing which were in 2018 at Oxford University, UK).

A topic guide questionnaire had ten open ended questions with a five-minute video about breast cancer international adverts that was shown to participants. Details about the use of videos in qualitative research is explained below.

#### **Elicitation interviews**

Elicitation interviews are one of the interventional methods used in qualitative research. It stimulates participants and researcher's interaction to the subject being discussed. Elicitation can be done by using written words, photographs, or videos. Video elicitation assists participants to explore their beliefs, thoughts, and experiences beyond the surface of what traditional interviews can do. The purpose of including a short video tool in this study was to enhance participants ability to communicate their experience, beliefs and emotions that are hard to put in words:

# *"It can capture the nonverbal behavior and interaction such as facial expressions and emotion"* (Tz-Li Wang, 2012).

At the end of the interview, the data was transcribed, organized, analyzed and reported (CFR, 2021). Study details were available in chapter seven.

## Summary

Different methods were employed to conduct the studies in this thesis. Each of them was able to address a specific research question yet this multi-method approach allowed the findings to be brought together to address the overall aim of the PhD to provide a comprehensive insight into breast cancer awareness and its screening methods among females in Kuwait.

The following chapters provide in-depth details of each of the individual studies.

# Chapter 5 Understanding awareness, beliefs and attitudes towards breast cancer and breast cancer screening behaviour in the Gulf region. A systematic review.

# 5.1. Introduction

As indicated in Chapter 1 Introduction, breast cancer incidence in the Gulf region is increasing. In 1998 the ASR of breast cancer increased for most of the GCC countries, with figures showing the lowest incidence in Oman 11/100,000 and the highest 39/100,000 in Kuwait, and by 2018 an increase to 35/100,000 and to 52/100,00 in Oman and Kuwait respectively (Tanner and Cheung, 2020). Females with breast cancer in GCC are often diagnosed at a late stage ((Shulman et al., 2010, Vieira et al., 2017). Mortality is partly associated with stage at diagnosis, which is attributed to awareness about the disease and the participation in screening (Elias et al., 2021). Currently the availability of screening programs for breast cancer in the GCC countries is variable and participation in screening is generally low and similarly variable. Knowledge and awareness of breast cancer are likely to influence screening behavior but factors affecting this are as yet unclear. In this chapter reports findings from a comprehensive systematic review that seeks to better understand knowledge and awareness in the GCC countries regarding breast cancer and breast cancer screening.

# 5.2. Aim, research question and objectives

The overall aim of conducting the systematic review was to examine and comprehend the beliefs and attitudes about breast cancer and breast screening within the GCC countries. Therefore, the overall research aim addressed was: To understand the awareness, beliefs and attitudes towards breast cancer and breast cancer screening behavior in the Gulf region.

The research question constituted three main objectives:

- 1. To capture the level of breast cancer awareness among the general female population in GCC countries.
- 2. To describe the beliefs/ attitudes towards breast cancer among women in

GCC countries.

3. To describe attitudes, beliefs and awareness of breast cancer screening among women in GCC countries.

# 5.3. PROSPERO registration

To ensure transparency the systematic review was registered in the International Prospective Register of Systematic Reviews (PROSPERO), the International prospective register of systematic reviews (Appendix 15)

http://www.crd.york.ac.uk/PROSPEROCRD42017058343

PROSPERO is a database of on-going reviews relating to health and social care. It allows the research community to establish whether other similar systematic reviews are on-going therefore avoiding duplication. (Page et al., 2018).

# 5.4. Method

# 5.4.1. Searching for papers

A scoping search was conducted to estimate the level of data available for the research question (Peters et al., 2015, Tawfik et al., 2019). The main searching terms were: "attitude," "awareness," "breast neoplasm," "early detection of cancer," "humans," "interpersonal relations". With the help of a college librarian, a comprehensive search strategy was developed for use across the multiple available databases. The detailed search strategy is provided in Appendix 7. The electronic search was applied to six main databases: Medline, PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINHAL), Excerpta Medica dataBASE (Embase), Web of Science (WOS) and ProQuest.

# 5.4.2. Inclusion and exclusion criteria

A pre-defined protocol was applied to plan the inclusion and exclusion criteria, the searches to be launched and the sources to be used. Selection and exclusion of the studies was conducted according to a strict inclusion and exclusion criteria, respectively. There was a restriction on the searched languages. Only Arabic and English language articles were included, as translation for other languages was not

available. A description of the inclusion and exclusion criteria is outlined in Table 5.1.

Table 5.1: Inclusion and exclusion criteria

Inclus	ion criteria:
1.	Studies from the Gulf Cooperation Countries (Kuwait, Saudi Arabia, Qatar, Oman,
	UAE and Bahrain.
2.	Adults (aged 18 years and over).
3.	Publications in Arabic & English.

#### **Exclusion criteria:**

- 1. Studies of cancer patients or terminally ill patients or individuals who are unable to consent.
- 2. Studies of healthcare professionals.
- 3. Studies involving children.
- 4. Articles with no primary data.
- 5. Systematic reviews.
- 6. Studies about breast cancer in males.

Following this, a literature search using the different databases was conducted. Handsearching, grey literature, citation search and contacting a librarian expert in the field was also conducted.

# **5.4.3.** Screening process

The search was conducted in stages. The first search was conducted in October 2016 until March 2017. It was restricted to the period of 1946 until October 2016, and a second search to update the review was, completed in March 2022. Both searches yielded 1787 papers of which 350 were duplicates and the remaining 1437 were imported to DistillerSR (Partner, 2022). Another 178 duplicates were identified by the DistillerSR, and a total of 1259 were ready to be screened by the DistillerSR. Further explanation is provided in the PRISMA flowchart Figure 5.1.

Screening of each paper was conducted by (Hanan Almajed (HM) at all stages. A second review was done by (Sara Macdonald (SR) and (Barbara Nicolle (BN). Conflicts were resolved by a discussion between the reviewers (HM), (SR) and (BN).

Papers were screened at two levels: title/ abstract and full-text screening. Papers were first included and excluded according to the title and abstract followed by a more detailed examination of full-text papers with reference to the inclusion and exclusion criteria. Reasons for excluding the papers were recorded. An update of the review was carried out in March 2022. Details of the screening process is provided in Figure 5.1.

# **5.4.4.** Quality appraisal

Quality of the studies is assessed to ensure an evidence based review, free of bias and relevant to the research question (Mhaskar et al., 2009). It is important to use an efficient and reliable instrument to assess the quality of the studies included in the review. Appraising the papers was conducted by HM and SM. Quality appraisal tools were matched to the appropriate study design. The Joanna Briggs Institute tool was selected to evaluate the quality of the cross-sectional and qualitative studies (Adelaide, 2020). Mixed method study designs were appraised using a tool adapted from O'Cathain et al.; 2008. Quality appraisal provided in **Error!** 

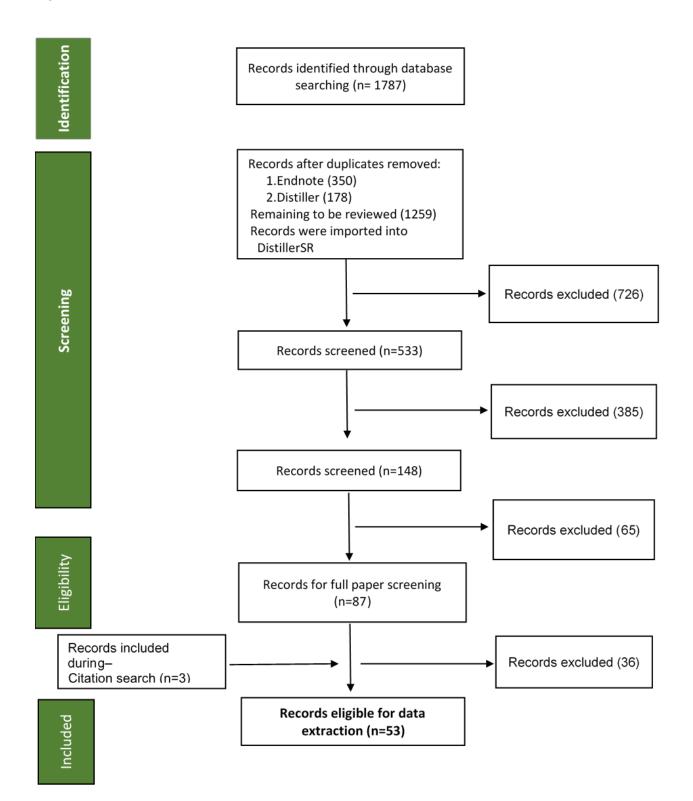
A score system was given for each type of the study designs included. It was given to assess the robustness of papers included. For the quantitative study design, the checklist included eight questions. Each question was given one score if the answer was 'yes' and zero score if the answer was 'no,' 'unclear' or 'not applicable'. A score of 7-8 was given an assessment of 'Very Good', 5-6 as 'Good', 4 as 'Fair' and <4 as 'Poor". A copy of the form is provided in appendix 9.

For the qualitative study design, the checklist included ten questions. Each question was given one score if the answer was 'yes' and zero score if the answer was 'no,' 'unclear' or 'not applicable.' A score of 8-10 was given assessment of 'Very Good', 6-7 as 'Good', 5 as 'Fair' and <5 as 'Poor'. A copy of the form is provided in appendix 10.

For the mixed study design, the checklist included nineteen questions: six questions concerning justification for a mixed methods approach, seven questions for the quantitative study design part and 6 questions for the qualitative study design part.

A score of >15 was assessed as 'Very Good', 8-15 as 'Good', 5-7 as 'Fair' and <5 as 'Poor'. A copy of the form is provided in appendix 11.

Quality appraisal was done by (HM) and (SM) each separately. In the case of disagreement, a discussion between the two would be caried out to resolve it.



# 5.4.5. Approach to analysis

A narrative approach was selected for analysing the data, specifically, thematic analysis (Jennie Popay, 2006).Thematic analysis is a reliable method for analysing and synthesising data and can integrate both qualitative and quantitative results. The first reviewer (HM) was responsible for coding the data and the second reviewer (SM) ensured that the coding was rigorous. Themes relating to the foci of the included studies were applied to the data (Ryan et al., 2018), and then integrated to achieve the research aim (Ryan et al., 2018).

# 5.5.Results

## 5.5.1. Overview

Fifty-three papers were included in this systematic review. A summary of the included studies is shown in Table 5.2.

The main focus of the papers was breast cancer and /or breast cancer screening and some included both. Sixteen papers discussed breast cancer awareness, sixteen papers were about breast cancer screening and the remaining 21 papers dealt with both awareness and screening (see Table 5.2).

All the included papers were conducted in the GCC countries; the majority were in Saudi Arabia (n= 35), followed by United Arab Emirates (n=5), Qatar (n=6), Kuwait (n=4) and Oman (n=3). Most were quantitative studies (n=47) that used a prevalidated questionnaire, three were qualitative (n=3) and three were mixed methods (n=3). The majority of the studies were set in primary healthcare clinics or in hospitals with participants coming for a routine healthcare appointment or were accompanying a patient. Instruments used to conduct the quantitative studies were mainly pre-designed/ pretested questionnaire, six used questionnaires that had been used by other similar studies and 12 of them did not state the type of tool they used. One mixed method study used the BCAM for the quantitative part of the study. The sample size varied between studies, the lowest being (n= 40) in Nageeti et.al, 2017, which was a mixed study design and the highest being 6380 participants in Milaat et.al, 2000, and was a quantitative study design.

# Table 5.2: Summary of the included papers.

First author's name/ Year	Country	Method	Quality appraisal
1. Nageeti/ 2017	Saudi Arabia	Mixed method	Fair
2. Mohammed/ 2012	Saudi Arabia	Cross-sectional	Poor
3. A.Alharbi/ 2012	Kuwait	Cross-sectional	Good
4. Alzalabani/ 2016	Saudi Arabia	Cross-sectional	Good
5. Alkhamis/ 2016	Saudi Arabia	Cross-sectional	Very Good
6. Bener/ 2002	*UAE	Qualitative	Fair
7. Milaat/ 1999	Saudi Arabia	Cross-sectional	Fair
8. Bener/ 2001	*UAE	Cross-sectional	Fair
9. Alam/ 2006	Saudi Arabia	Cross-sectional	Fair
10. Akhtar/ 2018	Saudi Arabia	Cross-sectional	Poor
11. Bener/ 2009	Qatar	Cross-sectional	Fair
12. Almoudi/ 2012	Saudi Arabia	Cross-sectional	Poor
13. Almoudi/ 2012	Saudi Arabia	Cross-sectional	Poor
14. Radi/ 2013	Saudi Arabia	Cross-sectional	Fair
15. Rasheed/ 2013	Saudi Arabia	Cross-sectional	Good
16. Donnelly/ 2013	Qatar	Cross-sectional	Very Good
17. Saeed/ 2014	Kuwait	Cross-sectional	Poor
18. E.Elobaid/ 2014	*UAE	Cross-sectional	Very Good
19. Alsaeed/ 2015	Saudi Arabia	Cross-sectional	Fair
20. Abolfotouh/ 2015	Saudi Arabia	Cross-sectional	Very Good
21. Almutairi/ 2016	Saudi Arabia	Cross-sectional	Fair
22. Donnelly/ 2015	Qatar	Cross-sectional	Very Good
23. Sabih/ 2012	*UAE	Qualitative	Very Good
24. Reganathan/ 2014	Oman	Cross-sectional	Poor
25. Latif/ 2014	Saudi Arabia	Cross-sectional	Poor
26. Jahan/ 2006	Saudi Arabia	Cross-sectional	Fair
27. Donnelly/ 2012	Qatar	Cross-sectional	Very Good
28. Alqattan/ 2018	Kuwait	Cross-sectional	Very Good
29. Al-Azmy/ 2012	Kuwait	Mixed	Fair
30. Mahfouz/ 2013	Saudi Arabia	Cross-sectional	Very Good
31. lbrahim/ 2017	Saudi Arabia	Cross-sectional	Good
32. Hussein/ 2013	Saudi Arabia	Cross-sectional	Poor

33.El Bcheraoui/ 2015	Saudi Arabia	Cross-sectional	Very Good
			-
34. Donnelly/ 2014	Qatar	Cross-sectional	Very Good
35. Amin/ 2012	Saudi Arabia	Cross-sectional	Poor
36. Amin/ 2009	Saudi Arabia	Cross-sectional	Very Good
37. Gonzales/ 2018	Saudi Arabia	Cross-sectional	Fair
38. Alshareef/ 2020	Saudi Arabia	Cross-sectional	Poor
39. Sabgul/ 2021	Saudi Arabia	Cross-sectional	Very good
40. Donnelly/ 2017	Qatar	Qualitative	Very good
41. Alrashidi/ 2017	Saudi Arabia	Cross-sectional	Poor
42. Allohaibi/ 2021	Saudi Arabia	Cross-sectional	Fair
43. Al-Azri/ 2020	Oman	Cross-sectional	Good
44. Gadi/ 2021	Saudi Arabia	Cross-sectional	Fair
45. Algamdi/ 2021	Saudi Arabia	Cross-sectional	Poor
46. Al Otaibi/ 2017	Saudi Arabia	Cross-sectional	Fair
47. Abdul-Aziz/ 2017	Saudi Arabia	Cross-sectional	Very good
48. Sabi/ 2021	Saudi Arabia	Cross-sectional	Good
49. Kharaba/ 2021	*UAE	Cross-sectional	Fair
50. Alshahrani/ 2019	Saudi Arabia	Cross-sectional	Fair
51. Al-Wassia/ 2017	Saudi Arabia	Cross-sectional	Very good
52. Alameer/ 2019	Saudi Arabia	Cross-sectional	Very good
53. Alkhasawneh/	Oman	Mixed methods	Very Good
2016			

Thematic analysis of the studies included resulted in five common themes between the studies, each with several subthemes, with some overlap between themes. These are listed below.

## 5.5.2.Main themes

The main themes extracted from the included papers were as follows:

- i. Beliefs and perception about breast cancer:
  - a. Fear is an independent major belief.
  - b. Myths about breast cancer and its treatment.
- ii. Barriers to screening methods:
  - a. Fear.

- b. Lack of knowledge.
- c. Shyness.
- d. Lack of infrastructure to breast cancer screening.
- iii. Awareness and knowledge about breast cancer:
  - a. Awareness and its association with sociodemographic factors.
  - b. Awareness level among the gulf population.
  - c. Awareness and the understanding of breast cancer and its screening methods.
  - d. Knowledge about risk factors and symptoms of breast cancer.
  - e. Breast cancer source of information.
- iv. The screening methods:
  - a. The participation in the screening methods.
  - b. Breast cancer screening and its association with sociodemographic factors.
  - c. Practicing BSE.
- v. Men's perspectives about breast cancer.

Each theme with its own subthemes will be presented below:

#### i. Beliefs and perception about breast cancer:

The findings from studies that reported on beliefs and perceptions about breast cancer are summarised in Table 5.3.

Beliefs about cancer was a common theme throughout the review. 17 studies reported participants beliefs (Al-Azri et al., 2020; Gonzales et al., 2018; Nageeti et al., 2017; Alkhasawneh et al., 2016; Al-Zalabani et al., 2016; Abolfotouh et al., 2015; Saeed et al., 2015; Elobaid er al., 2014; Donnelly et al., 2013; Hussain et al., 2013; Rasheed et al., 2013; Al-Azmy et al., 2012; Al-Amoudi et al., 2012; Al-moudi et al., 2012; Sabih et al., 2012; Bener et al., 2002; ; and Akhtar et al., 1995), most of them were cross-sectional (12), three were mixed and two were qualitative. Beliefs were associated with perceived barriers to screening and treatment of breast cancer within the female population of the GCC countries. This theme was discussed in few major contexts: fear as a major independent belief, myths about breast cancer, and its treatment.

Fear or lack of fear was a common theme. In four studies (Nageeti et al., 2017; Alkhasawneh et al., 2016; Abolfotouh et al., 2015 and Sabih et al., 2012) where two were mixed studies, one cross-sectional and one qualitative study, fear of cancer and the negative consequences of a cancer diagnosis was reported as a major concern for participants. Participants had a very pessimistic view about breast cancer causing pain, disfiguration, endless treatments,

disaster and death. Yet, three studies (Nageeti et al., 2017; Donnelly et al., 2013; Abolfotouh et al., 2015) also reported a more optimistic view for females, where they did not regard breast cancer as attracting stigma and that breast cancer could be prevented by engaging in screening methods.

Several studies also detailed beliefs about the causes of cancer (Nageeti et al., 2017; Bener et al., 2002; Al-Amoudi et al., 2012; Donnelly et al., 2013; Sabih et al., 2012; Elobaid er al., 2014). People believed that cancer comes from God, stating that God gave them life and he could take it back, that chemotherapy would kill them, and that cancer should be regarded as a punishment. These beliefs made some of them resistant to receiving any treatment or even participating in screening. Moreover, four out of these same six articles (Nageeti et al., 2017; Donnelly et al., 2013; Sabih et al., 2012; Elobaid er al., 2014) mentioned various other beliefs for causes of breast cancer, including unhealthy diet and overweight, family history, and tight bras; these are the three main ones stated, followed by other beliefs such as refraining from breast feeding, trauma, smoking, alcohol, pollution, perfumes, creams and mental stress. One of the included papers (Alkhasawneh et al., 2016) revealed that some participants believed that envy and evil eye were risk factors for breast cancer. This perception was found to be most common among the younger age group (< 40 years), married or had been married before, with high family income and no education.

Four articles (A Bener et al., 2002; Al-Amoudi et al., 2012; Al-moudi et al., 2012; Hussain et al., 2013) explored participants' beliefs about available breast cancer treatments. One of these articles (Al-moudi et al., 2012) stated that many participants believed mastectomy to be the ultimate treatment option for breast cancer. While another study (Hussain et al., 2013) found that participants believed treatment was successful for most patients but that patients contributed to poor outcome because of late-stage diagnosis of breast cancer. Several other traditional treatments were reported, such as using herbal medicine, cauterization, and religious practices including drinking Zamzam which is a holy water and reading Qura'n and Ruqua for prevention of breast cancer.

One study (Al-Azmy et al., 2012) assessed beliefs about breast cancer symptoms to be: bloody discharge, breast mass, abnormal arm swelling, nipple retraction, and discoloration of breast were the main symptoms mentioned. Two further articles (Bener et al., 2002; Donnelly et al., 2013) mentioned that most women believed in taking full responsibility for their health and have the right to be informed about their health issues.

First author's name/ Year	Study type	Research question/ Aim	Findings/ Outcome
Nageeti/ 2017	Mixed methods: questionnaire and focus group discussion (N=40).	- To assess the perspective of Saudi women in the Makkah region on breast cancer awareness and early detection.	<ol> <li>Females expressed their fear of cancer and its consequences. However, they believed that they will look after their body's health if needed.</li> <li>Some females believed that envy could be a reason for breast cancer.</li> <li>Many believed that stigma around breast cancer has reduced and find it easy to talk about breast cancer to others.</li> </ol>
Al-Zalabani/ 2016	Cross-sectional study (N=465).	- To identify breast cancer knowledge, practice and screening barriers among women attending public health centre (PHC) in Madinah, Saudi Arabia.	<ol> <li>Participants' beliefs about mammography that it would be painful and would expose them to radiation.</li> <li>Participants felt ashamed about having a mammography.</li> </ol>
Bener/ 2002	Qualitative: focus group discussion (N=41).	- To explore perceptions, knowledge, attitudes, and beliefs about breast cancer and its screening among Emirati national women in Al Ain, UAE.	<ol> <li>Participants felt they had the right to learn about their diagnosis and to contribute to their treatment decision, they have a responsibility for their own health; they believed that engaging in screening could result in better outcome through early detection; doctors are messengers from God providing guidance on the best treatment.</li> <li>For some a belief in God would have a positive effect on them and would help them if they needed the help and cure them and should never reject anything coming from God.</li> <li>Some participants believed in herbal medicine or the use of cauterization.</li> </ol>

## Table 5.3: Summary of articles examining beliefs about breast cancer

Akhtar/ 1995	Cross-sectional study (N=266).	- To identify factors including the beliefs,	1. Participants who believed that screening improved outcome were more likely to practice BSE.
		attitudes and perceived barriers among women residing in Al Qassim region in Saudi Arabia.	2. The practice of BSE was also determined by the belief that medical personnel were better to detect changes to the breast than the participants themselves.
Al-Amoudi/ 2012	Cross-sectional study (N=48).	- To assess the knowledge and attitude of early breast cancer detection and identify barriers against this detection among this group of women with special	<ol> <li>Many believed that breast examination could not prevent cancer.</li> <li>The thoughts that drinking Zamzam water and reading Qura'n are preventive measures.</li> </ol>
		needs.	
Rasheed/ 2013	Cross-sectional descriptive study (N=600).	- To assess the knowledge and perception of BSE among female patients attending PHCCs in Al Khobar city, Saudi Arabia.	<ol> <li>Very few felt their susceptibility to having cancer.</li> <li>Most believed in no cure to breast cancer.</li> <li>Assumption made by most of them that having breast cancer would put their life in danger and affect their married life.</li> </ol>
Donnelly/ 2013	Cross-sectional study (N=1063).	- To gain information about Arab speaking women's practice of breast cancer screening, and their knowledge, cultural beliefs, and values regarding breast cancer and its screening for early detection and treatment.	<ol> <li>Less than half of participants believed that breast cancer is preventable and can take full responsibility towards their health but have the right to be informed about the status of their health.</li> <li>Many believed that an unhealthy diet, not breast feeding, hereditary factors and fate or destiny could all explain cancer, however, few believed that cancer was a punishment from God, contagious or bad luck.</li> <li>The majority believed they would practice mammogram if their doctor talked to them about it, whereas only half of them would perform it if received a recommendation letter.</li> </ol>
			4. Participants who believed that cancer is preventable were more likely to practice BSE, CBE and mammogram.

			5. Participants who considered cancer is a punishment from God were less likely to practice the screening methods.
			6. A significant association was found between participants who believed that CBE/ mammogram could be painful or uncomfortable and not performing screening behaviour.
Elobaid/ 2014	Cross-sectional study (N=247).	- To assess breast cancer screening knowledge, attitudes, and practices	1. Less than half, believed that only females can get cancer and that breast cancer is the commonest cancer in females.
		among women of screening age (>/+ 40	2. A minority believed that breast feeding could protect females against breast cancer.
		years old) in the city of Al Ain, UAE.	3. Nearly one third of the participants who had a university degree believed that CBE and mammogram was not a good choice for their age and meant to be for older females.
Al Saeed/ 2015	Cross-sectional study (N=600).	- To determine the knowledge, attitudes and practices (KAP) of urban	1. Blood tests were believed to be one of breast cancer screening method. Two thirds believed that screening methods would prevent cancer
		women in Riyadh regarding breast cancer and its available screening and treatment modalities.	2. The majority acknowledged the importance of early detection and considered mammograms as an important method in early detection of breast cancer.
Abolfotouh/ 2015	Cross-sectional study (N=433).	- To explore the perception towards	1. The majority thought they would be unable to find a small lump on palpation.
		breast cancer and towards BSE among Saudi women, using the health	2. Almost half believed that they be able to differentiate between the normal and abnormal breast tissues.
		belief model (HBM).	3. The susceptibility to have breast cancer was not felt by more than half of participants.
			4. In case of breast cancer, participants believed that BSE could reduce the complications and surgical treatment.
			5. Only one third felt the seriousness of breast cancer and that it could threaten or change marital life.

Sabih/ 2012	Qualitative study (N=329).	- To explore attitudes and beliefs among major national groups of women residents in the emirates of Abu Dhabi (EAD) in relation to breast cancer and treatment.	<ol> <li>"Well Women" (WW) believed that risk factors for breast cancer are family history, genetic abnormalities and eating all kinds of unhealthy food. Some mentioned smoking, overweight and alcohol use would be other risk factors others mentioned perfumes and creams to be reasons for breast cancer.</li> <li>Participants thought that breast feeding could be a cause of breast cancer.</li> <li>Participants from South East Asia (SEA) believed that trauma and tightness of the breast whether by bras or being handled by the husband could be another cause.</li> <li>All "Regular Screeners" (RS) believed that unhealthy food would be a reason for breast cancer.</li> <li>Younger (WW) thought that pain was the most important symptoms of breast cancer, while older UAE (WW) thoughts that a lump would be more important that pain.</li> </ol>
Al-Azmy/ 2012	Mixed study: cross- sectional and case control study (N=520).	- To identify the proportion of women practicing BSE, factors that could affect its performance and explore women's awareness about its practice steps.	<ul> <li>6. (RS) believed that pain and having a lump are the most common symptoms.</li> <li>1. Most of participants who practiced BSE believed that bloody discharge, discolouration and breast mass, are signs of breast cancer.</li> <li>2. Only half participants who practiced BSE believed that abnormal arm swelling and nipple retraction could be signs for breast cancer and they were statistically significant.</li> </ul>
Hussain/ 2013	Cross-sectional study (N=1000).	- To elicit knowledge of breast cancer, perception of occurrence, and behaviour in relation to BSE.	<ol> <li>According to a positive family/ relative history, participants were divided into those:         <ul> <li>a. Who believed in early discovery, personal awareness and successful treatment.</li> <li>b. Who thought of late discovery, destiny and hopeless treatment.</li> </ul> </li> </ol>

Gonzales/ 2018	Cross-sectional	- To identify the health	1. The belief that cancer would not affect them was reported by more than half of
	study (N=400).	beliefs about BSE and its	participants and the perception of cancer as a serious disease by one third of them.
		relationships with the	
		frequency of BSE among	2. Participants who believed they could get cancer were confident in performing BSE and they
		women in the University	did practice BSE the previous year.
		of Tabuk at Saudi Arabia.	

Al-Azri/ 2020	Cross-sectional study (N=358).	- To identify knowledge, attitudes and barriers of Omani women towards	1. Participants who believed that cancer is a destiny also felt they don't need to perform any of the screening method and the chance of getting breast cancer would be low.
		breast cancer screening.	<ul> <li>2. Many thoughts the participants had about breast cancer and its screening <ul> <li>a. Too old to get breast cancer.</li> <li>b. Inevitable death from cancer even with early diagnosis.</li> <li>c. Absence of qualified doctors.</li> <li>d. Useless and harmful screening methods.</li> </ul> </li> </ul>
Alkhasawneh/ 2016	A mixed method study: what were the methods? (N=1372, quantitative, N=19 qualitative).	<ol> <li>To determine the level of awareness of Omani women about breast cancer in general and its early detection practices.</li> <li>To explore significant factors that affected or may affect their awareness related to this phenomenon.</li> </ol>	<ol> <li>Over half thought that evil eye could leads to breast cancer and younger age group, married, with no education, with high income and knowing friend or relative with breast cancer consider it a risk factor for breast cancer.</li> <li>Participants still perceive breast cancer as a deadly disease and talking about it considered a taboo.</li> </ol>

## ii Barriers to screening methods

Barriers to screening participation was a key theme identified in 21 of the included papers, which were summarised in Table 5.4. below. (Alhollabi et al., 2021; Al-Azri et al., 2020; Alshahrani et al., 2019; Abdulaziz et al., 2017; Al-Wassia et al., 2017; Al Khamis et al., 2016; Al Zalabani et al., 2016; Abolfotouh et al., 2015; Alsaeed et al., 2015; Elobaid et al., 2014;; Donnelly et al., 2013; Hussain et al., 2013; Alharbi et al., 2012; Amoudi et al., 2012; Sabih et al., 2012; Amin et al, 2009; Bener et al., 2009; Qattan et al., 2008; Bener et al., 2002; Bener et al., 2001 and Akhtar et al., 1995).

Out of the 21 papers described barriers to screening, 19 articles (Alhollabi et al., 2021; Al-Azri et al., 2020; Alshahrani et al., 2019; Abdulaziz et al., 2017; Al-Wassia et al., 2017; Al Khamis et al., 2016; Alsaeed et al., 2015; Elobaid et al., 2014; Donnelly et al., 2013; Hussain et al., 2013; Alharbi et al., 2012; Sabih et al., 2012; Amin et al, 2009; Bener et al., 2009; Qattan et al., 2008; Bener et al., 2002; Bener et al., 2009; In ported fear as a major barrier to taking part in breast cancer screening. One cross-sectional study (Al Khamis et al., 2016) where 290 females from Saudi Arabia participated, fear was nearly (1%) non-existent among the reasons for not conducting a screening. Instead, the most stated barrier was getting an appointment with the doctor (39%). Fear was reported in many forms including: general fear from breast cancer screening, fear from what they might discover, fear of cancer, fear of gossip, husband and social stigma, and fear of death.

The second most frequently mentioned barrier to screening was the lack of knowledge. This reason was framed in different ways, sometimes as lack of knowledge and thinking that screening is only for older females, other times as lack of knowledge as to how to practice BSE, lack of skills and lack of confidence to conduct BSE. Some females mentioned lack of knowledge as to access screening services, lack of importance of breast cancer screening and general lack of awareness on the subject. Twelve studies (Alhollabi et al., 2021; Al-Wassia et al., 2017; Al Khamis et al., 2016; Abolfotouh et al., 2015; Elobaid et al., 2014; Donnelly et al., 2013; Hussain et al., 2013; Alharbi et al., 2012; Amin et al., 2009; Qattan et

al., 2008; Bener et al., 2002; Bener et al., 2001; and Akhtar et al., 1995) out of the 21 articles that examined barriers, mentioned lack of knowledge as a reason for not seeking breast cancer screening. Another frequently given barrier to breast cancer screening was shyness where nine (Abdulaziz et al., 2017; Al Zalabani et al., 2016; Alsaeed et al., 2015; Donnelly et al., 2013; Amoudi et al., 2012; Sabih et al., 2012; Amin et al, 2009; Bener et al., 2009; and Bener et al., 2002) out of the 21 papers mentioned shyness as being a concern especially the reluctance to be examined by a male physician.

Lack of infrastructure to encourage breast cancer screening was mentioned as a barrier in five studies (Al Azri et al., 2020, Alharbi et al., 2012; Amin et al, 2009; Bener et al., 2002; and Bener et al., 2001) participants reported absence of health facilities to do screening, difficulty accessing appointments, and inconvenience of timing and logistics/transport. In addition, other articles reported miscellaneous and inconsistent results including: doubting the benefit of CBE, having a non-supportive husband, family/social gossip, distrust with the healthcare staff and preferred to have it done somewhere abroad, seeking traditional or herbal type of medication instead of performing screening, lack of knowledge in disabled people due to sign language, lazy about it, forgetting, and health insurance and its cost.

First author's	Study type	Research question/	Findings/ Outcome
name/ Year		Aim	
Amin/ 2009	Cross-sectional study (N=1315).	- To assess level and determinants of knowledge about, risk factors for and utilization of screening methods used for breast cancer early detection among adult Saudi women in Al Hassa, KSA.	1. Most common perceived barriers: traditions including shyness and not wanting to be examined by a male physician, lack of health facilities to take part in screening, Lack of knowledge and fear and work overload.
Al Qattan/ 2008	Cross sectional study (N=966).	- To determine the frequency of practicing breast self-examination (BSE) among Kuwaiti females and factors that may influence it.	<ol> <li>Reasons given for not performing BSE were as follows:</li> <li>a. Lack the knowledge about BSE.</li> <li>b. Fear of discovering the disease.</li> <li>c. Forgetting about it.</li> <li>d. Lack of appreciation to the importance BSE.</li> </ol>
Donnelly/ 2013	Cross-sectional study (N=1063).	- To investigate beliefs, attitudes, and BSC practices of Arabic- speaking women in Qatar.	1. Barriers commonly mentioned to perform a mammogram/ CBE: not recommended by their doctors, pain, embarrassment, fear and being ineffective.
Sabih/ 2012	Qualitative study (N=329).	- To explore attitudes and beliefs among major national groups of women residents in the Emirates of Abu Dhabi (EAD) in relation to breast cancer screening and treatment.	<ol> <li>Fear was the commonest barrier among "Well Women".</li> <li>Shyness and embarrassment were declared by people from Asia, South East Asia (SEA) and Arabs. For this reason, preference for a female doctor was reported.</li> <li>Also 'Well Women'' expressed their distrust with the healthcare staff and preferred to have screening done somewhere abroad.</li> </ol>

Table 5.4: Summary of articles examining barriers to screening methods

Bener/ 2002	Qualitative study (N=41).	- To explore perceptions, knowledge, attitudes and beliefs about breast cancer and its screening among Emirati national women in Al Ain, United Arab Emirates.	<ol> <li>For some, the belief in God and in herbal medicine prevented them from screening.</li> <li>Shyness, embarrassment, and lack of knowledge about screening was a barrier to screening.</li> <li>Female doctors are not present in all health services.</li> </ol>
Abolfotouh/ 2015	Cross sectional study (N=225).	- To study the perception towards breast cancer and BSE among group of Saudi women, using the health belief model (HBM).	<ol> <li>Barriers to BSE were the lack of knowledge and confidence in performing it.</li> <li>Participants who had low barriers, were the one who performed BSE.</li> </ol>
Alsaeed/ 2015	Cross-sectional study (N=600).	- To determine the knowledge, attitudes and practices (KAP) of urban women in Riyadh regarding breast cancer breast cancer and its available screening and treatment modalities.	1. Fear and lack of confidence in discussing such issues were the main barriers mentioned by participants.
Elobaid/ 2014	Cross-sectional study (N=247).	- To assess breast cancer screening knowledge, attitudes and practices among women of screening age (>/= 40 years) in the city of Al Ain, United Arab Emirates (UAE).	<ol> <li>Barriers to practicing any of the screening activities were as follow:</li> <li>a. BSE: the most common was fear, not having the time to do it, lack of knowledge to do it.</li> <li>b. CBE: fear, lack of time, never heard about screening and belief that screening applies only to older aged women.</li> <li>c. Mammography: lack the awareness and knowledge about screening, fear and belief that screening applies only to older aged women.</li> </ol>

Al Amoudi/ 2012	Cross-sectional study (N=48).	- To assess knowledge and attitude of early breast cancer detection and identify barriers	<ol> <li>Lack of information about the screening activities because communication through the sign language is absent which prevented widespread knowledge.</li> <li>Embarrassment, shyness, a preference for female doctors, the lack of nearby services and provide the service of the screening.</li> </ol>
		against this detection among this group of women with special needs.	specialized facilities were barriers to screening.
Bener/ 2009	Cross-sectional study (N=1002)	- To explore knowledge, attitude, and practices about breast cancer and to identify potential barriers to screening procedures among women.	<ol> <li>Many participants fear the diagnosis of breast cancer and as a result didn't want to be screened.</li> <li>According to each activity:         <ul> <li>A.BSE: many lack the skills performing it and were not shown previously by a healthcare staff.</li> <li>B. CBE: feeling shy and embarrass to be examined by a healthcare professional was the commonest barrier.</li> </ul> </li> </ol>
			C. Mammography: difficult appointment and discomfort of mammography were the most common barrier.
Akhtar/ 1995	Cross-sectional Study (N=266).	- To identify beliefs, attitudes and practices of BSE, as well as the perceived barriers to it among women residing in Al Qassim region.	<ul> <li>1.Barriers addressed:</li> <li>a. The lack of skills and confidence in performing BSE.</li> <li>b. Forgetting to do it or the ability to remember to do it</li> <li>c. Fear and worries.</li> </ul>
Bener/ 2001	Cross sectional study (N=1367).	- To evaluate knowledge, attitudes, barriers, and practices related to breast screening among Arabic women.	1. Preference of female doctor, fear/ worries and lack of transportation were the main obstacles to screening.

Al Khamis/ 2016	Cross-sectional study (N=290).	- To evaluate the level of breast cancer awareness	1. More than half mentioned at least one barrier.
	Study (11-270).	and perceived barriers to seeking medical care among Saudi women attending primary care services, using internationally validated tool.	2. Difficulty in scheduling an appointment was the commonest barrier and some worries about the diagnosis of cancer. Busy with work, lacking the knowledge and embarrassment were also mentioned.
Al Zalabani/ 2016	Cross-sectional study (N=465).	- To identify breast cancer knowledge, practice and screening barriers among women attending primary health centres (PHC) in Madina,	<ol> <li>Main reasons for not performing mammogram:         <ul> <li>Painful procedure.</li> <li>Painful procedure.</li> <li>Exposure to radiation.</li> </ul> </li> <li>Other barriers included:         <ul> <li>Lack of communication with the medical staff.</li> <li>Facility of the medical staff.</li> </ul> </li> </ol>
Alharbi/ 2012	Cross sectional study (N=428).	Saudi Arabia - To assess the breast cancer knowledge and awareness and factors associated with the practice of breast self- examination (BSE) among female teachers.	<ul> <li>b. Feeling a shame from performing the mammogram.</li> <li>1. Barrier for not performing BSE was lack of knowledge about the importance of BSE.</li> <li>2. Participants linked the performance of BSE with the presence of a lump, if a lump was not present, they would not perform BSE.</li> <li>3. Fear from practicing BSE was also mentioned by participants.</li> </ul>
Hussain/ 2013	Cross-sectional study (N=877).	- To elicit knowledge of breast cancer, perception of occurrence, and behaviour in relation to breast self-examination.	<ol> <li>The practice of BSE was linked to personal awareness and fear linked to the absence of performing BSE.</li> <li>Fear was a reason for not discussing breast cancer and BSE.</li> </ol>
Alhollabi/ 2021	Cross-sectional study (N=697).	- To evaluate the breast cancer knowledge (risk factors, causes, prevention and treatment) and to assess the breast self- examination (BSE) among women in Saudi Arabia,	1. Barriers to BSE according to participants were as follow: The lack of knowledge about its importance, fear of discovering breast cancer, and the discomfort or pain caused by mammogram.

		to explore possible correlation between education and knowledge and practice of breast cancer.	
Al-Azri/ 2020	Cross-sectional study (N=358).	- To identify knowledge, attitudes, and barriers of Omani women towards breast cancer screening.	<ol> <li>Half of participants fear mastectomy if were diagnosed with cancer and others were also worried about the treatment itself.</li> <li>Obstacles mentioned: Embarrassment about examination, hesitance to consult a doctor, worried about the diagnosis or treatment, preferred herbal treatment, busy, preferred a female doctor, stigma about breast cancer, religious beliefs, difficulty in communication, difficult appointment, pain from the examination and lack of support from others.</li> </ol>
Abdul-Aziz/ 2017	Cross-sectional study (N=816).	- To investigate the perceived barriers towards breast cancer screening in Al Hassa, Saudi Arabia.	<ol> <li>Significant barriers mentioned by participants who never had breast cancer screening were: cultural stigmatization, being shy to have their breast examined, fear from discovery, being busy and bad experience.</li> <li>Also they mentioned that dealing with none-local physician, to be examined by a male healthcare provider, difficulty finding transportation and inefficiency of the doctors were barriers to them.</li> </ol>
Alshahrani/ 2019	Cross-sectional study (N=500).	- To evaluate the knowledge, attitude, and practice of breast cancer screening methods among female patients attending five primary healthcare centers in Najran, Saudi Arabia.	<ol> <li>Barriers perceived by participants about the mammogram: being harmful, unavailability, being painful, some had no idea and others were afraid of the result.</li> <li>Barriers to CBE perceived by participants: no female doctor, painful, nearly half had no idea and were afraid of the result.</li> <li>Barriers to BSE were: painful, had no training, had no idea and were afraid.</li> </ol>
Al-Wassia/ 2017	Cross-sectional study (N=3048)	- To assess mammography utilization and knowledge, and to determine barriers associated with mammography utilization among Saudi women.	<ol> <li>Participants' reasons for not using the mammogram: Not appreciating the importance of it, lack the knowledge about its location, fear about the result, refused to have their private parts examined, risk of radiation and being painful.</li> <li>Participants expressed their feelings if they would go for screening: Inability to sleep, feeling of not wanting to go, worrying about the result, thinking of the pain, embarrassment and feeling indifferent.</li> </ol>

## iii Awareness and knowledge about breast cancer

One of the identified themes from the included studies was awareness of breast cancer. Forty studies (Algamdi et al., 2021; Allohabi et al., 2021; Kharaba et al., 2021; Sabi et al., 2021; Al-Azri et al., 2020; Alshareef et al., 2020; Alsharhani et al., 2019; Gonzales et al., 2018; Alrashidi et al., 2017; Nageeti et al., 2017; Al-Khamis et al., 2016; Alkhasawneh et al., 2016; Almutairi et al., 2016; Al-Zalabani et al., 2016; Abolfotouh et al., 2015; AlSaeed et al., 2015; Elobaid et al., 2014; Latif et al., 2014; Mohammed et al., 2014; Saeed et al., 2014; Renganathan et al., 2014; Hussein et al., 2013; Mahfouz et al., 2013; Radi et al., 2013; Rasheed et al., 2013; Al-Amoudi et al., 2012; Al-Amoudi et al., 2012; Amin et al., 2012; Donnelly et al., 2012; A.Alharbi et al., 2011; Amin et al., 2009; Bener et al., 2009; Alam et al., 2006; Jahan et al., 2006; Bener et al., 2002; Bener et al., 2001; Milaat et al., 2000; Akhtar et al., 1995 and Ibrahim et al., 1991) out of the 53 included studies reported people's awareness and knowledge of breast cancer, risk factors, symptoms and importance of examinations; these are summarised in Table 5.5. This theme was discussed in four major contexts: factors related to the awareness and knowledge of breast cancer, knowledge level about breast cancer awareness in the Gulf population, knowledge level about risk factors and symptoms of breast cancer, and sources used for awareness.

Nineteen studies (Algamdi et al., 2021; Allohabi et al., 2021; Alsharhani et al., 2019; Al-Khamis et al., 2016; Alkhasawneh et al., 2016; Al-Zalabani et al., 2016; AlSaeed et al., 2015; Elobaid et al., 2014; Saeed et al., 2014; Hussein et al., 2013; Radi et al., 2013; Rasheed et al., 2013; Amin et al., 2012; Amin et al., 2009; Bener et al., 2009; Alam et al., 2006; Jahan et al., 2006; Milaat et al., 2000 and Ibrahim et al., 1991) tackled how awareness of breast cancer was significantly correlated with age, marital status, and level of education. All these nineteen studies, with the exception of four cross-sectional studies (Algamdi et al., 2006) indicated that education was the major determinant of knowledge, with university students being more knowledgeable than school students and employees being more knowledgeable than university students. The two cross-sectional studies (Alam et al., 2006; Al-Zalabani et al., 2016) reported low to moderate levels of knowledge, regardless of the females' educational status,

marital status, and their family history of breast cancer. Moreover, five crosssectional studies (Allohabi et al., 2021; Hussein et al., 2013 Rasheed et al., 2013; Jahan et al., 2006; and Ibrahim et al., 1991;) concluded that age was not a statistically significant factor in breast cancer knowledge. Age was only relevant when also associated with the level of education and marital status of females, while in the five cross-sectional studies (Alshareef et al., 2020; AlSaeed et al., 2015; Elobaid et al., 2014; Saeed et al., 2014 and Amin et al., 2009) it was noted that women aged 30-50 and were educated, married, and employed, had better knowledge about breast cancer awareness.

Out of the 40 studies 17 (Algamdi et al., 2021; Allohabi et al., 2021; Alshareef et al., 2020; Nageeti et al., 2017; Al-K, hamis et al., 2016; Abolfotouh et al., 2015; AlSaeed et al., 2015; Mohammed et al., 2014; Renganathan et al., 2014; Saeed et al., 2014; Mahfouz et al., 2013; Al-Amoudi et al., 2012; Donnelly et al., 2012; Jahan et al., 2006; Bener et al., 2002; Milaat et al., 2000 and Akhtar et al., 1995) examined awareness and knowledge about breast cancer in the gulf population. One crosssectional study (Donnelly et al., 2012) interviewed 1063 females from Qatar and non-Qatari residents, and defined awareness as "a preliminary understanding of breast cancer and its screening" and basic knowledge as "a participant that has a higher level of understanding and accurate knowledge of breast cancer and its screening". It was found that the majority of participants were aware of breast cancer but have low awareness level about the screening activities. Eleven studies (Alshareef et al., 2020; Nageeti et al., 2017; Al-Khamis et al., 2016; Alkhasawneh et al., 2016; Abolfotouh et al., 2015; AlSaeed et al., 2015; Renganathan et al., 2014; Mahfouz et al., 2013; Donnelly et al., 2012; Jahan et al., 2006 and Bener et al., 2002) indicated that the level of both knowledge and awareness of symptoms, breast selfexamination or screening were inadequate. The remaining six studies (Algamdi et al., 2021; Mohammed et al., 2014; Saeed et al., 2014; Al-Amoudi et al., 2012; Milaat et al., 2000 and Akhtar et al., 1995) showed that most participants generally had a good knowledge and awareness about breast cancer risk factors and its presentation.

Nineteen studies (Algamdi et al., 2021; Al-Azri et al., 2020; Allohabi et al., 2021; Kharaba et al., 2021; Sabi et al., 2021; Alshareef et al., 2020; Alrashidi et al., 2017; Al-Khamis et al., 2016; Alkhasawneh et al., 2016; Almutairi et al., 2016; Elobaid et

al., 2014; Latif et al., 2014; Saeed et al., 2014; Mahfouz et al., 2013; Radi et al., 2013; A.Alharbi et al., 2011; Bener et al., 2001; Milaat et al., 2000 and Ibrahim et al., 1991) reported knowledge and awareness of the risk factors and symptoms of breast cancer. Ten of these studies (Kharaba et al., 2021; Sabi et al., 2021; Al-Azri et al., 2020; Alshareef et al., 2020; Al-Khamis et al., 2016; Almutairi et al., 2016; Saeed et al., 2014; Mahfouz et al., 2013; Alharbi et al., 2016; Almutairi et al., 2000) indicated good knowledge of breast cancer symptoms: size changes, shape of nipple, heaviness under the armpit, and discharge from the nipple. Four papers (Alshareef et al., 2020; Alrashidi et al., 2017; Mahfouz et al., 2013 and Alharbi et al., 2011) discussed risk factors and most participants correctly identified the role of breast feeding, the effect of smoking, family history of breast cancer, hormone replacement therapy, radiation and the use of alcohol. However, fewer than half correctly identified the importance of age or the protective effect of pregnancy before 40 years of age.

Eight studies discussed the sources of awareness of the participants (Algamdi et al., 2021; Gonzales et al., 2018; Nageeti et al., 2017; Al-Zalabani et al., 2016; Mahfouz et al., 2013; Donnelly et al., 2012; Alharbi et al., 2011 and Bener et al., 2002). One mixed method study, (Nageeti et al., 2017) where 40 females participated indicated that internet, media, and television were the main sources for their awareness, followed by health care providers. The same study (Nageeti et al., 2017) also reported the preference of awareness techniques where females aged below forty said they preferred awareness campaigns and interactive sessions in health-care facilities, while older females aged over 50 years preferred a variety of methods to acquire knowledge and awareness such as programmes disseminated by the media and TV shows.

First author's	Study type	Research question/	Findings/ Outcome
name/ Year		Aim	
Hussein/ 2013	Cross-sectional study (N=877).	- To elicit knowledge of breast cancer, perception of occurrence, and behaviour in relation to breast self- examination (BSE).	<ol> <li>Half were unaware about breast cancer and the majority knew a single cause to breast cancer.</li> <li>Most common risk factors mentioned were OCP and wearing unsuitable clothes.</li> <li>Factors increasing awareness were related to occupation; university students were more knowledgeable than school student and employees were more knowledgeable than university students.</li> <li>Participants who were informed about BSE were practicing BSE more than those who were not informed about BSE and the reason was personal awareness.</li> <li>Fear was the reason for those who were informed about BSE but did not practice it.</li> </ol>
Ranganathan/ 2014	Cross-sectional study (N=369).	- To assess the knowledge and awareness of breast cancer symptoms among Omani women.	<ol> <li>Most participants had average knowledge about breast cancer and very few had excellent knowledge.</li> <li>Lump symptoms was identified by less than half of participants.</li> <li>Commonest risk factors known were family history and exposure to radiation.</li> <li>Level of education was a determinant of the knowledge level.</li> </ol>
Latif/ 2014	Cross-sectional study (N=150).	- To assess the knowledge, attitudes and practices of university students towards breast cancer.	<ol> <li>A tight bra, evil eye and genetic factors were mentioned as risk factors.</li> <li>Nipple discharge, painful breast, painless lump, and nipple ulceration were known as symptoms of breast cancer.</li> </ol>
Alharbi/ 2011	Cross-sectional study (N=428).	- To assess breast cancer knowledge and awareness and factors associated with the practice of breast self-examination (BSE)	1. Many participants had information about breast cancer. The source of information was mainly from health professionals/workers, friends/neighbours, TV/Radio and printed media (books/brochures/magazines).

Table 5.5: Summary of articles examining awareness of breast cancer

		among female teachers.	<ol> <li>Breast mass, enlargement of neighbouring lymph nodes, and breast skin retraction were the symptoms known to participants.</li> <li>Teachers correctly answered about the effect of breast feeding, the effect of smoking, family history of breast cancer, HRT, using alcohol and the least recognized risk factors were menarche age and having benign breast disease.</li> </ol>
Mohammed/ 2014	Cross-sectional study (N=300).	- To assess the levels of breast cancer awareness among Saudi females, and to compare between housewives and employed women regarding knowledge and practical of breast cancer.	<ol> <li>Most participants had good knowledge about breast cancer risk factors.</li> <li>The study found good awareness and knowledge regarding risk factors and symptoms of breast cancer among women living in an urban area.</li> </ol>
Nageeti/ 2017	Mixed method study: a qualitative study and a quantitative study (N=40).	- To assess the perspective of Saudi women in the Makkah region on breast cancer awareness on early detection.	<ol> <li>Some participants had never attended any awareness campaign or lecture about breast cancer or watched a TV programme.</li> <li>Most females lack the basic knowledge about breast cancer. However, in focus group discussion they were aware of benefit from early detection of the disease.</li> <li>Low satisfaction with information sources and awareness programmes. They thought "these awareness programs are seasonal and not done throughout the year to accommodate our social commitments.</li> <li>Most females commented that "shopping malls are for shopping" and not for campaigns.</li> <li>Different approaches for communicating the knowledge on breast cancer and early detection methods were recommended by participants. Women aged below forty said they preferred awareness campaigns and interactive sessions in health-care facilities.</li> <li>While older females in the groups aged fifty and above preferred a variety of methods to acquire knowledge and awareness such as programs disseminated by the media and TV shows.</li> </ol>

	-		
Al-Zalabani/ 2016	Cross sectional study (N=465).	<ul> <li>To identify breast cancer knowledge,</li> </ul>	1. Less than half of participants who answered correct on the symptoms and risk factors knowledge.
	Study (11-105).	practice, and screening barriers	2. Source of information indicated: internet, lectures, TV, books/ magazines, family and friends.
		among women attending primary healthcare centres	3. The level of knowledge was low among all participants, and many had poor knowledge about breast cancer symptoms.
		(PHC), in Madina, Saudi Arabia.	4. Clinical picture about breast cancer were known better than risk factors.
Al-Khamis/ 2016	Cross-sectional study (N=290)	- To evaluate the level of breast cancer	1. All females had knowledge of one or more of the warning symptoms of breast cancer.
		awareness and perceived barriers to seeking medical care	2. Most identified symptoms were lump or thickening of breast, pain in breast or armpit and discharge from nipples.
		among Saudi women attending primary -	3. Least identified symptoms were discoloration of the skin surrounding the breast and nipple rash.
		care services using internationally	4. Age related risk was not well known by participants.
		validated tool.	5. Very few considered to be aware.
			6. Awareness was associated with high education.
Akhtar/ (1995)	Cross-sectional study (N=131).	The practice of breast self-examination (BSE) a recommended	1. The majority of those who practiced BSE were aware of the effectiveness of BSE in discovering changes that might occur to the breast.
		method of breast	2. Most of them who performed BSE acknowledged the fact that BSE would be helpful for early
		screening, depends	treatment and knew that early diagnosis would lead to better outcome.
		upon many factors	
		including the beliefs,	
		attitudes and perceived barriers of	
		the women of a	
		particular community.	
		The aim was to	
		identify these factors	
		among women in the	
		Al Qassim region.	

Donnelly/ (2012)	Cross-sectional	1. What are the	1. "Awareness: a preliminary understanding of breast cancer and its screening". A participant was
	study (N=1063)	participation rates of	assessed as having breast cancer awareness if she had heard of breast cancer and received some
		Arabic women in BSE, CBE, and	information about breast cancer from at least one source".
		mammogram?	2. "Basic knowledge" indicates that a participant has a higher level of understanding and accurate knowledge of breast cancer and its screening. A participant was assessed as having basic knowledge
		2.To what extent are Arabic women's	if she knew how to examine her own breasts, knew the most national screening recommendations for mammography, BSE and CBE."
		awareness and	2. Most of monthing and a booth burnet company and the model with such the independent of the set the
		knowledge of breast cancer and its screening, as well as	3. Most of participants heard about breast cancer and the majority got their information from the T.V. Only few had basic knowledge of breast cancer screening activities.
		other selected factors, associated with BSC behaviours.	4. Participants who practiced BSE had breast cancer awareness (more than those who didn't practice BSE and similar finding for CBE and mammography).
Mahfouz/ 2013	Cross-sectional study (N=1092).	- To determine the basic background	1. Knowledge about mammography and BSE was low.
		knowledge, attitudes, and related practice among women in Abha	2. Participants' knowledge regarding the signs and symptoms of breast cancer was highest for size changes and lowest for nipple discharge.
		city, in relation to breast cancer prevention and tools for early detection.	<ol> <li>The most common risk factors known by participants were hereditary followed by smoking.</li> <li>Most of participants knew that breast feeding is a protective factor along with nutrition and exercise however, fewer were knowledgeable about the pregnancy before 40 years of age as a protective factor.</li> </ol>
			5. The most common source of information among participants was found to be T.V and the least one was health care providers.
Ibrahim/ 1991	Cross-sectional study (N=500).	- To assess the awareness and attitude of adult	1. Age was not related to knowledge about breast cancer, risk factors, detection, signs and symptoms or management of breast cancer.
		females towards	2. Educational level was found to be significantly related to breast cancer knowledge, the majority
		various aspects of breast cancer.	of participants with high education knew that breast cancer is a malignant disease but many thought it is a fatal disease.
			3. Highly educated participants said that breast cancer is hereditary disease, and many knew that breast cancer is not an infectious disease and the association was significant.

Hussein/ 2013	Cross-sectional study (N=877).	- To elicit knowledge of breast cancer, perception of occurrence, and behaviour in relation to breast-self- examination.	<ol> <li>Less than half of highly educated participants knew that severe pain, breast pain, skin changes and non-painful mass could be symptoms of breast cancer, but the associations were significant.</li> <li>It was found that age doesn't influence breast cancer knowledge, however, participants' occupation was found to significantly influence the breast cancer knowledge.</li> <li>Employed females, and university students had a higher breast cancer knowledge score than housewives and school students.</li> <li>It was found that age, occupation, breast cancer score and being informed about breast cancer had positive effects on practicing BSE.</li> <li>Older participants (30- +40), employed, had high breast cancer score and who were informed</li> </ol>
Amin/ 2012	Cross-sectional study (N=599)	- To determine the possible correlates of Saudi women's interest in breast cancer genes testing including sociodemographic, the level of knowledge, the family history of breast cancer and the perceived personal risk.	<ul> <li>previously about BSE were more likely to practice BSE.</li> <li>1. The correct response for each of the breast cancer gene knowledge questions were minimal.</li> <li>2. Participants aged 18 - &lt;30 years had a higher knowledge score than the rest of the group and participants with the least education (&lt; secondary) had the lowest knowledge score than the rest of the group.</li> <li>3. The presence or absence of breast cancer in the family had no effect on the knowledge score.</li> <li>4. Participants aged 30- &lt;40, attained college degree or higher and were working; had a higher knowledge level than the rest of the group and this relation was statistically significant.</li> <li>5. Only 42.8% expressed their interest in knowing their breast cancer gene risk but the majority (90.3%) showed their interest in knowing more about the breast cancer genes.</li> <li>6. Significant association between the interest in breast cancer genes testing and age (30-&lt;40), college degree, positive family history of breast cancer, high level of knowledge score and higher perception of risk development.</li> </ul>
Milaat/ 2000	Cross-sectional study (N=6380).	- To assess the knowledge level of young women in secondary schools on the risk factors associated with breast	<ol> <li>Students with a good knowledge level had significantly higher age than the rest of group compared to students with low knowledge level.</li> <li>Married and have children had significantly higher knowledge level on breast cancer and its presentation. Students with a history of breast problems, who had had mammogram and who had family history of breast mass showed significantly higher knowledge levels.</li> </ol>

		cancer and early signs of presentation.	3. Presentation of breast cancer as a breast mass was answered correctly by participants but few knew that bleeding or changes in nipples could be signs of breast cancer
		-To identify their awareness of the use of BSE as a means of screening for breast masses and to assess their attitudes to this method.	4. Knowledge about BSE reported by half of participants.
Bener/ 2001	Cross-sectional study (N=1445).	- To evaluate knowledge, attitudes, barriers, and practices related to breast cancer screening among Arabic women.	<ol> <li>Responses to knowledge-based questions indicated low levels of knowledge about breast cancer.</li> <li>Only one third of the females knew that family history of breast cancer was a risk factor for the disease and half incorrectly stated that most breast lumps would become cancerous.</li> </ol>
Alam/ 2006	Cross-sectional study (N=864)	- To assess knowledge of breast cancer and sources of information about breast cancer among women in Riyadh.	<ol> <li>All participants had moderate knowledge about the breast changes, half of them knew about the change in size, half were aware about heaviness under the armpit, half had knowledge of discharge from the nipple and less than half of the sample knew about the change in the shape of the nipple.</li> <li>Knowledge of breast changes that occur when disease develops was below average for all symptoms.</li> <li>Participants had low to moderate level of knowledge, regardless their educational, marital status,</li> </ol>
Bener/ 2009	Cross-sectional study (N=1002).	- To explore knowledge, attitude and practice about breast cancer and to identify potential barriers to screening procedure among women.	<ul> <li>and their family history of breast cancer.</li> <li>1. Qatari females with higher education had a better general knowledge about breast cancer, although they were lower in number than females with lower education.</li> <li>2. Education appeared to be the major determinant of level of knowledge.</li> </ul>
Al-Amoudi/ 2012	Cross-sectional study (N=48).	- To assess the knowledge and attitude of early breast cancer	<ol> <li>The majority had heard about breast cancer.</li> <li>The knowledge about the symptoms were poor. Pain, change in the nipple and bloody discharge were the commonest identified symptoms.</li> </ol>

Al-Amoudi/ 2012	Cross-sectional study (N=500).	detection and identify barriers against this detection among this group of women with special needs. - To identify men's knowledge and attitude towards early detection of breast cancer.	<ol> <li>Breast mass was the most common symptom reported by the participants followed by change in size of breast, and pain.</li> <li>Very few reported bloody discharge and axillary mass as signs of breast cancer.</li> </ol>
Radi / 2013	Cross-sectional study (N=200).	-To investigate the level of breast cancer awareness among Saudi females living in Jeddah.	<ol> <li>Participants had poor knowledge about breast cancer warning signs and risk factors.</li> <li>Saudi females' knowledge about breast cancer warning signs differed significantly by their level of education; highly educated females had more knowledge about breast cancer warning signs than others.</li> <li>Females with college level education had significantly greater knowledge about breast cancer warning signs than the women of other levels of education.</li> <li>Findings indicated that Saudi females' level of awareness of breast cancer knowledge of breast cancer warning signs, risk factors, screening program and breast self-examination (BSE) was inadequate.</li> </ol>
Saeed/ 2014	Cross-sectional study (N=519).	- To assess women's awareness levels and knowledge in the state of Kuwait regarding the risk factors, symptoms, and diagnostic procedures of breast cancer.	<ul> <li>5. Awareness about breast cancer differed significantly by marital status, education and job.</li> <li>1. Known symptoms were abnormal breast enlargement, enlargement in the armpit and neighboring nodes, discoloration and texture, pain, nipple discharge and retraction, itchiness and discoloration and asymmetrical breast.</li> <li>2. High significant association was found between age, occupation, marital status, family history of various cancers incidence, and hearing about breast cancer, and knowledge of the breast cancer methods.</li> </ul>

			<ol> <li>The knowledge of symptoms and signs of breast cancer was significantly associated with age group above 50, graduate, employed, married, family history of cancer, family breast cancer history and the group who had heard about breast cancer.</li> <li>It was also noted that participants aged 50 and above were more knowledgeable about breast cancer risk factors, symptoms, and the age when mammograms begin.</li> <li>More than one third of respondents had a good overall knowledge of breast cancer symptoms, risk factors and breast examinations.</li> </ol>
			<ul> <li>6. Most identified signs and symptoms, lump, and enlargement of lymph node however, participants did not recognize other signs and symptoms, such as breast skin retraction, discharge from the nipple, itchiness and discoloration of nipple and asymmetrical breasts.</li> <li>7. Females in Kuwait show a reasonable awareness level on certain aspects of breast cancer.</li> </ul>
Rasheed/ 2013	Cross-sectional study (N=600).	- To assess the knowledge of risk factors and screening methods for breast cancer, perception of the disease, and practice of BSE among patients attending primary health care centres (PHCCs) in Al Khobar city, Saudi Arabia.	<ol> <li>Nearly half of the females had poor knowledge about breast cancer.</li> <li>The lowest knowledge score was obtained by females who were illiterate or had no formal school education whereas the highest score was taken by the college / university graduates.</li> <li>Age, educational level, and occupational status, were significant positive predictors of the knowledge score.</li> <li>Around two-thirds of females knew about the signs and symptoms of breast cancer, and painless breast lump being the most identified feature.</li> </ol>
Elobaid/ 2014	Cross-sectional study (N=247).	- To assess breast cancer screening knowledge, attitudes, and practices among women of screening age (40 years and older) in the city of Al Ain, United Arab Emirates (UAE).	<ol> <li>Few participants had good general knowledge of breast cancer, and few had very poor knowledge.</li> <li>UAE national females scored better than non-UAE national females. Generally, younger females (40-49) had better scores regarding knowledge than older females (&gt;49). The level of education was positively associated with better knowledge scores.</li> </ol>

AlSaeed/ 2015	Cross-sectional study (N=600).	- To determine the knowledge, attitudes, and practices (KAP) of urban women in Riyadh regarding breast cancer (BC) and its available screening and treatment modalities.	<ol> <li>Common misconceptions regarding symptomology of breast cancer:         <ul> <li>Active or passive smoking caused breast cancer.</li> <li>Never happens in women below 40 years.</li> <li>Breast cancer can happen after touching a breast cancer patient.</li> </ul> </li> <li>Saudi females had limited information about breast cancer.</li> <li>Educational level, age above 40 years and employment status had significant association with knowledge of breast cancer.</li> </ol>
Abolfotouh/ 2015	Cross-sectional study (N=433).	- To explore the perception towards breast cancer and towards BSE among Saudi women, using the Health Belief Model (HBM).	<ol> <li>The most common reported symptoms were breast discharge from the nipple, a lump and abnormal changes in breast size.</li> <li>The overall level of knowledge of breast cancer was low.</li> </ol>
Almutairi/ 2016	Cross-sectional study (N=174).	- To determine the level of awareness and knowledge of Saudi female patients about breast cancer risk about any information regarding BSE practices used by the physicians in the clinics and/ or by individual females at home.	<ol> <li>More than two third of the participants were aware of the symptoms of breast cancer. The symptoms most widely recognized by the participants were breast pain and breast lumps.</li> <li>Almost half of the participants had good knowledge about the risk factors and symptoms of breast cancer.</li> <li>The awareness of symptoms is higher than awareness about risk factors.</li> </ol>
Jahan/ 2016	Cross-sectional study (N=300).	- To determine the knowledge, attitudes and practices of women in Qassim region regarding breast self- examination (BSE), and also to explore	<ol> <li>The majority of participants heard about breast cancer, and one-third knew someone suffering from breast cancer.</li> <li>No significant association was found between age and number of correct answers but there was significant association between level of education and number of correct answers.</li> <li>Nearly one third had no idea of the presenting symptoms of breast cancer.</li> </ol>

		their level of knowledge regarding breast cancer.	4. The level of awareness in females of Qassim region about breast cancer and BSE was inadequate.
Bener/ 2002	Qualitative study (N=41).	- To explore perceptions, knowledge, attitudes and beliefs about breast cancer and its screening among Emirati national women in Al Ain, United Arab Emirates.	<ol> <li>Awareness of participants was found to be inadequate. They lack the understanding about the disease, its symptoms and risk factors. This thing has led to underutilization of the preventive measures.</li> <li>Awareness and knowledge about breast cancer helped participants to look after their health and took advantage of the available screening methods.</li> <li>Many of them knew they have low level of knowledge, and yet did not seek to improve awareness.</li> <li>The most common source of knowledge to participants were health care providers and media.</li> </ol>
Gonzales/ 2018	Cross-sectional study (N=400).	- To identify the health beliefs about breast self- examination and its relationships with the frequency of BSE among the women in the University of Tabuk at Saudi Arabia.	<ol> <li>Most participants knew about breast cancer.</li> <li>The main source of breast cancer information were mainly from Radio/ TV, then internet, newspapers and magazines, nurse or doctor, family member, and lastly from friends.</li> </ol>
Alshareef/ 2020	Cross-sectional study (N=400).	- To assess the level of awareness, knowledge and attitude of Saudi female teachers towards breast cancer, in primary, intermediate and secondary schools within the Makkah region.	<ol> <li>The most commonly known risk factors were: alcohol, x-ray exposure, family history, increased stress level, and oral contraceptive pills. Old age at pregnancy was found to be the least known risk factor to participants.</li> <li>The commonest signs and symptoms identified by participants was lump under armpit, followed by painless breast lump, and change in the shape or the size of the breast or nipples.</li> <li>The overall breast cancer knowledge was weak and very few participants had good knowledge about breast cancer.</li> <li>The knowledge about breast cancer was found to be more in teachers aged 46-55 years old and who were married, than the rest of participants.</li> </ol>
Alrashidi/ 2017)	Cross-sectional study (N=566).	- To assess the level of breast cancer related knowledge among a	1. The most common risk factor identified by participants was exposure to radiation, followed by smoking.

		Northern Saudi population.	
Allohabi/ 2021	Cross-sectional study (N=697).	- To evaluate the breast cancer knowledge (risk factors, causes, prevention and treatment) and to assess the breast self- examination (BSE) among women in Saudi Arabia, so as to explore possible correlation between education and knowledge and practice of breast cancer.	<ol> <li>It was found that more than two thirds of participants had moderate knowledge about breast cancer, one quarter had poor knowledge and only less than quarter had good knowledge.</li> <li>There was significant association between the educational level of participants and knowledge about breast cancer; participants with high level of education were found to be more knowledgeable about breast cancer. No significant association was found between the age or marital status and the level of knowledge.</li> <li>Women with higher education were more knowledgeable about risk factors. Highly educated females had better knowledge about causes of breast cancer, BSE and treatment than other aspects of breast cancer knowledge (spread and prevention).</li> </ol>
Al-Azri/ 2020	Cross-sectional study (N=358)	- To identify knowledge, attitudes and barriers of Omani women towards breast cancer screening.	<ol> <li>Two thirds knew that breast cancer is the commonest cancer in Oman, and the majority knew that if detected early it can be treated and nearly half of participants perceived themselves to be susceptible to breast cancer in the presence of a positive family history of the disease.</li> <li>Two thirds were aware that change in size, shape, symmetry, and colour are signs of breast cancer.</li> </ol>
Algamdi/ 2021	Cross-sectional study (N=675).	- To assess the level of cancer awareness and the relationship between the awareness and the relationship between the awareness of common cancer symptoms and risk factors and the sample's sociodemographic profile.	<ol> <li>There was a significant association between participants' education and the knowledge about cancer risk factors. Participants with high knowledge about risk factors were more likely to be university graduate, however, they were few.</li> <li>Family history had a significant association with the risk factors knowledge. More than half with no family history of breast had low knowledge about the risk factors than participants with positive family history.</li> <li>Nearly two third had low awareness about risk factors as compared to the rest, one third had moderate knowledge and only few had high knowledge about risk factors. Their associations were significant.</li> </ol>

			<ul> <li>4. There was significant association between the knowledge about breast cancer symptoms and: sex, nationality, source of information, and the overall awareness.</li> <li>5. Nearly one third of male and female participants had poor symptoms knowledge.</li> <li>6. Nearly half of Saudi participants had poor knowledge about the symptoms, whereas only few (10.7%) from non-Saudi had poor knowledge about breast cancer symptoms.</li> </ul>
Sabi/ 2021	Cross-sectional study (N=390).	- To estimate the awareness level of Saudi adults about risk factors and warning signs of cancer and observe the association of different determinants with cancer knowledge in Riyadh city.	<ol> <li>Most participants had general basic knowledge about breast cancer the role of screening methods.</li> <li>The most common warning sign of cancer known by participants were thickening or lump in the breast and unexplained weight loss.</li> <li>More than two thirds of participants did not know that being obese or overweight could be a risk factor for cancer and two thirds knew that genetic factors could be a risk for cancer.</li> <li>The overall knowledge of cancer was low.</li> </ol>
Kharaba/ 2021	Cross-sectional study (N=400).	- To evaluate the knowledge, attitude and practice of females in the UAE towards BC and breast self-examination practice in the seven Emirates.	<ol> <li>Sign/symptom identified by nearly two-thirds of participants were the old age and the presence of lump.</li> <li>Most participant would seek medical advice if they developed breast cancer, less than quarter would do nothing, very few would be scared or would go to prayer house.</li> </ol>
Alsharhani/ 2019	Cross-sectional study (N=500).	- To evaluate knowledge, attitude, and practices of breast cancer screening methods among female patients attending five primary healthcare centers in Najran, Saudi Arabia.	1. Predictors for the general knowledge about breast cancer were occupation, medical history and age at menarche being the highest, education being the second most predictor and lastly, history of benign breast cancer.

Alameer/ 2018	Cross-sectional study (N=150)	- To assess the effectiveness of health education in improving the knowledge and practices of female teachers regarding screening tools and the early detection of breast cancer.	<ol> <li>The overall knowledge of the control group and intervention group before the intervention were similar, however, after the introduction of the intervention the result varied. The intervention group scores increased following the intervention, but the control group scores remained the same.</li> <li>Most participants knew that with older age increased the chance of breast cancer.</li> <li>Nearly one third of participants from the control and intervention groups were aware that changes to nipples could be sign of breast cancer.</li> <li>Two thirds of participants were aware of breast cancer symptoms.</li> </ol>
Alkhasawneh/ 2016	Mixed method study (N=1372).	<ul> <li>To determine the level of awareness of Omani women about breast cancer in general and its early detection practices.</li> <li>To explore significant factors that affected or may affect their awareness related to this phenomenon.</li> </ul>	<ol> <li>Participants younger than 50 years of age were found to be more aware than older age group.</li> <li>Highly educated participants were more knowledgeable about breast cancer than participants with lower education and high family income was associated with better knowledge than others.</li> <li>Participants familiar with breast cancer were more knowledgeable than others and marital status had no significance association with breast cancer knowledge.</li> <li>Omani men need awareness as much as the Omani females through campaign or sending messages through social media to the husband, brother, and father in order to support the females around them.</li> <li>Healthcare providers required to teach their patients during health visit about breast cancer and the screening methods. Participants suggested to be informed about all the activities about the breast cancer so that people can attend and benefit from them.</li> </ol>

## vi. The screening methods

The systematic review of the literature identified screening activities as the fourth major theme discussed among the included studies. Out of the total 53 papers, 43 (Kharaba et al., 2021; Al-Azri et al., 2020; Alshareef et al., 2020; Alshahrani et al., 2019; Gonzales et al., 2018; Abudul-Aziz et al., 2017; Al Otaibi et al., 2017; Al-Wassia et al., 2017; Donnelly et al., 2017; Nageeti et al., 2017; Al Khamis et al., 2016; Alkhasawneh et al., 2016; Al Zalabani et al., 2016; Abolfotouh et al., 2015; Almutairi et al., 2015; Alsaeed et al., 2015; Bcheraoui et al., 2015; Elobaid et al., 2014; Latif et al., 2014; Mohammed et al., 2014; Renganathan et al., 2013; Radi et al., 2013; Rasheed et al., 2013; Amoudi et al., 2012; Al Amoudi et al., 2012; Alharbi et al., 2012; Azmi et al., 2012; Donnelly et al., 2012; Sabih et al., 2012; Amin et al., 2009; Bener et al., 2009; Qattan et al., 2008; Alam et al., 2006; Jahan et al., 2002; Bener et al., 2001; Milaat et al., 2000; Akhtar et al., 1995 and Ibrahim et al., 1991) discussed screening activities. Further details provided in Table 5.6.

According to the identified papers, screening activities included mainly: BSE, CBE, and mammogram. The studies included quantitative and qualitative methods and the main aim was to explore the prevalence of screening activities among the study populations, to evaluate the knowledge of the participants about breast cancer screening activities and related breast cancer screening activities to other independent socio-economic factors.

Among the 43 papers that discussed screening activities, 22 (Alshareef et al., 2020; Nageeti et al., 2017; Al Zalabani et al., 2016; Abolfotouh et al., 2015; Almutairi et al., 2015; Bcheraoui et al., 2015; Latif et al., 2014; Renganathan et al., 2014; Saeed et al., 2014; Truong et al., 2014; Hussain et al., 2013; Mahfouz et al., 2013; Radi et al., 2013; Rasheed et al., 2013; Al Amoudi et al., 2012; Alharbi et al., 2012; Azmi et al., 2012; Donnelly et al., 2012; Jahan et al., 2006; Bener et al., 2002; Milaat et al., 2000 and Ibrahim et al., 1991) explored the relationship between the knowledge of breast cancer among participants and their engagement in breast cancer screening activities. Knowledge about screening methods was low, with the majority of the studies reporting that while participants knew about breast cancer, their knowledge of all available screening techniques and their level of performance was low. Moreover, participants lacked knowledge about the recommended frequency, starting age and which screening method served what purpose. It is worth noting that older studies reported lower levels of screening participation that more recent studies. For example, in Bener et al., 2001 "It was clear that the practice of any of the screening activities considered to be low among the participant women" while Abolfotouh et al, 2015 reported that "the majority of participants had heard about the BSE". Information was sourced from previous campaigns, TV and the internet. However, more than half had never practiced BSE. Moreover, knowledge of breast cancer did not necessarily mean that women practiced BSE, as many participants reported more knowledge about BSE and CBE than mammogram.

The association between socioeconomic factors and breast cancer screening activities were also discussed in 21 studies (Donnelly et al., 2017; Alkhasawneh et al., 2016; Abolfotouh et al., 2015; Bcheraoui et al., 2015; Elobaid et al., 2014; Mohammed et al., 2014; Truong et al., 2014; Hussain et al., 2013; Alharbi et al., 2012; Azmi et al., 2012; Donnelly et al., 2012; Bener et al., 2009; Qattan et al., 2008; Alam et al., 2006; Jahan et al., 2006; Bener et al., 2002; Bener et al., 2001; Akhtar et al., 1995 and Ibrahim et al., 1991). The studies concluded that screening activities were associated with common predictors including: knowledge and awareness of breast cancer, its symptoms, and risk factors, being employed, living in semiurban areas, had 10 or less visits to the PHCCs, married females, those having a positive family history, higher level of education, higher husband's educational level, higher income and being aged 30-49 years old. Five studies (Nageeti et al., 2017; Latif et al., 2014; Mohammed et al., 2014 Akhtar et al., 1995 and Ibrahim et al., 1991) reported that women preferred being examined by doctors because they either did not know how to or lacked the confidence to perform BSE.

	C 11 1	• •	•	
Table 5.6: Summary	v of articles	eyamining	screening	methods
Tuble 5.0. Summur	y of alleles	Craining	Jereening	methods

First author's	Study type	Research question/	Findings/ Outcome
name/ Year		Aim	
Nageeti/ 2017	Mixed methods: qualitative and quantitative studies (N=40)	- To assess the perspective of Saudi women in Makkah region on breast cancer awareness and early detection.	<ol> <li>Nearly half of participants had never practiced BSE however, one third had done it few times.</li> <li>Two thirds knew how to perform BSE. Nearly two thirds reported that they had not been taught how to carry out BSE.</li> <li>Some preferred to be examined by a doctor rather than practicing BSE.</li> <li>Participants lack the knowledge on how to perform BSE and have little confidence in performing BSE.</li> </ol>
Mohammed/ 2014	Cross-sectional study (N=300).	- To assess the level of breast cancer awareness among Saudi females and to compare between housewives and employees' women regarding knowledge and practical of breast cancer.	<ol> <li>Most of participants heard about BSE and almost one third heard about it through media (TV, radio or newspaper), and one third heard about it through campaigns.</li> <li>More than two thirds knew that BSE should be practiced by females only, however, one third felt that both sexes should perform it. Nearly two thirds said that the starting age to do it is more than 25years.</li> <li>Many mentioned that BSE should be carried out weekly and less than one third said monthly. Half of participants knew that BSE should be done with four fingers.</li> <li>Three quarters did not have CBE. Most of participants did not have a mammogram, those who had, most had done it once.</li> <li>For most respondents, fear was the main motivation for their uptake of a mammogram.</li> </ol>
Alharbi/ 2012	Cross-sectional study (N=421).	- To assess breast cancer knowledge and awareness and factors associated with the practice of breast self-examination (BSE)	<ol> <li>When participants were asked about the practice of BSE, half of them did not know how to perform BSE and a third knew how to and had performed it.</li> <li>The majority did not receive advice on how to perform BSE, less than one quarter received a demonstration because of breast problem and the majority were not knowledgeable about the mammograms.</li> </ol>

Al Zalabani/ 2016	Cross-sectional study (N=465).	among female teachers. - To identify breast cancer knowledge, practice and screening barriers among women attending primary health centres (PHC) in Madina, Saudi Arabia.	<ol> <li>3. More than half of participants who practiced BSE, did so because of fear of breast cancer. and almost a third of them performed it because of pain in the breast or feeling a mass.</li> <li>1. Those who had done a mammogram were significantly more likely to be older than 50 years of age, Saudi nationals, university level education, employed, with high family income and family history of and friend history of breast cancer.</li> <li>2. Participants with poor levels of knowledge about breast cancer risk factors and screening were significantly less likely to participate in mammography.</li> <li>3. Two thirds of participants had poor knowledge about breast cancer.</li> </ol>
Al Khamis/ 2016	Cross sectional study (N=290).	- To evaluate the level of breast cancer awareness and perceived barriers to seeking medical care among Saudi women attending primary care services, using internationally validated tool.	1. More than half had never had their breast checked, one quarter checked it monthly and very few said that they checked it weekly.
Milaat/ 2000	Cross sectional study (N=6380).	<ul> <li>To assess the knowledge level of young women in secondary schools in the risk factors associated with breast cancer and early signs of presentation.</li> <li>To identify their awareness of the use of BSE as a mean of screening for breast masses and to assess</li> </ul>	<ol> <li>The level of breast cancer knowledge was significantly associated with some of the participants characteristics. Students who had a previous mammogram, visited a doctor for a breast problem or had any previous breast problem, had breast surgery and had a family history of breast mass were significantly more knowledgeable than the rest of students.</li> <li>It was discovered that more than one third of students who had performed BSE, had significantly higher knowledge of breast cancer risk factors.</li> <li>Female student were willing to learn about BSE and the majority requested to do so.</li> </ol>

		their attitudes to these methods.	
Bener/ 2002	Qualitative study (N=41).	- To explore perceptions, knowledge, attitudes, and beliefs about breast cancer and its screening among Emirati national women in Al Ain, United Arab Emirates.	<ol> <li>During the focus group discussions some females expressed their willingness in performing breast screening as a way of protecting themselves. This was expressed when they felt they would be susceptible to breast cancer.</li> <li>Females' knowledge and awareness about breast cancer's symptoms and risk factors might be the way to seek preventive measures. However, the opposite was correct, lack of knowledge was seen as a reason for not seeking the preventive measures.</li> <li>Some of the misconceptions were that mammography could cause disfigurement, the cure of breast cancer is not possible and if the disease spread nothing could be done.</li> <li>Many admitted that if they were taught about screening methods, they would have done it.</li> <li>Females felt responsible for their own health and their responsibility to look for preventive measures. Females believed that screening would lead to a better outcome and God act through it.</li> <li>Females with positive beliefs would perform the screening and those with negative beliefs would seek different path than screening like herbal medicine, cauterisation and other things.</li> </ol>
Bener/ 2001	Cross-sectional study (N=1376).	- To evaluate knowledge, attitudes, barriers, and practices related to breast cancer screening among Arabic women.	<ol> <li>It was clear that the practice of any of the screening activities considered to be low among females.</li> <li>BSE was performed in quarter of females who were younger (40-49 years), more educated (&gt; 6 years of education), one third employed, one third lived in semiurban areas, had visited the clinic 10 time or less in a year and one quarter came from low income families.</li> <li>CBE was noticed to be practiced more by one quarter younger age group (16%), one quarter had 1-6 years of education, nearly half employed, one quarter from urban area, one quarter had more than 10 visits during the year and one quarter came from high income families (14.5%).</li> <li>Mammogram was performed younger age group, with higher educational level, employed, lived in semi urban areas, had 10 or less visits to the health clinic during the year but came from low income families.</li> </ol>

			5. Predictors for performing BSE were being employed, living in semiurban areas and had 10 or less visits to the clinics. Predictors for the mammogram were employment, semiurban areas and 10 or less visits to the health clinics.
Alam/ 2006	Cross sectional study (N=864).	- To assess knowledge of breast cancer and sources of information about breast cancer among women in Riyadh.	<ol> <li>There was a strong association between married females with the knowledge and practice of BSE.</li> <li>Females with higher education were more knowledgeable and likely to practice BSE.</li> <li>Females with higher education knew and performed mammography more than others.</li> </ol>
Akhtar/ 1995	Cross-sectional study (N=266)	- To identify beliefs, attitudes, and perceived barriers of women of a particular community among women residing on Al Qassim region.	<ol> <li>It was found that sociodemographic factors had no significant relation with the performance of BSE.</li> <li>Most participants agreed that BSE is a way of screening for breast cancer and treatment options would be less severe in those who practice BSE.</li> </ol>
Bener/ 2009	Cross-sectional study (N=1002).	- To explore knowledge, attitude and practice about breast cancer and to identify potential barriers to screening procedures among women.	<ol> <li>Highly educated participants had a better knowledge about screening activities (BSE, mammogram) than those with lower educational level.</li> <li>BSE and CBE were performed most by the youngest age group 30-39 years of age and mammogram was best utilized most by 40-49 years of age.</li> <li>Most of married females used the screening methods more than the rest of participants.</li> <li>Having 5 children or less were using the BSE and CBE more than those with no children or have more than 5 children and females with more than 5 children had more mammography than the rest of other groups.</li> <li>Females performed CBE most had secondary education, were housewives, had higher income and had less than 5 visits to the clinic in a year.</li> </ol>

			<ul><li>6. Females utilized mammogram most had secondary school, sedentary, had middle income and visited the health clinic5-10 times a year.</li><li>7. Only one third practiced the BSE and the rest of them never did. CBE and mammography were not utilized by the majority.</li></ul>
Al Amoudi/ 2012	Cross sectional study (N=48)	- To assess the knowledge and attitude of early breast cancer detection and identify barriers against this detection among this group of women with special needs.	<ol> <li>More than two thirds of participants believed that BSE would not prevent breast cancer and one quarter believed that Zamzam water would prevent breast cancer.</li> <li>More than half of participants knew about BSE, half learnt about it, one third practiced BSE.</li> <li>Most lacked the knowledge about the benefits of the mammogram.</li> </ol>
Radi/ 2013	Cross sectional study (N=200).	- To investigate the level of breast cancer awareness among Saudi females living in Jeddah.	1. Nearly half of the study group knew how to perform BSE, but one third knew the proper timing, very few knew how to perform it.
Rasheed/ 2013	Cross sectional study (N=600).	- To assess the knowledge of risk factors and screening methods for breast cancer, perception of the disease and the practice of breast self-examination (BSE) among female patients attending primary health care centres in Al Khobar, Saudi Arabia.	<ol> <li>The majority knew that early detection could improve outcomes and survival, only one third knew that the mammogram is the gold standard secondary preventive measure.</li> <li>Nearly half of participants were not aware that effective BSE related to menstrual cycle.</li> <li>Higher knowledge was a predictor for BSE practice.</li> <li>Females aged 30- &gt;46 was twice as likely to perform BSE than those under 30 years of age. Participants with higher educational level were found to be 4 times likely to practice BSE than others.</li> </ol>

Saeed/ 2014	Cross-sectional study (N=519).	- To assess women's awareness levels and knowledge in the state of Kuwait regarding risk factors, symptoms and diagnostic procedures of breast cancer.	<ol> <li>Although most of participants were knowledgeable about BSE only half knew how to perform it; the remainder had not received any instruction on how to perform BSE.</li> <li>Almost half knew that it should be done monthly; a third knew the correct age to begin BSE.</li> <li>Half were aware of mammograms; only a quarter had it done before.</li> <li>Two thirds recognised that mammogram would help in breast cancer diagnosis.</li> </ol>
Al Saeed/ 2015	Cross- sectional study (N=600).	- To determine the knowledge, attitudes and practices (KAP) of urban women in Riyadh regarding breast cancer (BC) and its available screening and treatment modalities.	<ol> <li>More than half knew the meaning of BSE, half knew its importance, half knew how to perform it but only few were doing it regularly.</li> <li>Many of participants would encourage their friend or family to perform BSE.</li> <li>The majority believed that early detection improves survival.</li> <li>High educational level significantly associated with increased awareness about screening.</li> </ol>
Sabih/ 2012	Qualitative study (N=329).	- To explore attitudes and beliefs among major national groups of women residents in the Emirates of Abu Dhabi (EAD) in relation to breast cancer and screening.	<ol> <li>Well women WW, showed no knowledge about the available facilities for breast screening in the area. UAE nationals and Asian women showed better awareness and knowledge about the available facilities than the rest.</li> <li>Some of the younger age group from South East Asia (SEA) felt that they didn't need to worry about screening at this age however, few from Asia admitted that they had done BSE before.</li> <li>Older age group from the (WW) had a better knowledge about the available places for screening.</li> <li>Most of the study groups preferred to be examined by a doctor of the same gender WW and regular screeners (RS). The younger age group would change clinics, travel to another country or take a later appointment in order to be examined by a female doctor.</li> <li>UAE nationals didn't mind to be examined by a male doctor, however, Asian would go back to their country if no female available for their examination and Arabs preferred to have a chaperon during the examination.</li> </ol>

			6. Some preferred the herbal medicine, cauterization (UAE, SEA) or consulting a friend or a family member (1/3 RS, SEA).
Renganathan 2014	Cross-sectional study (N=369).	- To assess the knowledge and awareness of breast cancer symptoms among Omani women.	<ol> <li>The majority did not know about the screening program, nearly all of them haven't heard about mammography and only two thirds heard about the BSE.</li> <li>The result showed inadequate knowledge about the screening methods.</li> </ol>
Latif/ 2014	Cross-sectional study (N=150).	- To assess the knowledge, attitude and practices of university students towards breast cancer.	<ol> <li>Testing the students' knowledge about the different screening methods revealed that the majority knew that early diagnosis of breast cancer would improve the outcome and treatment, however, only few performed CBE, half had BSE and none had mammography done before.</li> <li>Most of participants (80%) agreed that visiting the doctor was the best for managing breast cancer.</li> <li>Knowledge about BSE and mammogram was judged inadequate. Half knew the benefit of doing mammogram.</li> <li>The level of knowledge of breast cancer was significantly associated with the practice of BSE.</li> </ol>
Jahan/ 2006	Cross-sectional study (N=300).	- To determine the knowledge, attitudes and practices of women in Qassim region regarding breast self- examination (BSE), and also to explore their level of knowledge regarding breast cancer.	<ol> <li>Most of the study group had never heard about BSE.</li> <li>It was found that BSE significantly associated with the level of education, employment status and the presence of breast cancer history.</li> <li>The majority strongly agreed that the earlier the diagnosis, the better the outcome. More than half strongly agreed that female over 20 should perform BSE.</li> <li>Almost all convinced that participants should have BSE education.</li> </ol>
Donnelly/ 2012	Cross-sectional study (N=1063).	- To investigate within the state of Qatar Arabic women's knowledge regarding	1. Awareness was defined as a preliminary understanding of breast cancer and it's screening. A female is a ware if she heard about breast cancer, received some information about it from at least one source"

		breast cancer and breast cancer screening (BCS) methods and their participation rates in BCS.	<ol> <li>2. "Basic knowledge" is a higher level of understanding and accurate knowledge about breast cancer and its screening. A female having a basic knowledge if she knew how to examine her own breast and knew the most recent national screening recommendations for mammogram, BSE and CBE.</li> <li>3. It was found that most of participants were aware of breast cancer, one third had awareness of BSE, less than half were aware of CBE and one third were aware of mammography. The overall basic knowledge was found to be very minimal.</li> <li>4. It was found that the awareness of breast cancer and the screening activities was related to the correct performance of BSE, CBE and mammogram. Also, basic knowledge was found to be related to good practice of all the screening activities.</li> <li>5. Attaining high level of education for both the husband and participant was also related to the screening activities.</li> <li>6. Other sociodemographic factors were found to be related to some of the screening activities. Being married was found to be related to CBE, being employed was found to related to BSE. Higher age group were found to be related to practicing BSE more than mammogram</li> </ol>
Al Azmi/ 2012	Mixed methods: Cross-sectional study (N=510) and a case control study.	- To identify the proportion of women practicing BSE, factors that could affect its performance and explore women's awareness about its practice steps.	<ol> <li>One fifth of the study group had practiced BSE.</li> <li>There were no significant differences between the groups in relation to sociodemographic factors. Participants in their 30s most likely to practice BSE.</li> <li>Nearly 35% knew up to 6 steps of BSE and none had all of the 12 steps correct.</li> </ol>
Mahfouz/ 2013	Cross-sectional study (N=1092).	- To determine the basic background knowledge, attitudes, and related practices among women in Abha city, in relation to breast cancer	<ol> <li>One third of participants practiced BSE before, however, the rest showed their interest in learning how to perform it in order to practice it in the future.</li> <li>The majority had CBE and two thirds had mammogram.</li> </ol>

		prevention tools and for early detection.	
lbrahim/ 1991	Cross-sectional study (N=500).	- To assess adult women awareness and attitude towards various aspects of breast cancer.	<ol> <li>It was found that highly educated participants had higher level of knowledge, however, large proportion of highly educated participants believed that mammography is a source of radiation.</li> <li>Most of highly educated females believed in regular breast check-up, many know about BSE and its importance for early discovery of breast cancer, however; only half of them had performed it.</li> <li>When participants were asked about mammogram, very few knew about it.</li> <li>Nearly half of the middle and high educated participants were aware that mammogram is for breast cancer early detection and a third from the low level of education.</li> <li>Many with primary education, from the middle and from the highly educated participants were unaware of the proper time to perform the mammogram.</li> <li>The majority across all level of education believed that breast cancer is curable when discovered early.</li> </ol>
Hussein/ 2013	Cross sectional study (N=1000).	- To elicit knowledge of breast cancer, perception of occurrence, and behaviour in relation to breast self- examination (BSE).	<ol> <li>It was found that performing BSE was significantly associated with age, occupation, breast cancer knowledge and previous information about BSE.</li> <li>Employee were the most category who practiced BSE among other groups and half of participants who scored better in the knowledge of breast cancer, had practiced BSE.</li> <li>Two thirds of participants who had previous information about BSE, were able to practice BSE.</li> <li>The most common reason in half of participants who practiced BSE was personal awareness.</li> </ol>
El Bcheraoui/ 2015	Cross-sectional study (N=10735).	- To investigate knowledge and practices of breast cancer screening among Saudi women aged 50 years or older in order to inform the	<ol> <li>One quarter of participants had practiced BSE more than 7 times during last year and nearly half had never practiced BSE at all.</li> <li>The majority never had CBE over the last year and never had mammogram as well.</li> <li>It was found that education, history of medical exam and being hypertensive would increase the likelihood of being screened by mammogram previously.</li> </ol>

		breast cancer national health programs.	4. Breast feeding and history of having CBE would likely predict that participants had mammogram before.
Donnelly/ 2014	Cross-sectional study (N=1063).	<ul> <li>To determine the factors that influence Qatari women's awareness of breast cancer and its screening activities.</li> <li>To find ways to effectively promote breast cancer screening activities among Arabic speaking women in Qatar.</li> </ul>	<ol> <li>The majority of the study group did not have BSE nor mammography awareness, but nearly half of them knew about CBE.</li> <li>It was demonstrated the majority had no basic knowledge about breast cancer screening.</li> <li>Only one quarter practiced BSE, one third practiced CBE and less than one third practiced mammogram.</li> <li>Age, marital status, participants and husband's education were closely associated with CBE awareness. Participants between the age of 40-49, married who had university degree with their husband were found to be more aware with CBE than the rest of participants.</li> <li>Non-Qatari participants, living in urban areas, employed and had higher educational level and with their husbands were found to be more aware of mammogram than the rest.</li> <li>Participants who had the doctor talking to them about breast cancer were more aware of CBE and mammogram than the others.</li> <li>Participants who had a family member or a friend with breast cancer had a better awareness of CBE and mammogram than the rest.</li> <li>Participants who received information about breast cancer from the media, doctor and healthcare provider were more likely to be significantly aware of CBE and mammogram than others.</li> <li>Predictors of CBE were: age, marital status, had the doctor talking to them and understood what he said and had doctors and media as their source of information.</li> <li>Predictors of mammogram were found to be: education (university) and source of information (family/ friend and media).</li> </ol>
ειομαία/ 2014	Cross-sectional study (N=247).	- To assess breast cancer screening knowledge, attitudes and practices among	<ol> <li>It was noted that UAE nationals were practicing all screening activities more than the non-UAE.</li> <li>Older women 50 years or older were utilizing the screening methods more than the younger age group.</li> </ol>

		women of screening age 40 years and older in the city of Al Ain, United Arab Emirates.	3. Participants with college or university level were using BSE/ CBE more than the rest.
Abolfotouh/ 2015	Cross-sectional study (N=225).	- To explore perception towards breast cancer and towards BSE among Saudi women, using the Health Belief Model (HBM).	<ol> <li>The majority of participants heard about the BSE. The major sources for their information were previous campaigns, TV and the internet. However, more than half of them had not practiced BSE.</li> <li>Nearly three quarter knew the proper starting age to perform BSE but less than half of them knew that it should be done monthly and less than half said that it should be performed 5 days after the menses.</li> <li>Two thirds of participants reported that the reason behind practicing BSE was the need to examine their breast regularly, one third to check the progression of some abnormal hormones, one quarter as advised by their doctor or that they might have breast cancer in the future and less than a quarter of them because of the family history of breast cancer.</li> </ol>
Almutairi/ 2015	Cross-sectional study (N=174).	- To randomly determine the level of awareness and knowledge among female Saudi patients about the factors and symptoms of breast cancer as well as any awareness about the practices for breast cancer self- examination.	1. The majority of the study group were aware of the benefit of BSE in detecting breast cancer early and considered to have a good knowledge and knew how to perform it. Nearly three quarter (69%) knew that it should be done monthly and only 62% knew that 7 days after the menses is the proper time to do it.
Donnelly/ 2017	Cross-sectional study (N=1063).	- The study explores the influence of socioeconomic status on breast cancer screening (BCS) among Arab women in Qatar.	1. Husband's educational level, participants' occupation and income were good predictors for screening activities. Annual income significantly predicted CBE and mammogram activities.

Al Qattan/ 2008	Cross-sectional study (N=966).	- To determine the frequency of practicing breast self- examination (BSE) among Kuwaiti females and factors that may influence it.	1. Source of information about breast cancer, source of information for the method of BSE, the frequency of it and the age of starting it were all different between the practicing and non-practicing group and the difference was significant.
Amin/ 2009	Cross-sectional study (N=1207).	- To assess level and determinants of knowledge about, risk factors for and utilization of screening methods used for breast cancer early detection among adult Saudi women in Al Hassa, KSA.	<ol> <li>The main reasons for performing the screening mammogram among participants were: for diagnosis fears and follow up. None of the participants thought of it as a part of their specific age recommendation.</li> <li>The reasons for performing CBE among participants were: lump/ pain in two thirds of participants, follow up in less than one third, few for assurance and as a result of acute problem.</li> <li>Participants had CBE done by: half by primary doctor, one third by private specialist, one quarter by surgeons and very few by female nurses.</li> <li>Participants who performed screening by CBE and mammogram according to the recommended age were only few for those aged 40 to &lt;50 years and one third for those 50 years and older.</li> </ol>
Gonzales/ 2018	Cross-sectional study (N=400).	- To identify the health beliefs about breast self- examination and its relationships with the frequency of BSE among the women in the University of Tabuk at Saudi Arabia.	<ol> <li>Most of participants heard about BSE, however, only few practiced BSE every month.</li> <li>Many participants expressed their willingness to practice BSE in the future, but only few would practice it every month and one third would never do so.</li> <li>It was found that a negative relationship between the frequency of BSE practice and the presence of barriers.</li> <li>The majority knew the benefit from practicing BSE but only one third had the confidence to perform it.</li> </ol>

Alshareef/ 2020	Cross-sectional study (N=400).	- To assess the level of awareness, knowledge and attitude of Saudi female teachers towards breast cancer, in primary, intermediate and secondary schools within the Makkah region.	<ol> <li>When participants were asked if they had a mammogram done before, less than quarter answered with 'yes': the majority was for a screening and one third was for diagnostic purposes.</li> <li>More than half of participants never had BSE: half of them did not know how to do it, think of it and one third thought that they didn't need it.</li> <li>Half of participants had a weak knowledge about screening. Only few knew what mammogram is and less than one third knew that it should be done regularly. Less than half of participants knew about the screening center within the region.</li> <li>The majority agreed on the importance of breast cancer screening and nearly two thirds would participate in a screening program if were asked.</li> </ol>
Al Otaibi/ 2017	Cross-sectional study (N=137).	- To assess the current knowledge and practices of women regarding breast self- examination and mammography screening in Riyadh, Saudi Arabia.	<ol> <li>More than half of participants had knowledge about BSE and the knowledge most commonly found in participants with age group 18-25 years. The association was significant.</li> <li>One third of university educated participants were more likely to have knowledge about BSE than other participants. Nearly half of married women were more likely to be aware about BSE than other participants.</li> <li>Although the knowledge about BSE in some participants was significant, however, the frequency of BSE practice was not significant.</li> <li>Awareness about breast cancer was significantly associated with education, participants with university education were more likely to be aware than participants with lower education level.</li> <li>Awareness about the mammogram had no significant association with any of the sociodemographic factors. The practice of mammogram was significantly associated with age and employment status.</li> </ol>
Al-Azri/ 2020	Cross-sectional study (N=358).	- To identify knowledge, attitudes and barriers of Omani women towards breast cancer screening.	1. The majority were knowledgeable about the availability of the screening program in the country.
Abudul-Aziz/ 2017	Cross-sectional study (N=816).	To investigate the perceived barriers	1. Very few participants who practiced screening activities (mammography and CBE) and nearly half of them were recommended by a healthcare provider.

		towards breast cancer screening in Al Hassa, Saudi Arabia.	<ol> <li>2. Factors were closely associated with breast cancer screening were: being older than 50 years, had a college degree or higher, living in urban area, had a history of benign breast lesion, used a hormonal contraceptive treatment and had more than 10000 riyal Saudi as family income.</li> <li>3. Factors like: employment status, marital status, history of breast cancer in the family or friends had no significant associations with the practice of screening activities.</li> </ol>
Kharaba/ 2021	Cross-sectional study (N=400).	- To evaluate knowledge, attitude, and practice of females in the UAE towards breast cancer and breast self- examination practice in seven Emirates.	1. The majority knew that early detection would increase the chance of survival, believed in the role of the screening methods, that cancer is preventable and that screening would be a cost-effective measure, however, nearly two thirds believed that mammogram would cause cancer.
Alshahrani/ 2019	Cross-sectional study (N=500).	- To evaluate the knowledge, attitude, and practice of breast cancer screening methods among female patients attending five primary healthcare centers in Najran, Saudi Arabia.	<ol> <li>More than one third of participants performed BSE at primary healthcare center, however, one third did not want to practice any of the screening method. One quarter had a mammogram done and CBE.</li> <li>The predictors for the screening methods knowledge were: education, occupation, history of benign breast cancer and parity being the highest, age at marriage being the second, age at menarche and the least predictor was age.</li> <li>More than half of participants got their information about breast cancer and breast cancer screening from the social media, very few got the information from their healthcare providers.</li> </ol>
Al-Wassia/ 2017	Cross-sectional study (N=3245).	- To assess mammography utilization and knowledge, and to determine barriers associated with mammography utilization among Saudi women.	<ol> <li>Nearly two thirds never had a mammogram before. Younger participants tend to use the mammogram more than older participants: 41-50 years &gt;51-60 years and &gt;60 years.</li> <li>Parity was significantly associated with the use of mammogram. Mothers who had one or 2 children were more likely undergone mammogram than females who didn't have children.</li> <li>Marital status was significantly associated with the use of mammogram (p=0.001); married females were more likely to use mammogram than single women.</li> </ol>

			<ul> <li>4. Education was also found to be associated with the mammogram knowledge; participants with educational level below high school were the least to use mammogram compared to others.</li> <li>5. There seemed to be regional variations in the use of mammogram across the country.</li> <li>6. More than two thirds who had positive family history of breast cancer, never use the mammogram. More than one third of participants perceived their knowledge about mammogram practice as poor and less than a third.</li> <li>7. Most participants knew that mammography is the gold standard preventive measure for breast cancer, two thirds knew its frequency use but nearly half knew the proper age to perform it.</li> </ul>
Alameer/ 2018	Cross-sectional study (N=150).	- To assess the effectiveness of health education in improving the knowledge and practices of female teachers regarding screening tools and the early detection of breast cancer.	<ol> <li>Nearly two thirds of participants practiced BSE before receiving any health education.</li> <li>After the health education, most of the intervention group practiced BSE and as a result they scored higher than the control group in which two third practiced BSE and scored less.</li> <li>After receiving the health education, three quarters of the intervention group and less than one third of the control group underwent CBE.</li> <li>Most of the intervention group and one third of the control group used the mammogram before receiving the intervention. However, the more participants underwent mammogram after the health education from the intervention group while the control group stayed the same.</li> </ol>
Alkhasawneh/ 2016	Mixed method study (N=1372).	<ul> <li>To determine the level of awareness of Omani women about breast cancer in general and its early detection practices.</li> <li>To explore significant factors that affected or may affect their awareness related to this phenomenon.</li> </ul>	1. Participants who were married, had secondary education, higher family income had a better early detection practice score.

#### v. Men's view about female breast cancer

Interestingly three articles (Gadi et al. 2021; Sabgul et al. 2021; and Donnelly et al., 2017) evaluated men's perspectives about breast cancer and breast cancer screening activities; these were summarized in Table 5.7. Two papers (Sabgul et al. 2021; and Donnelly et al., 2017) indicated that the majority of male participants had at least basic knowledge about some or all the screening methods. However, many of them did not know the details, the frequency, the proper time to perform and the age to start screening. In one study (Donnelly et al., 2017) male participants discussed the society and cultural beliefs about breast cancer. Male doctors, exposing a sensitive part to be examined, shyness and embarrassment were barriers to breast cancer screening. However, they showed their willingness to support their wives and encouraged them to look after their health.

First author's	Study type	Research	Findings/ Outcome
name/ Year		question/ Aim	
Almoudi/ 2012	Cross-sectional study.	- To identify men's knowledge and attitude towards early detection of breast cancer.	<ol> <li>About one third of participants believed that BSE would not prevent or have an impact on breast cancer</li> <li>Some participants believed in other treatment options that would provide cure from cancer like: drinking Zamzam water, reading Qura'n or using herbal medicine.</li> <li>Negative beliefs were also present in the mind of others and could be barriers against the screening methods. Such beliefs like: "breast cancer is a punishment from God", "there is no treatment for it" and "chemotherapy might cause death".</li> <li>More than half believed that mastectomy is the ultimate treatment option to breast cancer cases.</li> <li>Breast mass was the most common symptom reported by the participants followed by change in breast size and pain. Bloody discharge was reported by quarter along with axillary mass. Unfortunately, one third</li> </ol>
			<ul><li>of the participants did not know the symptoms of breast cancer.</li><li>6. One third of men participants believed that BSE does not prevent cancer, that breast cancer cannot be treated, and few reported that Zamzam water or Quran would recover the disease.</li><li>7. When asked about their attitude if their spouse got cancer; the majority said that they will never leave their wives.</li></ul>
			8. It was found that more than half knew the importance of practicing BSE but only one third would recommend it to their families. Most participants were unaware about the importance of the mammogram.
Donnelly/ 2017	Qualitative study.	- To investigates the attitudes and perceptions of Arab men in regards to breast cancer screening and what they see	<ol> <li>Most participants knew about the importance of breast cancer screening. They mentioned that a healthy family depends on the health of its woman.</li> <li>Participants thought it was important to practice the screening activities to discover the disease at its early stage and be able to treat it, however, few of participants were not very sure about the importance of breast cancer screening activities but most of them would encourage their wives to participate in screening activities.</li> </ol>

Table 3.7: Summary of articles examining men's view about female breast cancer

as both incentives and barriers to women's	3. Participants believed in their role toward their wives; they protect her and take care of her health. One mentioned that Islam urges men to look after their women because women play an import part in the family and society as well.
participation in BCS activities.	4. Cultural modesty is one of the reasons for females' refusal to be examined by others and reflects the cultural norms of GCC countries.
	5. Many participants said that being shy and embarrass is another reason for females' refusal to do breast examination. Exposing this part of their body is considered a sensitive issue. However, most of men support their females to practice screening activities and wouldn't mind being examined by health professionals.
	6. Few had good knowledge about BSE. The majority didn't know how BSE could be done but they knew that CBE should be done by a physician.
	7. Most of participants would name the mammogram as an x-ray and only few had a good knowledge of the mammogram. Few men admitted that they know about breast cancer but nothing about the screening activities.
	8. More than one third thought that breast examination should be done for the older age group 40 years and older and for the younger if indicated.
	9. Minimal number of men knew the clinics responsible for females' health that is operated by female doctors in the country. The rest didn't know but were sure that these clinics would encourage females to go and get examined.
	10. Most participants have a big concern about the examiner's gender. It was a very important point for them. They were repeating this point all over the interview.
	11. The support of a man and approval in everything is very crucial. In many families the females would not be able to go anywhere without his presence.
	12. Talking or discussing any private part is a taboo, embarrassing and socially/ culturally unacceptable. Participants pointed that Islam does not recommend it and consider it a taboo.
	13. One third of participants mentioned that when females chose to perform CBE, or when diagnosed with breast cancer they would be stigmatised.

			<ul> <li>14. Some husbands would abandon their wives if they were affected with breast cancer.</li> <li>15. Few men mentioned that breast cancer is a fatal disease and cannot be treated. Others refer to it as an infectious and contagious. Family members get scared if anyone within the family was diagnosed with breast cancer.</li> <li>16. Participants also mentioned that some people thought that a female with breast cancer can pass the disease to her breastfed baby.</li> <li>17. Participants asked the researcher for more information about the breast cancer disease including its cause, signs and symptoms, risk factors, treatment and types of screening methods in order to be able to encourage and support the women in their families.</li> <li>18. At the end of the interview, the researcher mentioned that participants were very enthusiastic to look for more information about be the participants were very enthusiastic to look.</li> </ul>
			for more information about breast cancer and its screening method. They very much wanting to help the women to look after their health.
Gadi/ 2021	Cross-sectional study.	<ul> <li>To evaluate men's knowledge about mammography screening.</li> <li>To assess men's behavior towards women</li> </ul>	<ol> <li>One third of participants knew that one or more of their close family had mammogram screening and nearly one third none of their family had a mammogram.</li> <li>Less than half knew about the proper frequency of a mammogram for the targeted age.</li> <li>Some recognised that a mammogram is the gold standard preventive method for screening. One quarter acknowledged about the proper age for a mammogram.</li> <li>More than half knew that they don't have enough knowledge about the screening methods. Only few reported having good knowledge about the mammogram.</li> </ol>
		regarding mammogram screening and the factors	5. Most participants recommended mammography to their female family members, and participants aged 31-40 were more likely to recommend it than others.
		influencing their behavior.	6. Participants with postgrad education were more likely to recommend mammogram to female family members.
			7. Participants residing in the Southern area were more likely to recommend mammogram than participants living in other areas.
			8. Older participants (>40 years) were more likely to have high knowledge score than other age group. Participants who had the lowest education level had the lowest knowledge score.

			9. Participants with positive family history of breast cancer had more knowledge score than participants with no history of breast cancer.
Sabgul/ 2021	Cross-sectional study.	To investigate husband's knowledge and wives' attitudes and practices related to breast cancer screening are not well understood in Saudi Arabia.	<ul> <li>With no history of breast cancer.</li> <li>1. Nearly three quarters heard about BSE, and less than one third knew the proper age for BSE.</li> <li>2. Nearly half didn't know the frequency of doing BSE.</li> <li>4. Two thirds knew what mammogram is, and more than one was knowledgeable about the proper age to perform it. The majority's wife did not have a mammogram ever, nor CBE or regular BSE.</li> <li>5. More than half of participants thought that their wives have the willingness to learn about BSE.</li> <li>6. The most common signs and symptoms known by the participants were drying and peeling of the nipples, change in the size of breast, nipple discharge, and nipple shape. Lymphadenopathy was the least known sign of breast cancer by participants.</li> <li>7. The majority identified hormonal replacement therapy as a risk factor to breast cancer. Other risk factors identified: oral contraceptive pills (OCP), older age group. Other risk factors were identified by less</li> </ul>
			<ul> <li>than half of participants.</li> <li>8. The most identified protective factor by participants was conception before the age of 30 years.</li> <li>9. When assessing the association between husband's sociodemographic factors and breast cancer knowledge with attitudes and practices of the wives toward breast cancer screening, it was found that husband's aged 40 and older was significantly associated with wives' screening by mammogram.</li> <li>10. Husbands' age of 40-49 was significantly associated with their wives CBE practice. Husbands aged 30 and older but younger that 50 were significantly associated with BSE practice by their wives.</li> <li>11. It was also found that being employed in private sector, having a higher household income and husband's knowledge about breast cancer were significantly associated with the wives' practice of the screening activities.</li> </ul>

## 5.6. Discussion

This systematic review aimed to understand awareness, beliefs and attitudes towards breast cancer and breast screening in the gulf region. The search resulted the inclusion of fifty-three studies originating from the GCC countries, mainly from Saudi Arabia. The majority were cross-sectional study designs (n=46). Synthesis identified five main themes.

It was evident from the review that awareness about breast cancer, its symptoms and risk factors, and breast screening was low among participants. While some studies found associations between levels of awareness and a range of sociodemographic factors the overall level of awareness was low compared to developed countries.

#### 5.6.1. Religion

Participants were found to have different beliefs about breast cancer and breast screening, and these were often related to religious beliefs and cultural norms. GCCs are religious countries and therefore believing in God plays a major role in in the everyday life of residents. For some participants, believing in God was a reason not to practice preventive measures or help-seeking behaviors. They believed that they had little control over their destiny and instead God is capable of taking care of them. This may explain delays in presentation and treatment. However, some participants would have the belief in using religious interventions rather than seeking medical help as a treatment from cancer. The importance of religion has been shown previously among African-Americans in USA (Jones et al., 2014) where they believed in a religious methods to treat their illnesses.

## 5.6.2. Men's control over women

Male dominance of females is common in GCC, although to a lesser extent in Kuwait. It is where there are boundaries on females' freedom and rights, they are not equal to men in so many aspects (Dr May Seikaly and Drs Corine van Egten, 2014). Several studies reported that the main reason for not seeking medical advice was their husband's disagreement to be examined by a healthcare professional especially in the absence of a female doctor. In one study, male participants expressed their disapproval to have their wives exposing a sensitive body part to a stranger (Aldosari, 2017, May). Up until recently, females in Saudi Arabia were not allowed to leave home without a chaperone, including for obtaining medical care (Weiner, 2020). This has been practiced as part of their culture however, reinforced by the Saudi law. In one study, it was mentioned that husbands would abandon their wives if discovered that they had cancer (Hwang et al., 2017), while another study, men gave their full-support to their wives (Eriksson et al., 2019). However, a secondary data analysis from the National Institute of Health (NIH) at Cancer Centre at Tampa, Florida stated that the relationship between partners/spouse remained the same as it was before the illness, who used to live happily with their spouse continued to be happy even after diagnosing the partner/ spouse with an illness, and those who had an unpleasant relationship would continue to have the same life (Morgan et al., 2011).

#### 5.6.3. Breast cancer misconception

The synthesis also illustrates that many females have misconceptions about breast cancer and breast screening. Some believed that cancer is an infectious disease and could be transmitted to others, which may explain reluctance to disclose or share information about cancer with each other. Moreover, it may lead to delayed presentation, diagnosis, and the commencement of treatment. This was a consistent finding with one study conducted in the USA, where 80 participants from different ethnic groups participated in focus group discussion (Facione and Giancarlo, 1998). It was found that some of the participants hid their symptoms and signs of breast cancer and were silent throughout cancer illness, which resulted in delayed presentation with the ultimate diagnosis of advanced disease. One participant of that study revealed.

"My sister was living alone. I wasn't there and she didn't discuss it with my other sisters. By the time she did, it had spread so there was no hope for her"

(Facione and Giancarlo, 1998)

### 5.6.4. Fear

Fear was found to be the most common barrier for breast cancer screening among participants. Although the advances in breast cancer management over recent years, which result in promising outcomes and improvements in survival rate, people still fear breast cancer (Vrinten et al., 2017). Participants fear the word cancer and they would usually call it "that disease" and its consequences including treatment (Donnelly et al., 2017). They thought that cancer is a fatal disease and could not be treated. When asked participants about their fear, they mentioned that one reason for their fear could be their lack of knowledge about breast cancer and its screening measures.

In this review another fear expressed by participants in multiple studies, was of a fear of mammography because of the pain they might experience and exposure to radiation. A similar finding was found in a study examined the reasons behind people's fear about cancer (Vrinten et al., 2017). This was another reason for the delay in presentation or practicing of preventive measures.

# 5.7. Strengths and limitations

The strength of this review because:

- It is the only systematic review that examined the understanding about awareness, beliefs and attitudes towards breast cancer and breast cancer screening behavior in the Gulf region and meeting all the objectives of the study.
- 2. Papers were selected from six databases and no limit to time period was used in order to include as many papers as possible.
- The review was registered in PROSPERO, which is an international database for registering the systematic review (University of York, 2016).
   Some of the limitations found in this review:
  - Bias may be present as most of the studies included were from Saudi Arabia. Although Saudi Arabia is part of the GCC countries, yet it has slight cultural differences. This could not be avoided as simply we included all available literature. Highlights the need for further research in GCC countries.

# 5.8. Summary

In appraising the quality of the papers included some were found to be good and others were very good which may impact on the overall quality of the evidence and the certainty of the conclusion. However, the presence of this mass papers regardless of the quality, indicated that awareness and uptake of screening is poor, reflecting the reality of the picture in GCC countries.

Using internationally published literature, this systematic review gave a description about the awareness, beliefs and attitudes about breast cancer and breast screening in the Gulf region. It also explored and identified reasons behind the low level of awareness within the region. Further studies examining the level of breast cancer knowledge and its screening methods in Kuwait in particular, and the possible ways to improve it are discussed in the following chapters.

# Chapter 6 Breast cancer knowledge and awareness among female residents of Kuwait. A quantitative study

# 6.1. Introduction

As outlined in chapter two data on the awareness and knowledge of female breast cancer in Kuwait are lacking. This is the first study to fully explore breast cancer awareness and knowledge in a nationwide study of Kuwaiti females.

The aim of this study was to evaluate the level of knowledge and awareness about breast cancer non-lump symptoms, risks, and screening programs in the general population of females in Kuwait attending general practice clinics in the five districts of the country. The study will also explore factors (sociodemographic factors, confidence skills and behaviour in relation to detecting breast cancer change, knowledge of the national screening program in Kuwait, anticipated delay in contacting the doctor, barriers to seeking medical help, knowledge of age-related lifetime risk and knowledge of risk factors) associated with awareness of non-lump symptoms and breast cancer knowledge. This was done using a modified validated tool; the Breast Cancer Awareness Measure (BCAM) (UK, 2009) and to identify possible points for intervention. Findings will assist in planning the development of an intervention responsive to the specific needs of this population.

# 6.2. Study Objectives

To meet the overall aim of this study, the following objectives were studied:

- 1- To describe BCAM domains (sociodemographic factors, breast cancer symptoms and signs, confidence skills and behaviour in relation to detecting breast change, knowledge of the national screening program in Kuwait, anticipated delay in contacting the doctor, barriers to seeking medical help, knowledge of age-related lifetime risk and knowledge of risk factors), in the study population.
- 2- To summarize the relationship between awareness of non-lump symptoms with the BCAM domains (sociodemographic factors, confidence skills and

behaviour in relation to detecting breast cancer change, knowledge of the national screening program in Kuwait, anticipated delay in contacting the doctor, barriers to seeking medical help, knowledge of age-related lifetime risk and knowledge of risk factors).

- 3- To investigate sociodemographic factors associated with awareness of nonlump symptoms and breast cancer knowledge (knowledge of the national screening program in Kuwait/ confidence, skills, and behaviour in relation to detecting breast cancer change).
- 4- To investigate the relationship between awareness of non-lump symptoms and breast cancer knowledge (knowledge of the national screening program in Kuwait/ confidence, skills, and behaviour in relation to detecting breast cancer change).

# 6.3. Study design and setting

This study used a cross-sectional design to address the aims and objectives of this study. The cross-sectional design is usually used for population-based surveys and provides a snapshot of the frequency of a characteristic in a population at a specific point in time and is therefore useful in collecting baseline information in that population (Setia, 2016).

The BCAM questionnaire, was used to collect information on breast cancer awareness among adult females in Kuwait. A detailed description of the instrument is provided in Section 6.3.2. and 6.3.2.1. The survey was targeted at adult females attending PHCC clinics in Kuwait. The choice of public versus private clinics stems from the fact that public clinics attract very heterogenous populations and are more representative of the country population than private clinics. In addition, the choice of general practice ensures the selection of a diverse population including patients presenting to the clinics for various complaints and not restricted by medical specialism, as well as people accompanying patients and who are thus not necessarily attending for medical help.

## 6.3.1. Study population

The study population consisted of four hundred adult female residents of Kuwait attending (GP) clinics. Adulthood was defined as 21 years and older, which is the legal age in the country. Participants were selected from five out of the six health districts in Kuwait; the 'Capital,' 'Hawally,' 'Farwaniyya,' 'Ahmadi' and 'Jahra' but the sixth district which is 'Al Sabah' was not chosen as this health district is composed of hospitals and specialized centers for different subspecialities.

The sample size of four hundred was based on sample size calculations described in Section 6.3.4.

Two public clinics within each of the health districts were chosen according to the highest number of patients they receive per year. Annual descriptive data for the number of patients visiting each clinic were available in the main office of each health district. Where a clinic was difficult to reach either geographically or due to patients' reluctance to participate, it was replaced by the clinic with the next highest number of patients in that same health district.

Eligible participants were those visiting the clinics for a consultation or accompanying a patient for any reason. They had to be 21 years or older, able to read and write in Arabic and they voluntarily agreed to take part in this study. Potential participants who failed to meet any of these criteria, were not eligible to participate in the study.

# **6.3.2.** Methods and data collection Data collection tool (the BCAM Questionnaire)

The BCAM (Linsell et al., 2010) was used in this study to assess breast cancer awareness and knowledge. The BCAM used was an adapted Arabic language version of the self-administered validated tool, developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer (Linsell et al., 2010). The questionnaire has been designed to evaluate breast cancer awareness in women.

The BCAM has been adapted, translated into Arabic and validated for the assessment of breast cancer awareness in Arab females and for the Omani population specifically. The translated instrument has strong criterion validity (R =0.58, P < 0.01) and a high internal consistency for the specific subscales for risk factors and warning signs (Cronbach's alpha 0.856 and 0.890, respectively) (Alkhasawneh et al., 2017). However, since the Arabic translation had been adapted to the Omani population, the opening sociodemographic section of the questionnaire was revised in order to be appropriate for the population of Kuwait. Furthermore, the original version of the Arabic BCAM did not include domains three and four of the original BCAM, which is a major limitation of the current Arabic version. Therefore, we further adapted the Arabic version to include these two domains on health-seeking behaviours: "anticipated delay in contacting the doctor" and "barriers to seeking medical help", consisting of one and ten questions, respectively. It was noted that domain 4 "Knowledge of the national screening program" that question one and two carried the same meaning, however, this was present in the validated Omani version, and they were left without changes. Other data that were collected included demographic and socioeconomic data, previous exposure to breast cancer and exposure to some breast cancer risk factors details provided in section 6.3.2.1.

The questionnaire could be completed within 10 to 15 minutes either in a selfcompletion manner or in a face-to-face interview, depending on the participants' preference.

#### 6.3.2.1. The content of the BCAM

The modified Arabic version of the BCAM used in this study consisted of 8 domains sociodemographic characteristics, signs and symptoms of breast cancer, confidence and skills in relation to detecting a breast cancer change, knowledge of the national screening program in Kuwait, anticipated delay in contacting the doctor, barriers to seeking medical help, knowledge of age-related and lifetime risk, and knowledge of the risk factors. An English translation of the questionnaire used is included in Appendix 13. The content of each domain is outlined below.

# Domain 1: Sociodemographic characteristics and exposure to breast cancer information.

This domain comprised several sociodemographic questions including four openended questions: 'what is your nationality?', 'what is your age?', 'total number of children'/or 'not married', and 'area of residence', and close-ended questions with predefined answers that the participant could select from: what is your marital status? (single/ married/ divorced/ widowed), educational level (below secondary "primary or intermediate"/ secondary or equivalent "high school"/ above secondary & below university "college"/ university and above "university"), what is your current employment status? (unemployed/ housewife/ working full time/ working part time/ retired/ student), total household income (less than 500 Kuwaiti Dinar/ between 500-1500 Kuwaiti Dinar/ between 1500-2500 Kuwaiti Dinar / between 2500-3500 Kuwaiti Dinar/ above 3500 Kuwaiti Dinar).

In addition, this section included three questions relating to previous "Exposure to breast cancer or breast cancer information": do you have a family member with history of breast cancer? (yes/ no/ I don't know), do you have a close friend with a history of breast cancer? (yes/ no/ I don't know), do you have any prior information about breast cancer? (yes/ no/ I don't know) and if yes, what is/ are your source(s) of information? (Please select all that apply doctor/ health educator at clinic/ tv/ radio/ newspaper, magazines/ internet/ friends and family/ others).

#### Domain 2: Breast cancer signs and symptoms

This domain assessed the participant's knowledge about breast cancer signs and symptoms. A list of signs and symptoms was provided, and the participant indicated whether they thought each was a sign or a symptom of breast cancer or not. The question was presented as follows: Please choose the answer you consider as a sign and/ or a symptom of breast cancer or not, only one answer is required for each question: a lump or thickening in the breast, a lump or thickening under the armpit, bleeding or discharge from the nipple, pulling in of the nipple inside, any rash on or around the nipple, redness of the skin of the breast, change in the size of the breast or nipple, a change in the shape of the breast or nipple, a pain in the breast or

underarm and lastly, dimpling on the skin of the breast. Possible answers were (yes/ no/ I don't know).

We considered a participant to be *aware* of breast cancer symptoms, if she knew five or more of the non-lump symptoms from the nine provided and to be considered *unaware* if she knew less than 5 of the non-lump symptoms from the nine symptoms provided (Linsell et al., 2010). Lump symptoms are widely known to people and that is why the knowledge of non-lump symptoms were chosen to be the awareness to breast cancer symptoms. One study that took place in the UK explored the awareness of breast cancer risks and symptoms among the elderly. The study demonstrated that although elderly women had some knowledge about breast cancer risks and symptoms, they showed a lack of awareness of the non-lump symptoms and poor knowledge of other risk factors (Linsell et al., 2008, Grunfeld et al., 2002).

# Domain 3: Confidence, skills and behaviour in relation to detecting breast cancer change

This domain measured three different themes in three questions. 1) How often do you check your breast? (Rarely or never/ at least once every 6 months/ at least once a month/ at least once a week). The answers to these questions were recoded into: "Once every 6 month/ rarely or never" as one answer and "at least once a week/ once a month" as one answer. 2) how confident are you at noticing a change in your breast? (Not at all confident/ not very confident/ fairly confident/ very confident), these answers were recoded as well into "not at all confident/ not very confident" and "fairly confident/ very confident". 3) what would you do if you noticed a change in your breast? (nothing/ use traditional methods, healing/ search the internet/ seek medical help, get a doctor's opinion/ I don't know).

### Domain 4: Knowledge of the national screening program in Kuwait

This domain questioned the participant's knowledge about the national screening program through the following questions: To your knowledge, is there a national breast cancer screening program in Kuwait? (yes, no), are you aware of the Kuwait National Mammography Screening Program and its activities? (yes, no), have you ever

been for breast cancer screening to any facility in Kuwait? (yes, no), If yes, where did you go for screening?

#### Domain 5: Anticipated delay in contacting the doctor

This domain addressed the time to contact the doctor if any change or abnormality were detected, which was evaluated using an open-ended question: If you find a change in your breast, how soon would you contact your doctor? The participants had the option of stating the time they take before seeking medical help. The participant also had the option to select 'I don't know'.

#### Domain 6: Barriers to seeking medical help

This domain sought to understand the barriers that prevent women from seeking medical help when they need it. It included one question that lists ten possible scenarios for the participant to judge whether it is a barrier or not. The question was phrased as follows: Some people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to the doctor? (Only one answer is required for each question): a) too embarrassed to go and see the doctor, b) too scared to go and see the doctor, c) I find my doctor difficult to talk to, d) difficult to make an appointment with the doctor, e) too busy to make time to go to see the doctor, f) too many other things to worry about, g) difficult to arrange transport to doctor's surgery, h) worrying about what doctor might find may stop me from going to the doctor, i) not feeling confident talking about my symptoms with the doctor). The participant could answer with one of the following for each scenario: yes often/ yes sometimes/ no/ I don't know. For the purpose of the analysis, the optional answers were further grouped into two categories: "yes often/ yes sometimes" and "no/ I don't know". In addition, this section included an open-ended question prompting the participant to list any other perceived barriers than the ones listed.

#### Domain 7: Knowledge of age-related and lifetime risk

This domain focused on the participant's knowledge of age-related breast cancer risk. It mentioned the following: Please select the appropriate response according to you: who is the most likely to develop breast cancer among women in Kuwait? (a

woman younger than 30 years/ a woman 30 to 40 years old/ a woman 40 to 50 years old/ a woman more than 50 years old/ I don't know). Optional answers were recoded further in the analysis into the followings: "a woman younger than 30 years old/ a woman 30-40 years old" because both answers were considered wrong ones and "a woman 40-50 years old/ a woman more than 50 years old" those answers were considered the correct ones because the incidence of breast cancer in the gulf region is around 47 years of age.

#### Domain 8: Knowledge of risk factors

This last domain assessed the participant's knowledge about breast cancer risks. The question listed 12 risk factors that the participant had to consider: *Please select to what degree you agree that the following are risk factors for breast cancer: (Only one answer is required for each question):* a) having a personal history of breast cancer, b) using oral contraceptives, c) being overweight (more than 30 kg above normal weight), d) having family members with history of breast cancer, e) having children later in life, f) not having children, g) having a period at an early age, h) having a delayed menopause, i) participating in regular physical activity or exercise. The participant could have responded with one of the following options: strongly agree/ agree/ strongly disagree/ disagree/ I don't know. However, for the analysis purposes and to ease the process, the optional answers were recoded into the followings: "strongly agree/ agree," "strongly disagree," disagree," and "I don't know".

#### 6.3.2.2. Pilot testing of the research instrument

Pilot testing allows the researcher to examine the instrument to be used for the purpose of the survey on a small number of people before conducting the main study. It is one of the crucial stages in planning a research study. The aims of pilot testing are:

- To determine the viability and detect the weakness of the research.
- To assess whether the questionnaire is suitable for use on the target population and whether it asks what it is intended to ask.
- To find out the time required to complete the questionnaire.

To test the willingness of the population in participating in such a research (Zailinawati Abu Hassan, 2006).

The researcher carried out pilot testing of the modified validated Arabic version of the BCAM in early November 2017 on 20 females (of a total of 35 who were approached) where their age ranged between 30-65 years who attended different public places such as the supermarket, nursery, etc. Some of the participants were relatives. After the pilot testing, some modifications to the questionnaire were introduced such as adjusting the language to become more appropriate to the local context and fine-tuning of the design of the questionnaire.

#### 6.3.2.3. Data collection and survey administration

Data collection was initiated in December 2017. It was convenient to start with the 'Capital' district, the home district of the researcher, given her familiarity with the clinics and their GPs within that district. The other clinics followed consecutively with no specific order.

Before the initiation of data collection, the researcher first contacted the director of the clinic, and introduced herself, explaining the purpose of the visit as well as the study and providing proofs of ministerial ethical approval to conduct the study. Subsequently, the clinic director would take the researcher on a tour in the clinic, after which the researcher was able to start approaching potential participants.

The researcher approached females systematically as they came into the clinic and while they waited in the clinic waiting room. A detailed approach to sampling is provided in Section 6.3.4. The researcher introduced herself and informed them about the study. Then she went through the participant information leaflet and the information sheet (Appendix 5) she would explain in detail the benefits and risks of participation and that their participation was voluntary and that it was possible to withdraw their consent at any time. Those who agreed to participate were then asked to sign an informed consent form (Appendix 3). After obtaining consent, the researcher handed out the survey to the participant who completed it either themselves or were interviewed by the researcher when preferred. If ever the participant had any questions, the researcher was able to answer them. At the end,

almost all the participants completed the survey by themselves. The researcher made sure that the participant completed all the questionnaire and did not miss any section or question.

Once the participant completed the questionnaire, she handed it back to the researcher who thanked her for her participation. The consent form and the questionnaire were given the same participant identification number. Paper copies of the questionnaire and consent form were stored separately in the researcher's home in a secure office. Once inputted electronically to an excel spreadsheet, the data were stored on the University of Glasgow's J drive, which is backed up regularly. This was stored in a folder that had access restricted to the student, her supervisors and IHW administrators. Names of participants were collected via the consent form can be linked to the questionnaire via participant identification number. Only the researcher has access to this.

Data collection was carried out during weekdays (Sunday to Thursday according to working days in Kuwait). The researcher had to drive twice in a day to the clinic if she did not get the required number of participants; in the morning and afternoon and would return home at the end of the day.

It took the researcher six months to collect the required data. The researcher had to be chaperoned by her husband in two districts that were the furthest from the Capital district (Jahra and Ahmadi) as it was unsafe for the researcher to collect data alone there. In those two districts, the cultural differences do not allow women to do certain things: like driving a car, going out without a male relative whether a brother, a father, or a husband and without covering the hair with veil and wearing long baggy clothes. It exhibits a masculine society. The researcher's husband for this reason had to take some days off work.

## 6.3.3. Improving response rate

In order to maximize participation rates, the researcher adopted several approaches to ensure transparency with the participants and encourage participation:

- Clearly introduced herself and provided full disclosure.

- Provided detailed information related to the study before participation; including the purpose of study, the study procedures or activities, the time required to complete the questionnaire, and how and where their answers would be utilized.
- Assured the participants that confidentiality would be respected at all times and that all the data provided would not be shared with anyone outside the study team.
- Showed the participants appreciation to their input, time and contribution to the study and thanked them for their participation. Provided the study survey or questionnaire in a clear and easy format to complete.

The nature of the questions being mostly close-ended rather than open-ended, might have played a role in encouraging participation (VanGeest et al., 2007), given that they would require less effort than open-ended questions to be completed. Finally, it was important to highlight the pivotal role of GPs in encouraging participation of patients attending their clinics. She/ he would speak to the patients in the waiting area before entering their appointments and while waiting to be seen by the doctor. Most of the patients would complete their survey before being called and those who were called in the middle, they would come back after finishing their consultation to complete the survey, however, very few left without coming back and in that case other patients would be approached to compensate for the missing number.

### 6.3.4. Sample size and sampling method

The sample size required for this study was based on the stratified sampling method. Since participants were chosen from all over the districts and in order for our sample to be random and representative of the population, a stratified sampling method was selected. Based on data published on IndexMundi (IndexMundi, 2016) the female population of Kuwait aged 21 and above was estimated at approximately 800,000 in 2016. Considering a margin of error of 5%, a representative sample size for the population of interest was calculated:

$$n = \frac{N}{1 + Ne^2} = 400$$

With n: sample size, N: Total population size, e: margin of error

The required sample size was then stratified by the included districts, and subsequently clinics and hence 40 subjects had to be sampled from each clinic, nevertheless, we aimed at recruiting 50 participants per clinic to account for non-response.

Participants were selected using systematic random sampling. We estimated that each clinic received on average 50 females (be it patient or accompanying person) per day and that we would be able to approach 10 subjects (n) per day. Based on the sampling fraction n/N in our case 10/50, we approached the first female attending the clinic and then each 5<sup>th</sup> female and so on. Women who did not fit the eligibility criteria or did not agree to participate in the study, were replaced by the subsequent 5<sup>th</sup> female.

## 6.3.5. Ethical considerations

The study was conducted in accordance with the World Medical Association Declaration of Helsinki (1964) and its revisions (Tokyo [1975], Venice [1983], Hong Kong [1989], South Africa [1996] and Edinburgh [2000]). Ethical approval (project number: 200170015) was sought from the University of Glasgow, College of Medicine, Veterinary and Life Sciences Committee and from the Standing Committee for Coordination of Health and Medical Research in Kuwait before any research activities were performed (Appendix 1, 2).

The investigator was responsible for reporting to the ethics committee the changes made to the study protocol and any updates as required by the committee. In addition, before any participant completed the survey, they had to voluntarily agree to participating in the study and sign an informed consent form. They were also advised that they could withdraw consent at any time.

## 6.3.6.Data management

Questionnaire responses were entered into a Microsoft Excel spreadsheet by the researcher, according to a data dictionary that was established at the time of questionnaire development (Appendix 12).

# 6.3.7. Statistical analysis

Statistical analyses were conducted using IBM SPSS Statistics for Windows, version 25 (IBM Corp., Armonk, N.Y., USA). Statistical analyses consisted of descriptive and inferential statistics. After importing the data into SPSS and then cleaning it, it was ready for analysis.

Descriptive statistics were presented using frequencies and percentages for the categorical data and mean and standard deviation (SD) for the continuous data. Recoding of variables was done for the convenience of the analysis.

Categorization of the age variable in order to look at breast cancer and breast cancer knowledge by different age groups rather than the median/ mean age group was conducted, which is more informative for intervention planning.

The associations between the awareness of non-lump symptoms with sociodemographic factors, confidence, skills & behaviour in relation to detecting breast cancer change, knowledge of the national screening program in Kuwait, barriers to screening, knowledge of age related, and lifetime risk and risk factors were evaluated by cross tabulation and by using Chi square test.

Binary logistic regression models were used to address objectives 3 and 4:

- 3- To investigate sociodemographic factors associated with awareness of nonlump symptoms and breast cancer knowledge (knowledge of the national screening program in Kuwait/ confidence, skills, and behaviour in relation to detecting breast cancer change).
- 4- To investigate the relationship between awareness of non-lump symptoms and breast cancer knowledge (knowledge of the national screening program in Kuwait/ confidence, skills and behaviour in relation to detecting breast cancer change).

Using the logistic regression analysis, four models were generated to further examine the findings obtained from the above analysis. Model 1 examined the relationship between the outcome variable (Awareness) with sociodemographic variables, frequency of checking the breast, breast cancer knowledge and action taken in response of noticing any changes to the breasts. Model 2 was a multivariable analysis evaluating the relationship between the sociodemographic variables with the awareness of non-lump symptoms. Model 3 was a multivariable logistic regression analysis measuring the association between the sociodemographic variables, family history of breast cancer, friend history of breast cancer with the awareness of non-lump symptoms. Model 4, which was the last one, a multivariable logistic analysis to examine all the included variables with the awareness of non-lump symptoms.

The odds ratio (OR) with corresponding 95% confidence intervals and p-values were generated. The level of significance was set at 5% and 95% confidence intervals were presented where appropriate. Rounding up percentages to one decimal place, which resulted in more than 100% in the tables provided in the result section.

Data obtained from this study will be compared to BCAM data obtained from other regional countries as well as from the UK. Although the researcher aimed at having the data complete, very few data were missed or not being answered by participants; this is outlined in the results.

# 6.4. Results

## 6.4.1. Descriptive results

We approached 556 participants and invited them to participate in the survey. Out of the 556, 156 (28%) were excluded as they were not eligible and failed to meet all the inclusion criteria; either because they were non-Arabic speakers, less than 21 years of age or simply because they refused to participate because of personal reasons or limited time in the clinic. The remaining 400 were eligible, provided full informed consent to participate in the study and thus represent the study population.

## 6.4.2. Sociodemographic characteristics

Table 6.1 summarises the sociodemographic characteristics of the study population. We merged some variables' components to create new categories because they carried small numbers. Those were:

- All 'Missing' and 'Ambiguous' components within variables were collapsed into one component called 'missing/ Ambiguous'.
- Nationality variable: 'Kuwaiti', 'Syrian', 'Egyptian', 'Lebanese', 'Other Gulf', 'Other Arabic' and 'Others' into the new components called 'Kuwaiti', 'Syrian', 'Egyptian' and 'Others'.
- **Marital status** variable: 'single', 'married', 'divorced' and 'widowed' components into 'single', 'married' and 'divorced/ widowed'.
- **Employment** variable: 'unemployed', 'Housewife', 'working fulltime', 'working parttime', 'retired' and 'student' into the new components 'unemployed', 'Housewife', 'working fulltime/ parttime' and 'others: retired/ student'.
- Total household income variable: 'less than 500 k.d', 'between 500-1500 k.d', 'between 2500-3500 k.d' and 'above 3500 k.d' into 'less than 500 k.d', 'between 500-1500 k.d', '>1500-2500 k.d' and '>2500 k.d'.
- Total number of children variable: 'one child', 'two children', 'three children', 'four children', 'more than 4 children', 'no children' and 'not married' into '1-2 children', '3-4 children', 'more than 4 children' and 'no children/ not married'.

The age ranged between 21-67 years old with a mean age of 35 years old and a standard deviation (SD) of (+/- 9.26). Most of the included participants (75.0%) were aged between 21-40 years old. A similar proportion were married (76%). In terms of nationality, nearly 85% were of 'Kuwaiti' nationality, with the remainder being Egyptian (5.8%) Syrian (2.8%) or other (6.5%). 41% of the surveyed participants had a college degree, while 27.8% had a university degree or above, and 21.8% a secondary degree or equivalent. The remaining (9.5%) had an education below secondary school level. Also, 84.5% were employed and 65% had a monthly household income of >500-1500 Kuwaiti Dinar, while 10.8% had a household income of less than 500 Kuwaiti Dinar. The average household income per capita in 2019

was 30,482 US dollars (The World Bank Group, 2022). The proportions of participants with no children, 1-2 children, 3-4 children, more than four children, were almost equal, ranging between 22.8% and 26.8%.

population (N=400)	
Characteristic	*n (%)
Nationality	
Kuwaiti	338(84.5)
Syrian	11 (2.8)
Égyptian	23 (5.8)
Other	26 (6.5)
Missing	2 (0.5)
Age (years)	
21-30	156 (39.0)
31-40	144 (36.0)
41-50	74 (18.5) <sup>´</sup>
51-60	21 (5.3)
61-69	5 (1.3)
Missing	0 (0.0)
Marital status	- ()
Single	60 (15.0)
Married	305 (76.3)
Divorced/widowed	35 (8.8)
Missing	0 (0.0)
Area of residence	- ()
The Capital	67 (16.8)
Hawally	97 (24.3)
Jahra	80 (20.0)
Ahmadi	79 (19.8)
Farwaniyya	76 (19.0)
Missing	1 (0.3)
Educational level	()
Below secondary (primary or intermediate)	38 (9.5)
Secondary or equivalent (high school)	87 (21.8)
Above secondary and below university (college)	164 (41.0)
University and above	111 (27.8)
Missing	0 (0.0)
Employment status	
Unemployed	18 (4.5)
Housewife	21 (5.3)
Working (full-time/part-time)	338 (84.5)
Others (retired/student)	23 (5.8)
Missing	0 (0.0)
Total household income	
Less than 500 K.D	43 (10.8)
>500-1500 K.D	260 (65.0)
>1500-2500 K.D	70 (17.5)
>2500 K.D	27 (6.8)
Missing	0 (0.0)
Total number of children	
No children/not married	107 (26.8)

Table 6.1: Description of sociodemographic characteristics of the st	Jdy
population (N=400)	

1-2 children	91 (22.8)
3-4 children	107 (26.8)
More than 4 children	93 (23.3)
Missing	2 (0.5)
	1 ( ) ( ) ( ) ( ) ( ) ( ) ( ) ( ) ( ) (

\*n is the number of participants. The total number of participants = 400

### 6.4.3. Exposure to breast cancer information

When asked whether they had any family or close friend with a history of breast cancer, the majority responded that they did not (75.0% and 64.5% for family history and close friend history, respectively). Nevertheless, almost 60% were previously exposed to some type of information around breast cancer, with the major source of such information being the internet (33.0%), followed by TV (18.1%), family and friends (17.0%) and doctors (10.4%). Table 6.2 provides a detailed description of the prior exposure of study participants to information about breast cancer.

Characteristic	*n (%)
Family history of breast cancer	· · ·
No	300 (75.0
Yes	79 (19.8)
l don't know	21 (5.3)
Close friend history of breast cancer	
No	258 (64.5)
Yes	100 (25.0)
l don't know	42 (10.5)
Prior information about breast cancer	
No	162 (40.5
Yes	238 (59.5
Missing	0 (0.0)
Source of information (if present)	
Doctor	28 (10.4)
Health educator at clinic	13 (4.8)
T.V	49 (18.1)
Radio	4 (1.5)
Newspaper/magazine	19 (7.0)
Internet	89 (33.0)
Friends & family	46 (17.0)
Other	14 (5.2)

\*n is the number of participants. The total number of participants=400

## 6.4.4. Recognition of breast cancer signs and/or symptoms and skills in relation to detecting breast changes

Table 6.3 lists the signs and/ or symptoms associated with breast cancer and the proportion of study participants who were able to recognize each of them or not. The two most recognized signs were a lump or thickening of the breast and a lump or thickening of the armpit (55.5% and 54.5%, respectively). While the least recognized signs and/or symptoms were redness of the skin of the breast (24.8%), followed by pulling in of the nipple inside (25.8%) and any rash on or around the nipple (27.5%).

Interestingly, for all the listed signs and/or symptoms except dimpling on the skin of the breast, the proportion of participants who could not recognize (answered "no") to a sign or symptom was higher than that of those who were uncertain (answered "I don't know') whether the listed sign or symptom was indeed indicative of breast cancer.

Sign and/or symptom	Yes *n (%)	No *n (%)	l don't know *n (%)	Missing or ambiguous *n (%)
A lump or thickening of the breast	222 (55.5)	126 (31.5)	52 (13.0)	0 (0.0)
A lump or thickening under armpit	218 (54.5)	131 (32.8)	51 (12.8)	0 (0.0)
Bleeding or discharge from the nipple	156 (39.0)	154 (38.5)	90 (22.5)	0 (0.0)
Pulling in of the nipple inside	103 (25.8)	162 (40.5)	135 (33.8)	0 (0.0)
Change in position of the nipple	149 (37.3)	146 (36.5)	105 (26.3)	0 (0.0)
Any rash on or around the nipple	110 (27.5)	181 (45.3)	109 (27.3)	0 (0.0)
Redness of the skin of the breast	99 (24.8)	184 (46.0)	117 (29.3)	0 (0.0)
Change in the size of breast or nipple	177 (44.3)	144 (36.0)	79 (19.8)	0 (0.0)
Change in the shape of breast or nipple	191 (47.8)	146 (36.5)	63 (15.8)	0 (0.0)
A pain in one or both breasts	185 (46.3)	152 (38.0)	62 (15.5)	1 (.3)
A pain in one or both armpits	168 (42.0)	153 (38.3)	79 (19.8)	0 (0.0)
Dimpling on the skin of the breast	123 (30.8)	137 (34.3)	140 (35.0)	0 (0.0)

Table 6.3: Frequencies of study participants recognizing or not breast cancer signs and/or symptoms

\*n is the number of participants. The total number of participants=400

As for detecting breast changes, only 8.0% of the participants answered that they checked their breasts weekly or monthly, and half of the participants were very to fairly confident that they could notice a change in their breast. If they did notice a change, 80.0% answered they would seek medical care, while 12.5% would search the internet for a diagnosis. It is also interesting to note that 3.0% and 4.3% said they would do nothing or would not know what to do respectively if they noticed any change in their breast (Table 6.4)

Question	*n (%)
How often do you check your breast?	
Once a week/once a month	32 (8.0)
Once every 6 months/rarely or never	368 (92.0)
low confident are you of noticing a change in our breast?	
Very confident/fairly confident	202 (50.5)
Not very confident/not at all confident	198 (49.5)
Vhat would you do if you noticed a change in	
our breasts?	
Seek medical advice	320 (80.0)
Search the internet	50 (12.5)
Use traditional methods/healing	1 (0.3)
Nothing	12 (3.0)
I don't know	17 (4.3)

\*n is the number of participants. The total number of participants= 400.

### 6.4.5. Knowledge of Kuwait National Screening Program

When asked whether they knew of any national cancer screening program in Kuwait, 82.3% of the participants answered positively. However, only 59.3% were aware of the Kuwait National Mammography Screening Program specifically and its activities and only 24.0% had been for breast cancer screening in Kuwait.; 60% of whom went to public hospitals to have the screening done (Table 6.5).

Question	*n (%)
To your knowledge, is there a national	
breast cancer screening program in	
Kuwait?	
Yes	329 (82.3)
No	71 (17.8)
Are you aware of the Kuwait National	
Mammography Screening Program and	
its activities?	
Yes	237 (59.3)
No	163 (40.8)
Have you ever been for breast cancer	
screening to any facility in Kuwait?	
Yes	96 (24.0)
No	304 (76.0)
If yes, where did you go for screening?	
Public	59 (61.5)
Private	25 (26.0)
Missing/ambiguous	12 (12.5)

Table 6.5: Knowledge of Kuwait National Screening Program among the study population

\*n is the number of participants. The total number of participants= 400

#### 6.4.6. Anticipated delay in contacting the doctor

We asked the participants how soon they would contact their doctor if they found a change in their breast and almost half answered that they would contact their doctor not later than a week from detecting a change. A small proportion (1.8%) said they would contact them sometime later, whilst almost 44% did not know what to do in such a situation.

#### 6.4.7. Barriers to seeking medical help

The number one barrier to seeking medical help among the study population was being too scared to go and see the doctor (71.3%). In addition, almost half or more than half of the participants agreed that the following were barriers to seeking medical help: finding the doctor difficult to talk to (49.3%), too busy to make time to go to the doctor (58.3%), difficulty to make an appointment with the doctor (59.3%), embarrassment from seeing the doctor (59.5%), worrying about what the doctor might find (63.0%) and worrying about too many other things (63.7%). Factors perceived as barriers by less than half of the participants were: difficulty to arrange transport to doctor's surgery (29.5%) and not feeling confident talking about the symptoms with the doctor (40.8%) (Table 6.6).

Possible barriers	Yes often/Yes	No/I don't know	
	sometime	*n (%)	
	*n (%)		
Too embarrassed to go and	238 (59.5)	162 (40.5)	
see the doctor			
Too scared to go and see the	285 (71.3)	115 (28.7)	
doctor			
I find my doctor difficult to	197 (49.3)	203 (50.7)	
talk to			
Difficult to make an	273 (59.3)	163 (40.8)	
appointment with the doctor			
Too busy to make time to go	233 (58.3)	167 (41.8)	
to the doctor			
Too many other things to	255 (63.7)	145 (36.3)	
worry about			
Difficult to arrange transport	118 (29.5)	282 (70.5)	
to doctor's surgery			
Worrying about what the	252 (63.0)	148 (37.0)	
doctor might find may stop			
me from going to the doctor			
Not feeling confident talking	163 (40.8)	237 (59.3)	
about my symptoms with the			
doctor			

\*n is the number of participants. The total number of participants= 400

### 6.4.8.Knowledge of age-related lifetime risk of breast cancer

When asked who is most likely to develop breast cancer, 62.7% replied that women between 40-50 and older than 50 years old were more likely to develop the disease. Over one third (37.3%) felt that younger age group 30-40 or younger than 30 were more susceptible to breast cancer.

### 6.4.9. Knowledge of risk factors

Table (6.7) lists factors and the proportion of participants who agreed that they represent risk factors for breast cancer. Participating in regular physical activity or exercise/sports was perceived as a risk factor by most of the participants (70.5%), followed by stress and psychological tension (64.3%), personal and family history of breast cancer (57.8% and 55.3% respectively). Also, almost half of the participants believed that evil eye was a risk factor for breast cancer (48.0%). Only 13.5% of the participants agreed that having children late in life and not having children at all were risk factors for breast cancer. Additional risk factors and their corresponding data are shown in Table 6.7.

Proposed risk factor	Strongly	Strongly	l don't know
rioposed lisk lactor	agree/Agree	disagree/	*n (%)
	*n (%)	Disagree	(///
	(///	*n (%)	
Having a personal past	231 (57.8)	45 (11.3)	124 (31.0)
history of breast cancer			
Using oral contraceptives	165 (41.3)	70 (17.5)	165 (41.3)
Being overweight (more than	124 (31.0)	125 (31.3)	151 (37.8)
30 kg above normal weight) Having family members with	221 (55.3)	98 (24.5)	81 (20.3)
history of breast cancer		· · ·	
Having children later in life	54 (13.5)	150 (37.5)	196 (49.0)
Not having children	53 (13.5)	176 (44.0)	171(42.8)
Having a period at an early	30 (7.5)	184 (46.0)	186 (46.5)
age			
Having a delayed menopause	71 (17.8)	138 (34.5)	189 (47.3)
Participating in regular	282 (70.5)	49 (12.3)	69 (17.3)
physical activity or exercise/sports			
Stress and psychological	257 (64.3)	55 (13.8)	88 (22.0)
tension			
Consuming a lot of fatty food	207 (51.7)	72 (18.0)	121 (30.3)
Evil eye/ envy	192 (48.0)	114 (28.5)	94 (23.5)

Table 6.7: Risk factors for breast cancer as perceived by the study population

\*n is the number of participants. The total number of participants= 400.

# 6.5. Awareness of non-lump symptoms and its association with other factors of interest

In this part of the analysis, the relationship between awareness of non-lump symptoms with the rest of BCAM domains (Sociodemographic factors, Confidence skills and behaviour in relation to detecting breast cancer change, Knowledge of the national screening program in Kuwait, Anticipated delay in contacting the doctor, Barriers to seeking medical help, Knowledge of age-related lifetime risk and Knowledge of risk factors) are summarized.

By using cross-tabulation between awareness of non-lump symptoms and the different variables of interest.

Furthermore, more data transformation (recoding) was carried out in order to make analysis and interpretation clearer. Such a transformation of variables is discussed below, where appropriate.

### 6.5.1. Awareness and its association with sociodemographic factors

Using a chi-squared test and a level of significance of 0.05 the association between the "Unaware" and "Aware" group in relation to sociodemographic factors was explored; results are shown in Table (6.8). There was a significant association between the area of residence and the "Unaware" and "Aware" groups. A greater proportion of participants residing in Hawally (29.5%), and the capital districts (25.9%) were considered aware of breast cancer non-lump symptoms than the rest of the districts. Looking at the educational level, it was found that participants with above secondary/ below university (41.7%) followed by participants with university degree or above (36%) were more likely to be aware than participants holding other degree. Having had a prior information about breast cancer was significantly associated with being aware of non-lump symptoms. However, a great proportion of participants who did not have a close friend with breast cancer (57.6%) were aware than the rest.

Sociodemographic variable	Unaware * N= 261	Aware ** N= 139	P. value***
Nationality			0.104
Kuwaiti	227 (87.0%)	111 (79.9%)	
Syrian	5 (1.92%)	6 (4.32%)	
Égyptian	15 (5.75%)	8 (5.76)	
Others+	12 (4.60%)	14 (10.1%)	
Missing/ Ambiguous	2 (0.77%)	0 (0.00%)	
Age (years)	, , , , , , , , , , , , , , , , , , ,		0.260
21-30	110 (42.1%)	46 (33.1%)	
31-40	92 (35.2%)	52 (37.4%)	
41-50	46 (17.6%)	28 (20.1%)	
51-60	10 (3.83%)	11 (7.91%)	
61-69	3 (1.15)	2 (1.44%)	
Marital status			0.131
Single	46 (17.6%)	14 (10.1%)	
Married	193 (73.9%)	112 (80.6%)	
Divorced/ widowed	22 (8.43%)	13 (9.35%)	
Area residence			<0.001
Capital	31 (11.9%)	36 (25.9%)	
Hawally	56 (21.5%)	41 (29.5%)	
Jahra	51 (19.5%)	29 (20.9%)	
Ahmadi	59 (22.6%)	20 (14.4%)	
Farwaniyya	63 (24.1%)	13 (9.35%)	
Missing	1 (0.38%)	0 (0.00%)	
Educational level	, , ,		0.003
Below secondary	33 (12.6%)	5 (3.6%)	
Secondary or equivalent	61 (23.4%)	26 (18.7%)	
Above secondary and	106 (40.6%)	58 (41.7%)	
below university(college)			
University and above	61 (23.4%)	50 (36.0%)	
Employment status			0.130
Unemployed	9 (3.45%)	9 (6.47%)	
Housewife	10 (3.83%)	11 (7.91%)	
Working: fulltime/ part	228 (87.4%)	110 (79.1%)	
time	14 (5.36%)	9 (6.47%)	
Others: retired/ student			

### Table 6.8: Awareness and its association with sociodemographic factors

Total household income_			0.221
Less than 500 k.d++	34 (13.0%)	9 (6.47%)	0.221
Between 500-1500 k.d	163 (62.5%)	97 (69.8%)	
>1500-2500 k.d	46 (17.6%)	24 (17.3%)	
>2500 k.d	18 (6.90%)	9 (6.47%)	
2200 K.U	10 (0.90%)	9 (0.47%)	
Total number of children			0.493
No children/ not married	72 (27.6%)	35 (25.2%)	
1 to 2 children	55 (21.1%)	36 (25.9%)	
3 to 4 children	67 (25.7%)	40 (28.8%)	
More than 4 children	65 (24.9%)	28 (20.1%)	
Missing/ ambiguous	2 (0.77%)	0 (0.00%)	
Family history of breast			0.152
cancer	16 (6.13%)	5 (3.60%)	
Don't know	200 (76.6%)	100 (71.9%)	
No	45 (17.2%)	34 (24.5%)	
Yes			
Close friend history of			0.012
breast cancer			
Don't know	30 (11.5%)	12 (8.63%)	
No	178 (68.2%)	80 (57.6%)	
Yes	53 (20.3%)	47 (33.8%)	
Source of information			<0.001
No	134 (51.3%)	28 (20.1%)	
Yes	127 (48.7%)	111 (79.9%)	

Unaware\*: aware of less than 5 non-lump symptoms

Aware\*\*: aware of 5 or more non-lump symptoms

P.value\*\*\*: of chi-squared test.

Others+: Lebanese, other gulf countries, other Arabic countries and others. k.d++: Kuwaiti dinar.

The level of significance= 0.05

## 6.5.2.Awareness and its association with confidence, skills and behaviour in relation to detecting breast cancer changes

Table 6.9 shows the frequency of checking the breast was not associated with the awareness of non-lump symptoms, however; confidence in checking the breast and the response to changes in the breast were more likely to be associated with breast cancer non-lump symptoms, p = <0.001 and p = 0.002 respectively.

Variable Name	Unaware N=261	Aware N=139	*P.value
Frequency of checking			0.265
<u>the breast</u>	243 (93.1%)	125 (89.9%)	
at least once every 6 months/ rarely or never			
	18 (6.9%)	14 (10.1%)	
at least once a week/ at			
least once a month			
Confidence in checking			0.000
the breast	115 (44.1%)	87 (62.6%)	
Very confident/ fairly			
confident	146 (55.9%)	52 (37.4%)	
Not very confident/ not at	140 (JJ.7%)	JZ (37.4%)	
all confident			
Response to changes in			0.002
<u>the breast</u>			
Don't know	17 (6.5%)	0 (0.00%)	
Seek medical advice	179 (75.5%)	123 (88.5%)	
Search the internet	36 (13.8%)	14 (10.1%)	
Use traditional methods/	0 (0.0%)	1 (0.7%)	
healing			
Nothing	11 (4.2%)	1 (0.7%)	

Table 6.9: Awareness and its association with confidence, skills and behaviour in relation to detecting breast cancer changes:

\*P.value of chi-squared test.

Unaware\*: aware of less than 5 non-lump symptoms Aware\*\*: aware of 5 or more non-lump symptoms

## 6.5.3.Awareness and its association with the knowledge of the screening program in Kuwait

Table 6.10 shows that participants who were aware of non-lump symptoms and knew about the national breast cancer screening program in Kuwait (87.8%) were almost similar to those who were unaware of non-lump symptoms (79.3%). The association was significant (p=0.035).

Also, those who were unaware of non-lump symptoms were more likely to not have been for screening in Kuwait (81.2%) compared to those who were aware of breast cancer non-lump symptoms (66.2%) and this difference was significant (p= 0.001).

Variable Name	Unaware N=261	Aware N=139	*P.value
<u>Is there a national</u> <u>breast cancer screening</u> <u>program in Kuwait?</u> No Yes	54 (20.7%) 207 (79.3%)	17 (12.2%) 122 (87.8%)	0.035
Are you aware of the Kuwait National Mammography Screening Program and its activities? No Yes	111 (42.5%) 150 (57.5%)	52 (37.4%) 87 (62.6%)	0.321
Have you ever been for breast cancer screening to any facility in Kuwait?			
No Yes	212 (81.2%) 49 (18.8%)	92 (66.2%) 47 (33.8%)	0.001

Table 6.10: Awareness & Knowledge of the National Screening Program in Kuwait

\*P.value of chi-squared test.

Unaware\*: aware of less than 5 non-lump symptoms Aware\*\*: aware of 5 or more non-lump symptoms

### 6.5.4. Awareness and its association with the barriers to screening

Table 6.11 shows that most of the barriers were not likely to be associated with being aware/ unaware of the non-lump symptoms. However, participants who were unaware of the non-lump symptoms were more likely to be too busy to make time to go to the doctor (62.8%) than participants who were aware of the non-lump symptoms (49.6%) and those who were unaware, were more likely to say that too many things to worry about (68.2%) than the aware participants (55.4%).

Table 6.11: Awareness and its association with the barriers to screening					
Variable Name	Unaware	Aware	*P. value		
Too ombowroed to go			0.715		
Too embarrassed to go			0.715		
and see the doctor	404 (20.0%)				
No/ don't know	104 (39.8%)	58 (41.7%)			
Yes often/ yes	157 (60.2%)	81 (58.3%)			
sometimes					
Too scared to go and			0.810		
see the doctor					
No/ don't know	74 (28.4%)	41 (29.5%)			
Yes often/ yes	187 (71.6%)	98 (70.5%)			
sometimes					
I find my doctor			0.175		
difficult to talk to					
No/ don't know	126 (48.3%)	77 (55.4%)			
Yes often/ yes	135 (51.7%)	62 (44.6%)			
sometimes					
Difficult to make an			0.174		
appointment with the					
doctor					
No/ don't know	100 (38.3%)	63 (45.3%)			
Yes often/ yes	161 (61.7%)	76 (54.7%)			
sometimes		/ 0 (0 /0)			
Too busy to make time			0.011		
to go to the doctor			0.011		
No/ don't know	97 (37.2%)	70 (50.4%)			
Yes often/ yes	164 (62.8%)	69 (49.6%)			
sometimes	104 (02.0%)	09 (49.0%)			
sometimes					
Too many other things			0.011		
to warry about					
No/ don't know	83 (31.8%)	62 (44.6%)			
Yes often/ yes	178 (68.2%)	77 (55.4%)			
sometimes	170 (00.2/0)	11 (33.7/0)			
Joinetimes					
Difficult to arrange			0.489		
transport to doctor's					
surgery					
No/ don't know	181 (69.3%)	101 (72.7%)			
Yes often/ yes	80 (30.7%)	38 (27.3%)			
sometimes	(, •)	( , , ,			
Jonicenies	L	1			

Table 6.11: Awareness and its association with the barriers to screening

Worrying about what the doctor might find may stop me from going to the doctor No/ don't know Yes often/ yes sometimes	97 (37.2%) 164 (62.8%)	50 (36.0%) 88 (63.3%) 1 (0.7%) missing/	0.384
Not feeling confident talking about my symptom with the doctor No/ don't know Yes often/ yes sometimes	150 (57.5%) 111 (42.5%)	ambiguous 87 (62.6%) 52 (37.4%)	0.321

\*P.value of chi-squared test.

Unaware\*: aware of less than 5 non-lump symptoms Aware\*\*: aware of 5 or more non-lump symptoms

### 6.5.5.Awareness and its association with the knowledge of age-related and lifetime risk

Table 6.12 shows that aware participants were more knowledgeable (71.5%) about the age women are likely to develop breast cancer in Kuwait as compared to participants who were unaware (58.1%), and the association was significant (p.value = 0.008).

Table 6.12: Awareness and its	association with the know	vledge of age-related and	d lifetime risk
Variable Name	Unaware N=260	Aware N=137	*P.value
Who is most likely to develop breast cancer among women in Kuwait?			0.008
A woman younger than 30 years old/ A woman 30 to 40 years old	109 (41.9%)	39 (28.5%)	
A woman 40 to 50 years old/ A woman more than 50 years old	151 (58.1%)	98 (71.5%)	
Missing cases	3 (0.8%)	1	

...

...

P.value of chi-squared test.

. .

. ...

. ..

. . .

### 6.5.6. Awareness and its association with the knowledge of risk factors

Table 6.13 shows the association between awareness of non-lump symptoms and the knowledge of breast cancer's risk factors. Using oral contraceptives was more likely to be associated with participants' awareness of non-lump symptoms, p-value=0.006. Also having a family history of breast cancer was most likely to be associated with participants' awareness of non-lump symptoms, p-value< 0.001. However, having a personal past history of breast cancer was borderline, p-value= 0.053.

.....

7	Table 6.13: Awareness	and its association	with the knowled	lge of risk factors
				· · · · · · · · · · · · · · · · · · ·

Variable Name	Unaware	Aware	*P.value
	N=261	N= 139	
Having a personal			0.053
past history of breast cancer.			
Don't know	91 (34.9%)	33 (23.7%)	
Strongly disagree/ disagree	30 (11.5%)	15 (10.8%)	
Agree/ strongly agree	140 (53.6%)	91 (65.5%)	
Using oral			0.006
<u>contraceptives.</u> Don't know	120 (46.0%)	45 (32.4%)	
Strongly disagree/	48 (18.4%)	22 (15.8%)	
disagree Agree/ strongly agree	93 (35.6%)	72 (51.8%)	
Being overweight			0.046
(more than 30 kg above normal weight)			
Don't know	104 (39.8%)	47 (33.8%)	
Strongly disagree/ disagree	87 (33.3%)	38 (27.3%)	
Agree/ strongly agree	70 (26.8%)	54 (38.8%)	
Having family			<0.001
members with history of breast cancer			
Don't know	64 (24.5%)	17 (12.2%)	
Strongly disagree/ disagree	73 (28.0%)	25 (18.0%)	
Agree/ strongly agree	124 (47.5%)	97 (69.8%)	
Having children later in life			0.789
Don't know	129 (49.4%)	67 (48.2%)	
Strongly disagree/ disagree	99 (37.9%)	51 (36.7%)	
Agree/ strongly agree	33 (12.6%)	21 (15.1%)	

disagree			
Strongly disagree/	41 (15.7%)	14 (10.1%)	
<u>tension.</u> Don't know	67 (25.7%)	21 (15.1%)	
<u>psychological</u>			
Stress and			0.006
Agree/ strongly agree	173 (66.3%)	107 (70.4%)	
disagree	172 (66 2%)	109 (78.4%)	
Strongly disagree/	34 (13.0%)	15 (10.8%)	
<u>sports</u> Don't know	54 (20.7%)	15 (10.8%)	
activity or exercise/			
<u>Participating in</u> regular physical			0.025
Darticipatian in			0.025
Missing/ ambiguous	1 (0.4%)	1 (0.7%)	
disagree Agree/ strongly agree	40 (15.3%)	31 (22.3%)	
Strongly disagree/	88 (33.7%)	50 (36.0%)	
Don't know	132 (50.6%)	57 (41.0%)	
<u>Having delayed</u> menopause			0.205
			0.205
Agree/ strongly agree	19 (7.3%)	11 (7.9%)	
Strongly disagree/ disagree	120 (46.0%)	64 (46.0%)	
Don't know	122 (46.7%)	64 (46.0%)	
early age.			0.771
Having period at an			0.971
Agree/ strongly agree	35 (13.4%)	18 (12.9%)	
disagree			
Don't know Strongly disagree/	117 (44.8%) 109 (41.8%)	54 (38.8%) 67 (48.2%)	
Not having children	117 (11 20)	54 (28 8%)	0.443

<u>Consuming a lot of</u> <u>fatty food</u> Don't know Strongly disagree/ disagree Agree/ strongly agree	92 (35.2%) 46 (17.6%) 123 (47.1%)	29 (20.9%) 26 (18.7%) 84 (60.4%)	0.009
Evil eye/ envy Don't know Strongly disagree/ disagree Agree/ strongly agree	64 (24.5%) 74 (28.4%) 123 (47.1%)	30 (21.6%) 40 (28.8%) 69 (49.6%)	0.795

P.value of chi-squared test.

# 6.6. Logistic regression analysis of awareness of non-lump symptoms (dependant variable) and different variables

Four models were used to analyse the results of the questionnaire whereby we explored how independent variables affected the participant's awareness of non-lump symptoms (dependent variable).

We used univariable and multivariable logistic regression models were used.

As outlined in the methods, four models were used to address the associations of breast cancer non-lump symptoms with different predictor variables, results are provided in Table 6.14. Each model is outlined below.

### 6.6.1. Model 1 Univariate analysis

Firstly, univariable associations between each of the sociodemographic factors and awareness of non-lump symptoms was assessed. Compared to Kuwaiti participants, other nationalities were significantly more likely to be aware of breast cancer non-lump symptoms, OR 1.80 (95% CI 1.03, 3.12). Moreover, compared to the youngest age category (21-30 years), the oldest participants (50-61 years) were over twice as likely to be aware of the non-lump symptoms, OR 2.40 (1.03, 5.60). Compared to

the capital district, participants in Jahra, Ahmadi and Farwaniyya districts were significantly less likely to be aware of non-lump symptoms, OR 0.50 (0.25, 1.00); OR 0.30 (0.14, 0.60), and OR 0.20 (0.90, 40) respectively. For educational level, results showed that compared to those who have below secondary, secondary or equivalent level education, participants with university or above educational attainment were almost 2.5 times more likely to be aware of non-lump symptoms, OR 2.50 (1.43, 4.31). Compared to those who were working full time/ part time, participants who were unemployed/ housewives/ retired or a student were significantly more aware of the non-lump symptoms, OR 1.82 (1.05, 3.15).

These variables were not associated with the awareness of non-lump symptoms: family income, number of children, marital status, or family history of breast cancer. However, compared to those who haven't got a friend with a history of breast cancer, participants with a friend with breast cancer were twice as likely to be aware of non-lump symptoms, OR 2.00 (1.30, 3.20).

Frequency of checking the breast was not associated with awareness of non-lump symptoms. Compared to those who reported being very confident or fairly confident in checking their breast, participants who said they were not confident or not at all confident were significantly less aware of non-lump symptoms, OR 0.50 (0.31, 0.72). In addition, compared to those who reported that they would seek medical advice if they noticed a change in their breast, participants using traditional/ healing methods/ do nothing or don't know, were significantly less aware of non-lump symptoms, OR 0.40 (0.22-0.72). Finally, awareness of non-lump symptoms was not associated with participants' knowledge of the national breast cancer screening program.

#### 6.6.2.Model 2

In model 2, multivariable logistic regression was used to assess the relationship between all sociodemographic factors (nationality, age, marital status, residence, education, employment, income, children, family history of breast cancer and friend history of breast cancer) and awareness of non-lump symptoms. Independent of all other sociodemographic variables, compared to the youngest age category (21-30 years), those within the (31-40 years) and (41-50 years) age categories were significantly more likely to be aware of the non-lump symptoms, OR 2.07 (1.15, 3.74) and OR 2.58 (1.2, 5.54) respectively. As in univariable analysis, compared to participants living in the capital district, participants living in Farwaniyya, Ahmadi and Hawally were significantly less likely to be aware of the non-lump symptoms, OR 0.20 (0.08, 0.48), OR 0.32 and (0.14, 0.70) and OR 0.45 (0.21, 0.98) respectively; and similarly, participants who had above secondary or below university (college) educational attainment were significantly more likely to be aware of the non-lump symptoms, OR 2.08 (1.18, 3.67); however those who attained university level or above were not significantly more likely to be aware of non-lump symptoms following adjustment for other sociodemographic factors. In addition, compared to participants with the least income (less than 500 Kuwaiti dinars), participants with middle income (between 500-1500 Kuwaiti dinars) were more aware of the non-lump symptoms, OR 4.17 (1.60, 10.85). Results showed that awareness of non-lump symptoms was not associated by the number of children the participants had, or their marital status, employment status or nationality.

#### 6.6.3.Model 3

Model 3 used multivariable logistic regression analysis to quantify the association between sociodemographic factors, family history of breast cancer, friend history of breast cancer and awareness of non-lump symptoms. Independent of other variables, age category (31-40 years) and (41-50 years) were significantly more likely to be aware of non-lump symptoms compared to the youngest age group (21-30 years), OR 1.98 (1.09 3.61) and OR 2.23 (1.02, 4.89) respectively. When looking at geographical location, compared to participants residing in the capital district, participants residing in Farwaniyya, Ahmadi and Hawally were significantly less aware of breast cancer non-lump symptoms, OR 0.20 (95% CI 0.08, 0.50), OR 0.33 (0.14, 0.72). Looking at educational attainment, participants who attained above secondary but below university (college) educational level were at least twice as likely to be aware of the non-lump symptoms compared to participants who attained below secondary, secondary or equivalent educational level, OR 1.98 (1.11, 3.50). Compared to participants who received a salary of less than 500 k.d; participants who receive between 500 and 1500 k.d were significantly four times as likely to be aware of breast

cancer non-lump symptoms, OR 4.019 (1.53, 10.51). Finally, nationality, employment status of participants, the number of children were not associated with awareness. Neither were the additional variables added about a family history of breast cancer or having a close friend with a history of breast cancer.

### 6.6.4.Model 4

Lastly, model 4 extended model 3 by adding frequency of checking the breast, confidence in checking the breast, if notice a change and knowledge of national breast cancer screening program to assess the relationship between all variables of interest and the awareness of non-lump symptoms. As in the univariable analysis, results showed that compared to Kuwaiti participants, other nationalities were significantly more aware of breast cancer non-lump symptoms, OR 2.85 (1.10, 7.41), after adjusting for all other variables. Also, consistent with the other models, results showed that compared to participants living in the capital district, those who live in Farwaniyya, Ahmadi and Hawally were significantly less likely to be aware of breast cancer non-lump symptoms, OR 0.21 and (0.08, 0.51), OR 0.34 (0.15, 0.78), OR 0.61 (0.26, 1.43) respectively, compared to participants who attained below secondary, secondary or equivalent educational level, participants who have above secondary but below university (collage) educational level were almost as twice as likely to be aware of breast cancer non-lump symptoms, OR 1.96(1.09 3.52), participants with the income level that ranges between 500 and 1500 k.d were significantly as four times more likely to be aware of breast cancer non-lump symptoms, OR 4.090 (1.501, 11.144) compared to participants with the least income (less than 500 k.d), compared to participants who are very confident and fairly confident in checking the breast, participants who are not confident or not at all confident in checking their breast were significantly less likely to be aware of breast cancer non-lump symptoms, OR 0.51 (0.31, 0.82).

However, in this model with adjustment for all variables of interest, many variables no longer showed an association with breast cancer awareness of non-lump symptoms namely: employment status of participants, the number of children the participants have, the positive family history of breast cancer, friend history of breast cancer, the frequency of checking the breast, how participants respond when noticing a change in their breast and the knowledge about the presence of the national breast cancer screening program. However, those variables did not show the association in all the previous models. Table 6.14: Univariate/ Multivariable Logistic Regression Analysing the relationship between the awareness of non-lump symptoms (dependent variable) and the variables of interest

	Model 1* Unadjusted/ univa N= 400	riate	Model 2** N= 400		Model 3*** N= 400		Model 4**** N= 400	
Variable	OR [95% Cl]	P. Value	OR [95% Cl]	P. value	OR [95% CI]	P. value	OR [95% Cl]	P. value
<u>Nationality</u> Kuwaiti	1 (reference)		1 (reference)		1 (reference)		1 (reference)	
others	1.78 (1.02, 3.11)	0.040	2.33 (0.94, 5.77)	0.066	2.42 (0.97, 6.03)	0.056	2.85 (1.10, 7.41)	0.031
<u>Age</u> <u>category</u> 21-30 31-40 41-50 51-69	1 (reference) 1.35 (0.83, 2.19) 1.45 (0.81, 2.60) 2.39 (1.03, 5.55)	0.222 0.206 0.042	1 (reference) 2.07 (1.15, 3.74) 2.58 (1.20, 5.54) 2.65 (0.89, 7.88)	0.037 0.015 0.015 0.079	1 (reference) 1.98 (1.09, 3.61) 2.23 (1.02, 4.89) 2.32 (0.76, 7.08)	0.092 0.024 0.045 0.139	1 (reference) 1.73 (0.94-3.19) 2.03 (0.91-4.55) 1.93 (0.61-6.14)	0.244 0.078 0.083 0.261
<u>Marital</u> <u>status</u> Married Single/	1 (reference)	0.420	1 (reference)	0.228	1 (reference)	0.255	1 (reference)	0.467
divorced/ widowed	1.46 (0.88, 2.41)	0.139	0.70 (0.35, 1.43)	0.338	0.71(0.35, 1.45)	0.355	0.76 (0.37, 1.57)	0.467
<u>Residence</u> Capital	1 (reference)		1 (reference)	0.002	1 (reference)	0.002	1 (reference)	0.004
Hawally	0.63 (0.33, 1.18)	0.149	0.45 (0.21, 0.98)	0.044	0.42 (0.19, 0.92)	0.031	0.43 (0.19, 0.96)	0.040

Jahra Ahmadi Farwaniyya	0.49 (0.25, 0.94) 0.29 (0.14, 0.58) 0.17 (0.08, 38)	0.001	0.61 (0.27, 1.38) 0.32 (0.14, 0.70) 0.20 (0.08, 0.48)	0.239 0.005 0.000	0.62 (0.27, 1.41) 0.33 (0.14, 0.72) 0.20 (0.08, 0.50)	0.006	0.61 (0.26, 1.43) 0.34 (0.15, 0.78) 0.21 (0.08, 0.51)	0.261 0.011 0.001

	Model 1*		Model 2**		Model 3***		Model 4****		
Variable	Unadjusted/ univar OR [95% Cl]	iate P. value	OR [95% CI]	P. value	OR [95% CI]	P. value	OR [95% CI]	P. value	
Education Below secondary/ secondary or equivalent	1 (reference)	0.005	1 (reference)	0.031	1 (reference)	0.047	1 (reference)	0.074	
Above secondary and below university (college)	1.65 (0.98, 2.78)	0.055	2.08 (1.18, 3.67)	0.011	1.98 (1.11, 3.50)	0.019	1.96 (1.09, 3.52)	0.025	
University and above	2.48 (1.43, 4.31)	0.001	1.99 (0.97, 4.10)	0.059	1.98 (0.96, 4.06)	0.063	1.74 (0.82, 3.65)	0.144	
Employment Working: fulltime/ part time	1 (reference)		1 (reference)		1 (reference)		1 (reference)		
Unemployed, Housewife, student, retired.	1.82 (1.05, 3.15)	0.032	1.40 (0.64, 3.06)	0.392	1.37 (0.62, 2.99)	0.429	1.28 (0.57, 2.86)	0.543	

	Model 1* Unadjusted/ univariate		Model 2** Model 3*** Mo		Model 3*** Model 4****			
Variable	OR [95% CI]	P. value	OR [95% CI]	P. value	OR [95% CI]	P. value	OR [95% CI]	P. value
Income Less than 500 k.d	1 (reference)	0.120	1 (reference)	0.004	1 (reference)	0.005	1 (reference)	0.008
Between500-1500 k.d	2.24 (1.03, 4.88)	0.041	4.17 (1.60,10.85)	0.003	4.01 (1.53, 10.51)	0.005	4.090(1.501-11.144)	0.006
More than 1500 k.d	1.94 (0.83, 4.54)	0.123	2.37 (0.82, 6.84)	0.109	2.20 (0.75, 6.39)	0.148	2.336(0.773, 7.058)	0.13
Children No children/ not married	1 (reference)	.0.509	1 (reference)	0.415	1 (reference)	0.382	1 (reference)	0.536
1-2 children 3-4 children More than 4 children	1.34 (0.75, 2.41) 1.22 (0.70, 2.15) 0.88 (0.48, 1.61)	0.317 0.474 0.693	0.98 (0.46, 2.08) 0.74 (0.43, 1.62) 0.52 (0.21, 1.28)	0.972 0.463 0.157	0.95 (0.44, 2.02) 0.70 (0.31, 1.53) 0.49 (0.19, 1.24)	0.899 0.373 0.134	95 (0.43, 2.06) .78 (0.35, 1.74) .54 (0.21, 1.37)	0.899 0.551 0.199
Family history of breast cancer No/don't know	1 (reference)				1 (reference)		1 (reference)	
Yes	1.55 (0.94, 2.57)	0.086			1.38 (0.79, 2.41)	0.257	1.29 (0.73, 2.29)	0.377

Friend history of breast cancer No/don't know	1 (reference)		1 (reference)		1 (reference)	
Yes	2.00 (1.26, 3.18)	0.003	1.63 (0.96, 2.77)	0.067	1.60 (.93, 2.7)	0.084

	Model 1*		Model 2**		Model 3***		Model 4****		
	Unadjusted/ univariate			T -		1 -			
Variable	OR [95% CI]	Ρ.	OR [95% CI]	Ρ.	OR [95% CI]	Ρ.	OR [95% CI]	Ρ.	
		value		value		value		value	
<b>Frequency</b>									
of checking									
<u>the breast</u>									
Once a	1 (reference)						1 (reference)		
week/ once									
a month									
Once every 6	1.51 (0.7, 3.14)	0.261					1.19 (0.499, 2.85)	0.692	
months/									
rarely or									
never									
Confidence									
in checking									
the breast									
Very	1 (reference)						1 (reference)		
confident/							. , ,		
fairly									
confident									
Not very	0.47 (0.30, 0.71)	0.000					0.51 (0.317, 0.82)	0.006	
confident/									
not at all									
confident									

	Model 1* Unadjusted/ univariate		Model 2**		Model 3***		Model 4****	
Variable	OR [95% CI]	Ρ.	OR [95% CI]	Ρ.	OR [95% CI]	Ρ.	OR [95% CI]	Ρ.
		value		value		value		value
<u>lf notice a</u>								
change								
Seek	1 (reference)						1 (reference)	
medical							, ,	
advice								
	0.40 (0.22, 0.72)	0.002					.62 (.31, 1.22)	0.16
Traditional/		0.002					.02 (.31, 1.22)	0.10
healing/								
nothing/								
don't know								
Knowledge								
of national								
-								
<u>breast</u>								
<u>cancer</u>								
screening								
<u>program</u>								
Yes	1 (reference)						1 (reference)	
No	0.53 (0.29, 0.96)	0.037					.73 (.36, 1.48)	0.39

Model 1\*: univariate analysis of breast cancer non-lump symptoms with all the independent variables.

Model 2\*\*: univariate analysis of breast cancer non-lump symptoms with sociodemographic variables only.

Model 3\*\*\*: multivariable analysis of breast cancer non-lump symptoms with sociodemographic variables, family history and friend history of breast cancer.

Model 4\*\*\*\*: multivariable analysis of breast cancer non-lump symptoms with sociodemographic variables, family history, friend history, and knowledge of screening program (Q4A: confidence, frequency, behaviour)

### 6.7. Discussion

This study aimed to evaluate the level of knowledge and awareness of breast cancer non-lump symptoms, risks and breast cancer screening among the general population of females in Kuwait. Participants were recruited from PHCCs in five out of six districts of the country. The study used an internationally validated tool, the BCAM.

Breast cancer is an important public health problem worldwide and particularly in Kuwait where breast cancer death rate is higher than MENA region and internationally (Al Ramadhan, 2017, WHO, 2021). Understanding awareness of breast cancer and its screening program is the first step to start addressing/ understanding why breast cancer constitutes a major health problem in Kuwait. This study demonstrated a lack of knowledge about breast cancer and the screening program in Kuwait.

The awareness about signs and symptoms of breast cancer was generally low, only 55% of participants considered a lump to be a sign of breast cancer. The percentage even lower for the non-lump symptoms. Although most participants (82%) knew about the screening program, only 24% of the eligible females took part in the screening program and only 8% practiced BSE. However, the majority (80%) agreed on seeking medical advice if they noticed any changes to their breasts.

The overall awareness of breast cancer non-lump symptoms amongst participants was low (35%); a similar result (38%) was found among female participants at Sharjah university where participants were students, aged 18 years and older (Rahman et al., 2019a). The authors justified choosing university students for their research as students were expected to have good knowledge about breast cancer and might be capable of disseminating the information to their family and sharing the information they got to their friends and relatives and ultimately contributing to their community. The questionnaire used in this study was adapted from similar studies conducted in Egypt (Boulos and Ghali, 2013), Nigeria (O.J. et al., 2013) North-East London (Forbes et al., 2011), and Turkey (Karayurt et al., 2008). The questionnaire comprised 3 parts: sociodemographics,

risk factors and signs and symptoms and BSE. The awareness of signs and symptoms was assessed in a similar way to our study; by knowing 5 or more signs/ symptoms of breast cancer would be considered aware and knowing 4 or less signs/ symptoms would be considered unaware (Rahman et al., 2019b).

The low awareness finding from this study may partly explain the delay in breast cancer presentation and diagnosis (Ramirez et al., 1999, Jones et al., 2014), and this ultimately would result in decreasing the survival rate (Richards et al., 1999, Leon-Rodriguez, 2017). The most common symptoms recognised by the participants in this study were the breast cancer lump symptoms (~ 56%), a finding that is common among women in general. This was the reason for indicating non-lump symptoms as a way for evaluating participant's knowledge and awareness about breast cancer as mentioned earlier, however, the knowledge proportion was not optimal, in fact it was low. Research carried out on the knowledge of symptoms and risk factors of breast cancer among women in Mumbai, India, showed that having a lump was considered the most well-known symptom for breast cancer, and women who were aware of breast cancer considered lump in breast (75%), change in shape and size of breast (57%), lump under armpit (56%), pain in one breast (56%) as the important and common symptoms (Prusty et al., 2020); a very similar finding to the current study.

Additionally, a study done about breast cancer awareness in Saudi women showed that knowledge about breast changes in breast cancer disease were below 50% for all the symptoms where changes in size of the breast was identified by 49% of the women (Alam, 2006). Another study about breast cancer awareness in Nigeria revealed that when asked to list five possible symptoms of breast cancer, 16% of healthcare providers could not name a single accurate symptom; however, 57% could name four or five accurate symptoms, (Pruitt et al., 2020)). The findings show that although awareness and perception of breast cancer has become more widespread, specific knowledge about the symptoms of breast cancer could be an area of improvement especially when designing awareness campaigns.

The highest proportion of participants agreed that participating in regular physical activity or exercise/ sport (70.5%) was a risk factor for breast cancer,

which it is not, physical activity is protective of developing breast cancer. However, in the original questionnaire the question was written differently. As a risk factor "Doing less than 30 minutes of moderate physical activity five times a week". Whereas in the Omani version of BCAM, the author mentioned that she intentionally changed the question to a false risk factor to avoid response bias (Al - Khasawneh et al., 2016). In this study, the participants seemed to misunderstand the question and may not have read it properly, rather than truly believing that exercise was a risk factor for breast cancer, but this is unclear. Other common risk factors were stress and psychological tension (64.3%), having a personal past history of breast cancer (57.8%), having family members with history of breast cancer (55.3%) and consuming a lot of fatty food (51.7%). The remaining risk factors were recognised by less than 50% of participants. A study exploring the awareness of breast cancer by women in Riyadh revealed that knowledge of breast cancer, risk factors and protective factors for breast cancer were moderate, and the most commonly identified risk factors were smoking, HRT, and exposure to radiation (Alam, 2006). Different risk factors were identified among women in India whereby a review of breast cancer awareness showed that reproductive history and obesity were among the top listed risk factors (Gupta et al., 2015). Different risk factors have been shown to be recognized by different populations. The discrepancy found in the responses received from participants suggests that the knowledge of risk factors was still low and there was no common widely known risk factors identified by women globally.

The foremost obstacle preventing participants in this study from seeking medical help was fear (71%). These results were consistent with countless other studies in the GCC done on the barriers to screening for breast cancer among women where fear was identified as one of the major factors (Taha et al., 2014, Abdel-Aziz et al., 2017, Azami-Aghdash et al., 2015).

In the current study, as further sociodemographic and lifestyle factors were entered into the logistic regression models for awareness of breast cancer, the association between some variables and breast cancer awareness was altered, whereas others (middle income family and confidence in checking the breast) remained significantly associated with awareness of non-lump symptoms after adjustment for all other variables.

Kuwaiti nationals were less likely to be aware of breast cancer non-lump symptoms than other nationalities although the number of Kuwaiti participants constituted the majority (84.5%) of participants. (Models: 1 and 4). Area of residence was significantly associated with participants awareness. Compared to participants living in the capital area, those living in (Al Jahra/ Al Ahmadi) were less likely to be aware of breast cancer non-lump symptoms. This is not unexpected, because lifestyle in the capital district differs from others most probably due to better infrastructure, better education system and advanced health care facilities.

The results showed an unexpected pattern in the awareness levels of participants from across different levels of education. Participants who had above secondary level of education but lower than university level were more likely to be aware than those with university and above level of education compared to participants who had below secondary/ secondary or equivalent level of education, a finding which was found across three models (2, 3, 4). However, for most of the previous studies, attaining higher education was associated with higher awareness about breast cancer (Nisha and Murali, 2020, Eyad Fawzi AlSaeed, 2015).

It is unclear why are findings different. It may be our categorisation of the variable.

*Amin.*,2012 found that having a secondary level of education or higher were more likely to have a better knowledge and more aware about breast cancer than the rest of participants. The ORs for university education show an increased odds of awareness across all models, however, the relationship is not statistically significant, with wide confidence interval, which suggests that this could be due to the number of participants with university education.

Another contradictory result found in this study was that middle class (income between 500-1500 k.d) participants were more likely to be aware than other socioeconomic classes and that association was found across all the regression models (1, 2, 3, and 4). Again, the ORs were raised but with wide confidence

interval and not statistically significant, this relationship is likely to be an anomaly with the number of participants in this higher income group rather than a true finding.

Participants who were checking their breast every 6 months or rarely were not significantly associated with the awareness of non-lump symptoms compared to participants who were checking it weekly or monthly. A similar finding found in *Donnelly.,2012*, where women in Qatar who were aware of breast cancer symptoms were more likely to practice BSE and those with poor knowledge were less likely to practice BSE. Also, *Hussain., 2013,* concluded that good knowledge and awareness about breast cancer would positively affect the practice of BSE.

Unaware participants were more likely to use herbal treatment/ do nothing or don't know what to do when noticing changes in their breast. This could be due to lack of attention to health providers and the availability of the medical facilities especially for the Kuwaiti participants, where the services offered free of charge for them. Fear of finding out something is wrong, cultural norms and taboo could be other reasons which were mentioned earlier in chapter two.

In a study done by *Al-Mousa et al.*, 2020, where the level of knowledge, attitude and practices around breast cancer and mammography screening among Jordanian women was examined using a self-administered questionnaire developed for this study by research experts. The results showed as the level of knowledge about the signs and symptoms of breast cancer increased, the knowledge about the screening mammography increased and the association was statistically significant. However, in the current study this relationship was only observed in the univariate model and after adjusting for other factors there was no longer a significant relationship between screening programme knowledge and awareness. Breast cancer awareness measure studies (BCAM): Several studies carried out in the Gulf region (Saudi Arabia, Oman and United Arab Emirates) have also used the BCAM to measure cancer awareness (Radi et. al.; 2013, Elobaid et.al.; 2014, Abolfotouh et.al.; 2015, Alkhamis et.al.; 2016 and Alkhasawneh et.al.; 2016). One major difference between this study and those elsewhere in the Gulf region was the recruitment strategy. Here the aim was via random sampling to access a sample of females that were representative of the wider population of females in Kuwait, however those other studies largely employed convenience sampling techniques for example, in Radi (2013) a convenient sample of 200 females from Jeddah (SA) were recruited from shopping malls, in Abolfotouh (2015) a convenient sample of 225 females were approached in a primary healthcare centre in Riyadh (SA), in Alkhamis (2016) a sample size of 435 females were recruited in primary healthcare clinic in Riyadh (SA) using a convenient sampling technique, however, in Akhasawneh (2016) the number of females who participated in the study was large (1372) recruited from 7 governorates within Oman. In Elobaid (2014), two hundred forty seven females from religious, cultural and community centres in Al Ain (UAE) were selected randomly.

This study found that 55% of participants were aware of a lump as a sign of breast cancer and this is similar to those reported by Radi (2014), 50,5%. These figures are much lower than those reported by Alkhamis (2016), who found that as many as 83% of their sample recognised that a lump may signify cancer and in Abolfotouh (2015), nearly three quarters (74.8%) of participants reported that a breast lump can be a sign of breast cancer, however, in Alkhasawneh (2016) and Elobaid (2014) the information regards signs and symptoms of breast cancer was not clearly mentioned.

Similarly, the knowledge of the breast cancer screening programme and screening participation in this study chimes with that reported by Radi (2014) and Alkhamis (2016) yet Elobaid (2014) and Abolfotouh (2015) found that nearly half of their sample participated in breast cancer screening.

Although cultural influences unique to the Gulf region, such as believing in evil eye/envy as being a cancer risk factor was not reported in the other studies conducted in the Gulf region because it has not been investigated it, Alkhasawneh (2016) reported that two-thirds of their respondents felt that such influences were important, as did half of all participants in this study.

### 6.7.1. Strengths of the study

This study was the first nation-based cross-sectional study of breast cancer awareness in Kuwait that used an internationally validated tool, the BCAM (Linsell et al., 2010). The use of a standard measure allows the comparison of the level of breast cancer awareness across countries and to identify target groups in particular need of awareness raising campaigns. However, a modification of the Omani version of the BCAM was done in order to adapt for the Kuwaiti culture and this was not validated further. However, little was changed in order to make it appropriate for the Kuwaiti population. The opening sociodemographic section of the questionnaire was revised in order to be appropriate for the population of Kuwait. Furthermore, the original version of the Omani BCAM did not include domains three and four of the original BCAM, which is a major limitation of the current Arabic version. Therefore, we further adapted the Arabic version to include these two domains on health-seeking behaviours: "anticipated delay in contacting the doctor" and "barriers to seeking medical help" consisting of one and ten questions, respectively. Pilot testing was done before starting the work field to examine the questionnaire and its applicability in the Kuwaiti context and only some modifications were done including language adjustment and fine tuning of the questionnaire design.

The study included participants from five districts of Kuwait, again, aiming to have a representative sample of the population and had a fairly high participation rate (72%).

The study had minimal missing data. The researcher made extra effort in asking participants to complete all questions before leaving.

### 6.7.2. Limitations of the study

There were some study limitations. The modified Omani version of the BCAM did not include the first question from the original BCAM; "Have you had breast cancer before?" (Linsell et al., 2010), and it was therefore not included in the version used in this study. However, the response would be biased for those with a history of breast cancer due to their previous knowledge about the disease. By knowing who previously or currently had breast cancer, they could have been excluded from the study. The prevalence and the number of breast cancer cases in the country was 2805 (5 years survival) (WHO, 2021) and 7.5% (n=400) of the study population might be affected with it. However, awareness was low overall, even if people with previous or current breast cancer were included, further underlining the need for improving awareness amongst all Kuwaiti females.

There was a similarity in the meaning of question 4a "To your knowledge, is there a national breast cancer screening program in Kuwait?" and 4b "Are you aware of the Kuwait National Mammography Screening Program and its activities?" which might have confused participants, but unfortunately, despite proof reading and piloting this was only realised after conducting the survey.

The environment where the survey took place was not very encouraging as participants were either waiting to be called for their appointment or wanted to leave after finishing the consultation. We are aware however that the choice of a healthcare setting from the first place might skew the results positively given that participants who have recently attended to a healthcare setting might be more knowledgeable and aware about health and illness in general compared with those who have not, however, this was the most appropriate place to access a broad sample of the general population across a wide age group (20-69). For example, choosing secondary care medical centres would not have been appropriate as visitors are more likely to be too unwell or distracted to be asked to take part in a survey.

### 6.8. Summary

Evaluating the level of breast cancer awareness and breast cancer screening awareness was done through the distribution of the survey to the female population of Kuwait. The main conclusion drawn was that the awareness was low. Many factors were found to be associated with this low level. Despite the effort made by the health authorities, key stakeholders and NGOs, there is an urgent need for breast cancer education across the country. New and different strategies and implementation methods should be adopted to target the people in need. Health education about breast cancer and the screening program should be compulsory for healthcare providers in order to participate in distributing the knowledge and improving the level of awareness in the community. In order to have an in-depth understanding of breast cancer and screening awareness and from a professional point of view, a qualitative study was conducted to explore the reasons behind the low awareness and the best approaches to raise breast cancer and breast cancer screening awareness; this is presented in the next chapter.

# Chapter 7 How to improve breast cancer awareness - A qualitative study

## 7.1. Introduction

In Chapter 5 Understanding awareness, beliefs and attitudes towards breast cancer and breast cancer screening behaviour in the Gulf region, the systematic review presented a synopsis about awareness, beliefs and attitudes towards breast cancer and breast screening behaviour in the Gulf region and Chapter 6 Breast cancer knowledge and awareness among female residents of Kuwait. A quantitative study provided an overview and description of breast cancer awareness and knowledge among Kuwaiti females, as measured by the (BCAM). It was concluded from these chapters that breast cancer awareness is low.

Given the low levels of awareness found amongst Kuwaiti females, there is a need to explore current approaches to awareness raising in Kuwait and consider alternative approaches to optimise levels of breast cancer awareness amongst Kuwaiti women. One way to achieve a higher level of awareness and to educate the population is through public awareness campaigns. Breast cancer campaigns in Kuwait managed to have positive result, however, not up to the required level, reflected by the low uptake of the national screening program and the late presentation of cancer cases as mentioned in the previous chapters.

According to the American Cancer Society (2019/2020), breast screening uptake among people aged (40-44), (45-54) and (+55) was 49%, 69% and 68% respectively.

In UK, it was reported that screening uptake reached up to 65% overall (Breast Cancer Research UK, 2022). This suggests that awareness is much higher than Kuwait and the rest of GCC countries. It is not clear why this might be. The researcher had the desire to examine some of the measures/approaches that are used in countries with high levels of awareness to consider how transferrable they are to the Kuwaiti or GCC context.

This chapter outlines the methods and results from a qualitative study involving key stakeholders in breast cancer in Kuwait, which sought to address research objective 3 of this PhD: To identify the best approaches to improve breast cancer awareness.

## 7.2. The impact of COVID-19

The original plan was to conduct a series of focus groups with key stakeholders, but the impact of the global COVID-19 pandemic required an alternative approach and instead key stakeholders working in the area of breast cancer in Kuwait were invited to participate in individual interviews with the researcher.

## 7.3. Method

Non-probability purposive sampling was used to select and recruit participants to the study. The researcher used a gatekeeper, the head of National Breast Screening Program in Kuwait, to help in suggesting stakeholders that could participate in this study.

The stakeholders who were identified by the gatekeeper, were employed in hospitals or polyclinics in different health regions of the country.

The inclusion only of professional stakeholders was deliberate as the immediate aim of the study was to identify policy mechanisms to improve breast cancer awareness campaigns. Such key decision makers could offer perspectives based on their long-standing experience of breast cancer in the Kuwaiti context. While the intention was not necessarily to include only senior experienced staff it was not deliberate their inclusion, and their perspective again adds to the validity and applicability of the findings.

The aim was to include 15 participants in the study. The interviews were guided by a topic guide that not only allowed a general conversation on their perspectives of the awareness of breast cancer among females in Kuwait but also discussed in more detail international breast cancer awareness campaigns and their potential applicability in the Kuwaiti context. The interviews were carried out in English because participants studied in English, so it is easier for them to speak about the medical knowledge in English. However, English is the second language to the participants and the researcher. It was decided by the supervisors and the researcher to keep quotes verbatim and therefore there has been no correction or modification to the participant quotes included in this chapter.

## 7.3.1. Study population

The study participants were stakeholders closely involved in breast cancer management, research and advocacy, control and/ or prevention in Kuwait. These included:

- Clinicians involved in the diagnosis and management of breast cancer, specifically at least one general practitioner and oncologist.
- Members/ advocates from non-governmental organizations with a primary interest in breast cancer in general. One member from Cancer Awareness Nation (CAN), non-governmental organization founded as part of an awareness campaign launched in 2006 in Kuwait and aimed at improving cancer awareness and promoting screening for cancer.
- Policy makers involved in setting action plans aimed at controlling and preventing breast cancer, including one representative from the Ministry of Health.

## 7.3.2 Sampling methodology/Identification of participants and consent

The identified participants were approached initially via e-mail and asked for their interest and availability to participate in the study. The researcher provided a brief introduction of the study its aim, and the topics planned for discussion (Appendix 6). A positive response and willingness to participate, after having had the opportunity to ask the researcher any questions they had, was considered as a formal consent to participate in the study. Participants who agreed to participate were contacted again and invited to the individual interviews and were given a written consent to sign before the start of the session (Appendix 4). Two copies were given for each participant to sign; one kept as a record and a second one was stored in the researcher's office and no one else other than the researcher had access to them.

The interview took place in the participant's workplace whether this was a PHCCs or a hospital.

## 7.3.3. Topic guide

The interview topic guide was informed by findings from the BCAM study of Kuwaiti females (Chapter 6 Breast cancer knowledge and awareness among female residents of Kuwait. A quantitative study). The topic guide included ten open ended questions that explored participants general perception of breast cancer in Kuwait, and their knowledge and existing activities and campaigns aimed at improving breast cancer awareness in Kuwait, the national screening program, including uptake and success of the program. The preliminary findings of the Kuwaiti BCAM (Chapter six) were also shared so that participants could give their view on the findings, particularly low awareness levels, variations in awareness by geographical areas, perceived barriers, social beliefs and their suggestions on how to optimize both breast cancer awareness and the awareness and uptake of the screening program. In particular, culturally specific questions, such as the influence of the 'evil eyes' were included. Participants were shown a video containing five international breast cancer advertisements and were asked to comment on the content of the advertisement and the applicability of them in the Kuwaiti context (Appendix 14).

#### 7.3.4. Breast cancer awareness campaigns

To facilitate discussion, a series of short campaign videos, previously used in the UK and USA were shown to interviewees. They were chosen among numerous available adverts during the study development process but because of time constraints, only six of them were included in the study. All of them carried the target message required and that is to increase awareness of breast cancer and encourage people to be involved in breast cancer activities, however, each one of them was presented in a different way. This diversity would expose interviewees to different ways of presenting adverts.

#### 7.3.5. Video brief

The time of the video was nearly 5 minutes (4:41) so that the interviewees would not become disinterested if watching a lengthy video. Videos can be viewed at the following URL (<u>https://youtu.be/1M3tyrRYafU</u>) and descriptions can be found in the (Appendix 15).

The video is composed of snapshots from several breast cancer awareness advertisements. Taken from different sources, such as UK charity Breast Cancer, Pitstop Health, The Estee Lauder Companies (USA), Cancer Research Centre UK and the Scottish Government; these videos highlighted the importance of screening, success stories for breast cancer survivors and important messages directed to the general public and women at risk. Some of the videos delivered emotional messages that showed how breast cancer affects patients and their family, while others were more educational and delivered factual information.

These videos encouraged viewers to speak with healthcare providers about any unusual changes that females notice which could help them to diagnose a health condition at an early stage and thus highlighting the importance of regular screening. The messages in the videos were designed to create awareness and encourage and reassure eligible females to take the breast screening tests and not to be worried.

## 7.3.6. Ethical approval

The study was carried out in accordance with the World Medical Association Declaration of Helsinki (1964) and its revisions (Tokyo [1975], Venice [1983], Hong Kong [1989], South Africa [1996] and Edinburgh [2000]). Ethical approval was granted by the University of Glasgow, College of Medicine, Veterinary and Life Sciences Committee and from the Standing Committee for Coordination of Health and Medical Research in Kuwait before any research activities were performed. The investigator was responsible for reporting to the ethics committee the changes made to the study protocol and any updates as required by the committee.

## 7.3.7. Pilot interview

The crucial step of pilot testing of the topic guide and interviewing was undertaken before conducting the main study. The pilot interview was held with the head of the cancer registry at Kuwait Cancer Centre. The interview lasted for about 40 minutes. At the end, the interview was reviewed by the supervisor and myself to check on the flow, the viability and to detect any weakness or mistakes that might have occurred during the interview. The first interview worked well with no gaps and no changes required to be made and it was decided that it was suitable to be the first interview included in the study.

#### 7.3.8. Data collection

Data collection for the individual interviews commenced in November 2020. The interviewees, as mentioned earlier, were stakeholders involved in breast cancer management and in the screening program. The interviews took place in the

workplace of the interviewee in a suitable and quiet environment. The researcher carried out the interview. The session was audio recorded. The time frame for the interview varied from 30 minutes to 90 minutes. The session started with welcoming and appreciative words for the interviewees because the collection of data was carried out during the difficult COVID-19 pandemic and in that time all medical and health personnel were extremely busy. After that, the researcher started the interview as per the topic guide described above in Section 7.3.3.

After watching the video, participants were asked to think about what they would consider to be the best approaches to improve the awareness of breast cancer and the uptake of breast cancer screening in Kuwait.

#### 7.3.9. Transcribing the interviews

The interviews were transcribed in full verbatim with the aid of a skilled transcribers agency in Glasgow. The investigator reviewed each transcription to check for accuracy and completed any missing words.

## 7.4. Data analysis

In this gualitative study, inductive thematic analysis using a framework approach was used (Gale et al., 2013). Thematic analysis strives to identify patterns of themes in the interview data. The framework approach comprises five stages: 1. 'Familiarization' with the main ideas and themes in the interview. The researcher read the transcripts many times to acquaint herself with the data in order to develop the themes. 2. 'Identifying a thematic framework' - labelling all the important ideas, themes, and concepts so that they were retrieved and examined carefully. A task that was shared between the researcher and the primary supervisor and were discussed together. 3. 'Indexing' the data - the researcher was able to create categories or units that comprised a large number of theoretical ideas that could be applied to interview transcripts, a process which is called coding. Multiple discussions were carried out with the primary supervisor during this process to ensure that no possible emerging themes were missed. The researcher was able to 4. 'chart' the data in relation to certain parts of the framework. Finally, 5. the researcher 'mapped and interpreted' the data, got a thorough understanding, and constructed the associations between themes.

Assessment of the analysis was carried out by the primary supervisor to ensure the accuracy of the process.

## 7.5. Results

The total number of stakeholders contacted was 26 however, only 14 participants agreed to participate as most of them were busy during that period of time.

Fourteen participants were interviewed, 8 of them were females and 6 were males. All came from different medical backgrounds yet were involved in breast cancer and screening program awareness. Table 7.1 summarises the job roles and gender of the study participants.

Interviewee number	Interviewee's job role	e Interviewee's gender		
1	Epidemiologist	F		
2	General surgeon and breast oncoplastic	F		
3	Radiation oncologist.	M		
4	Clinical oncology	M		
5	Clinical oncology	M		
6	Family medicine	F		
7	Radiology and Breast imaging unit	F		
8	Radiology and Imaging department	F		
9	Public health specialist	M		
10	Clinical oncology	Μ		
11	Palliative medicine	F		
12	Psychotherapist	F		
13	Family medicine and M Technical support department			
14	Family medicine	F		

Table 7.1: Participants' Demographics

## 7.5.1 Video adverts

Once the video was shown to participants, each of them gave their thoughts about the adverts, their views on suitability and suggested the possible way to adjust them to the Kuwaiti context. A summary of their replies is outlined below in Table 7.2 and details of their responses are provided later on within the discussion.

Interviewee's	Advert 1	Advert 2	Advert 3	Advert 4	Advert 5	Advert 6
Response	(young child with	(factual)	(storytelling)	(cancer research)	(facts/ diagrams)	(a woman exposing
	her breast cancer					her breast)
	mother)					
1	Very emotional but will be attached to emotion rather than the message.	This one is good	It is good to tell a story but if it was a successful one.	Yes, curable disease. It is a fact but not the whole fact.	I agree with it.	Will never be allowed on the screen in any Arab country.
2	Encouraging.	Nice and short.	Difficult in our population.	One of the best.	Unless it is professional site, it's difficult to put these pictures.	It's a bit over for our conservative culture.
3	Showing how early diagnosis is important. Very nice.	We have this in Arabic	We can see this one here as well	Research helping people to improve.	l support it.	No, it's not a way to reach people.
4	Very emotional.	We tried that here. People are not good with numbers	Very emotional and strong but I don't think it will work in Kuwait.	We don't have research.	BSE is not a recommendation.	It will not be legalised.
5	Not very applicable.	I think it would be fine.	A lot of resistance from people telling their story.	Not applicable here.	Good, but maybe the majority will not accept it.	Oh, that's impossible.
6	Applicable, but has to be modified	Yes, applicable.	Can be done but in another way	We don't have research here.	Nice educating video.	Not acceptable to see women without clothes even for educating purposes.
7	I don't think it will help much.	Any ad that contains terms like invasive will not give the effect that we are seeking.	Good idea.	Not applicable.	This is a good message.	Oh, no.

Table 7.2: Summary of participants replies' to breast cancer video adverts

8	It will have a negative impact on our ladies	Good.	It doesn't fit the middle east.	There is hope in it.	BSE is no longer a must. In Kuwait, we are not allowed to present breast even as drawing in TV advertisement.	This one, no way.
9	In my opinion it can be a message to stakeholders, sponsors or partners, but it didn't convey a health message to the public	Very short and non- interactive advertisement.	Applicable but with modification	This is one of the good advertisements.	Very informative	The Kuwaiti culture and in general the middle east culture does not support the display of a naked women on the media.
10	No, I don't think its valid here in Kuwait.	lts ok.	It is good. We did this before.	Cancer research in our area is lacking.	It is really good.	It's not suitable for us at all.
11	It's very interesting. It can have good effect.	Nowadays people don't want to read. It's not that effective	I feel this is the strongest one. Its applicable in Kuwait.	Not applicable.	Very informative and encouraging.	Forget about it.
12	Yes, you need the family to support each other.	Definitely agree.	We need something like that.	We are trying to do it here.	We couldn't put this on TV.	I would love to do that, but who has the courage to do it and who is ready to put it on Kuwait television?
13	Giving the message in this way is very terrifying.	It is ok.	Maybe it is a good one, but should tell the good part of their story not the bad one.	It can be applied here but should be modified.	The only problem with this is broadcasting it in public places.	No, for sure
14	Very promising. This ad full of hope. Yes, can be applied with modification	Yes, a short video but the data and statistics be from Kuwait.	It's a nice idea but people don't have the courage to tell their stories.	This is to support researchers. We do have it here but not sure if for breast cancer or even cancers.	This is an excellent ad, its short educational video.	This one may not be accepted in our community. It is a very sensitive issue.

## 7.5.2 Themes and subthemes

The main themes and related sub-themes identified from the analysis are listed in Table 7.3. The eight themes were: fear, low levels of awareness, perspective of younger women, late diagnosis, approaches to raise awareness, cultural issues namely taboo, stigma and modesty, reluctance to use emotional content for advertisement, and the need for early education. The 'interviewees' views on these themes are presented below, illustrated by key quotations selected from the interviews. However, reading through the themes it is clear that there is overlap and shared content across some themes due to the nature of the topic. A discussion of the responses in relation to the literature is presented in Section 7.6. and 7.6.1.

Main Theme	Sub-theme
1.Fear	<ul> <li>i. Knowledge/ Awareness or lack of it</li> <li>ii. Body image</li> <li>iii. Social stigma and taboo</li> <li>iv. Media/ Advertisement</li> </ul>
2.Low level of awareness	I. Awareness and screening uptake ii. Capital versus other districts iii. Campaigns iv. Sociocultural factors
3. Younger females	
4.Late diagnosis	I. Prevalence of late diagnosis ii. Late presentation and awareness iii. Barriers to diagnosis
5.Current approaches to raise awareness	i. NGO ii. Government iii. The private sector iv. Area of improvement
6.Cultural issues	
i.Taboo/ Stigma	a. Perception of breast cancer b. Impact on breast cancer
ii. Modesty	
7.Reluctance to use emotional content to raise awareness	
8.Solution: Education- start early	

Table 7.3: Themes and subthemes identified in the analysis

#### 7.5.2.1 Theme 1: Fear

One of the emerging themes that came out in of the interviews was fear in the female population. The correlation between breast cancer and fear is not new, in fact the literature has long been exploring this relationship and the relation between knowledge about breast cancer, spirituality, psycho-oncological care and other factors associated with fear of breast cancer. Interviewees spoke about females' fear of being diagnosed with breast cancer:

"People fear breast cancer because they think it's a killer disease, they will die if they get it." (Interviewee 3)

Fear of cancer can manifest in several ways, some females try to manipulate the naming and prefer calling it other names, as a coping mechanism, as reported by one interviewee:

"Actually, one client she decided to call the cancer infection. She says, my mind can handle it better." (Interviewee 12).

Even though stakeholders realized there has been improvement in breast cancer and screening awareness from previous studies, however most participants agreed that females are still afraid to take part in screening because they are too afraid to find out they are sick. A study was conducted by one of the interviewees, a researcher in breast cancer (interviewee 3), among females in Kuwait where respondents were asked about their reaction when noticing or finding a lump in their breast. They found that more than half of participants (60%) were too scared to seek medical advice. Though this seemed to improve with time:

"When the survey was repeated few years later, it was noticed that the number of women who were reluctant to seek medical attention because of fear had gone less (30% to 40%)." (Interviewee 3).

However, this study was not published, and details were not available.

Fear from breast cancer comes with the risk of late detection or screening, one interviewee said that fear is among the reasons for the late presentation of breast cancer:

"Many people you know in our area are too scared. That's why they come in a late presentation."

In fact, the majority of the interviewees spoke about fear from breast cancer during the interviews. According to the interviewees, fear was associated with knowledge or lack of it, with social stigma, body image, and media and advertisements.

These associations with fear are presented in detail below.

#### i. Fear and Knowledge/ Awareness or lack of it

It is commonly believed that low levels of breast cancer awareness are usually associated with a lower level of education (Solikhah et al., 2019), however, the interviewees noticed that low levels of awareness were also found among women with high level of education:

"I can tell from my experience, highly educated ladies, they are afraid to come" (Interviewee 2).

Participants claimed that highly educated females utilize all the available resources to learn about breast cancer and educate themselves and instead of becoming more aware, they panic and get terrified:

"They read about the disease, and they go into the extent of how bad is the disease and the complication of the disease and they just feel afraid to examine" (Interviewee 2).

Fear from cancer is not only obvious in people with limited education, but also highly educated people are scared and suffer from fear of being diagnosed with cancer:

"Low level of awareness usually associated with lower level of education" (interviewee 2)

People fear breast cancer because they think it's a killer disease, they will die if they get it. The interviews revealed that cancer is still not very well understood nor tolerated by many females.

"It is not easy actually to convince the people that the cancer is not a killer disease." (Interviewee 3).

#### ii. Fear and Body Image

Body image was reported as another reason why females' fear cancer, some females develop negative body image after being diagnosed with breast cancer especially when thinking about the consequences of the treatment. They are frightened by the idea of losing their hair and breast. This could create a selfdistorted image which reflects negatively on their social and marital life:

"Some of them are afraid as I told you, to be stamped that they are breast cancer patients, that they will affect their marital life, that they will have disfigured breasts, they might lose their breasts, they might have chemo and lose their hair, so they will have some problems in marital and they might lose their life as a wife" (interviewee 2)

This self-conscious body image was especially reported to be present in females of younger age, whose rejection of screening is more common frequent than for older females according to one interviewee:

"They are worried, they don't want to know that they have cancer and they are worried about the breast disfigurement that might happen if they do surgery for their breast." (Interviewee 8).

A major concern observed in one study was "body image," which led to feelings of unattractiveness, self-consciousness, and solitude (Al-Azri et al., 2014), as corroborated by one interviewee's experience:

"She doesn't want even her husband to know, and she's not going to tell him because she's wearing hijab so he's not going to know if she has lost her hair or not. She doesn't want to." (Interviewee 12).

#### iii. Fear and Social Stigma/ taboo

Breast cancer has long been associated with social stigma and taboo. Some societies are more conservative than others, especially in relation to the reputation of its females. Breast cancer diagnosis is not a matter that affects only the patient but also other females in her family. For example, one interviewee mentioned a patient's daughters would not be sought for marriage quoted:

"she's afraid that the people will be trying to avoid getting married to her daughters because of their hereditary factor" (Interviewee 2). One interviewee indicated that females are scared from cancer, they fear the consequences of cancer. They don't want to be labelled as breast cancer patients and become a stigma among others:

"They are worried about the breast disfigurement that might happen if they do surgery for their breast." (Interviewee 8)

Sometimes, people try to hide their diagnosis because of the fear of losing their family where breast cancer is seen to affect marital life and leads to social isolation. A study on the psychosocial impacts of breast cancer on Omani females reported that many females were reluctant to inform their friends about the diagnosis and they preferred to only share the news with close family members (Al-Azri et al., 2014). Similarly, in Kuwaiti culture if a female gets breast cancer it is very common that she would not speak about it:

"No, I don't want my children to know; I don't want my friends to know." (Interviewee 5).

One interviewee believed that women in different regions should be targeted in different ways, given their socioeconomic level and awareness levels. He also highlighted the role of primary health care in encouraging females to seek medical attention where he stated that the best way to overcome the fear inside women who are reluctant to seek medical advice or do the screening mammogram is by using good communication skills at a GP clinic or 'diwaniya':

"Awareness, good presentation, good communication skills, we are talking purely about communication skills from the healthcare provider. If they talk in a way that it's not a formal medical visit, we need them to speak to them." (Interviewee 9).

#### iv. Fear and Media/Advertisement

In response to the impact of advertisements and media on females' awareness about breast cancer, participants spoke about fear. Even though breast cancer campaigns seek to educate females about breast cancer and convince them to take preventative measures to protect themselves against it however, the opposite is happening. "It evoked a lot of fear in the community" and "it was all over the country" (Interviewee 1).

The media is thought to contribute to why females are afraid of breast cancer, a number of interviewees believed that the media presents cancer as a killer disease and whoever gets it would die, which in return affects females 'perception of the sickness and creates fear:

"All over the world, people are showing through series, through programs, through movies that cancer is a killer disease. When they want to get rid from any man or woman or want the sympathy from the audience, they act that this lady in the movie is getting cancer and she's going to die". (Interviewee 3).

Some participants blamed the media for its reluctance in spreading awareness of breast cancer by stating that there aren't enough campaigns available to raise awareness and the available ones are not consistent with the activities they provide, thus contributing to females not learning about breast cancer enough which eventually leads to their fear of it:

"I think they're failing, because it is erratic. It's an occasion, in October every year suddenly appear about breast cancer, so women will avoid, when you mention the word breast cancer. They will avoid to educate or to know about it" (Interviewee 4).

Interestingly it was also mentioned by interviewees that fear hinders the impact of media on creating awareness among females. Where because of fear, females tend to avoid listening to the word 'cancer' itself or watching TV content about breast cancer or even looking at an advert about breast cancer. All these reactions reflect their inside anxiety towards the disease. When asked about the storytelling type of adverts and its applicability in the Kuwaiti context one interviewee said that:

"I believe in Kuwait, people are very scared of the title cancer, breast cancer, and whenever you talk about it, whenever they see an ad, they will change the channel, they will change... they will turn it off, they will turn away from it." (Interviewee 4).

This was also consistent with another interviewee's view on media and awareness where they defended females who fear to seek medical advice when noticing a change to her breast by blaming the media. Commenting on the content of advertisements, another interviewee believed that discouraging words when advertising about breast cancer should be avoided because:

"They are afraid of this term, invasive cancer. So, any ad that contains these terms maybe will not give the effect of what we are seeking." (Interviewee 7).

Alternatively, one interviewee thought that fear from breast cancer should not exist in females' heart, and those advertisements should avoid using emotional content that creates fear and rather use encouraging informative content that gives hope and demonstrates success stories about early diagnosis and how it can lead to better treatment results:

"I think it's more a scary advertisement for the public, rather than giving hope"

"So, she has to think even about, that breast cancer is not that fatal like before, and there are manageable cases, most of them are cured with early diagnosis and being treated at the beginning." (Interviewee 9)

#### 7.5.2.2 Theme 2: Low Levels of Awareness

During the course of the interviews, another recurring theme was brought up by the interviewees: low levels of awareness among females about breast cancer awareness. Low levels of awareness were discussed in relation to several sub themes, namely: low levels of screening uptake, the difference in awareness levels between the capital and other districts, the role of media and campaign in spreading awareness, and the socio-cultural factors that affect awareness levels. Although in this study education has been shown to be irrelevant of awareness, knowing the importance of early screening and diagnosis was still lacking among women, especially those living outside the capital.

#### i. Awareness and screening uptake

The interviewees linked the low uptake of breast cancer screening in Kuwait and the late presentation of breast cancer patients to the low levels of awareness among females. The level of awareness among the females in Kuwait seems to be lower than other countries as seen in chapter six. This may explain the low uptake of mammography to screen for breast cancer. As a result, they miss the benefits of early screening. The interviewees attributed the late presentation for seeking medical aid to low levels of awareness among breast cancer patients. One interviewee stated that:

"Part of the delay of presentation of our breast cancer patients is the awareness of how serious this problem" (Interviewee 2)

Late presentation and low uptake of screening is in turn posing a burden on the healthcare sector, another interviewee added that as a result of the low levels of awareness, the prevalence of breast cancer is high causing a large burden on the medical services:

"It is an important disease. It has a large burden. And people need to be more aware about it." (Interviewee 5).

#### ii. Awareness in the capital versus other districts

The interviewees also spoke about the difference in awareness levels among females between the capital and other remote districts in Kuwait. People living away from the capital have lower awareness levels compared to people living in the capital area. They believed that areas outside the capital are at a disadvantage in getting the required awareness program they need than those in the capital city. One interviewee stated that

"As I said earlier, who are living on the periphery, or outside the Capital, need more for the awareness program." (Interviewee 3).

Another interviewee gave an example on Al Jahra district which is located at the northside of the capital. Females there have limited access to media and social networks, they also show lower awareness levels compared to the capital highlighting the need to increase awareness efforts outside the capital:

"if I'm talking about woman in Al Jahra for example, it's going to be very different from targeting a woman in Capital health region... here [they] are more educated, they are here, more open to the media, the social networks, or social gatherings, that's educational more, so they are also open to the internet and other resources, so they can be more aware about the health." (Interviewee 9).

#### iii. Awareness and campaigns

The interviewees highlighted the importance of media campaigns in raising awareness. Many thought that the current campaigns are not enough; others believed that the tools used are insufficient. One interviewee believed that people's awareness can be increased through the use of social media; however, its reach can be limited especially for people who do not have access to social media, such as the elderly and those living in distant areas. Interviewees mentioned that a different way of communication is needed in order not to miss anyone:

"A lot of people don't know about the screening program." (Interviewee 5)

"There is marked deficiency in this issue" (Interviewee 10).

One interviewee thought that the message from the NGOs and the campaigns is not reaching them:

"So, do we see those campaigns translate into improvement in the screening over the years? The answer is, no. So, I would say probably, they are not successful, no." (Interviewee 5).

In addition, he described his experience with an awareness campaign he had been part of:

"I did once, awareness program at the 360 Mall in Kuwait. So, I went there and we had a booth in the middle of the 360 Mall...and when, oh, this is breast cancer awareness, they just continued to walk. They had no interest to listen to it." (Interviewee 5).

#### iv. Awareness and sociocultural factors

Moreover, several socio-cultural factors play a role in spreading the awareness about breast cancer especially among family members where heredity could play a role. According to one interviewee females diagnosed with breast cancer tend to keep the issue as a secret from even close relatives which in return delays any possible early diagnosis and treatment for other family members:

"That patients they are not telling their relatives that they have cancer. They are hiding it. I don't know why"

"Because if they tell each other then we can screen the families, we can do some genetic testing, we can do proper screening program for them for early detection to detect the disease early" (Interviewee 10)

However, some interviewees felt that females' awareness about breast cancer is now increasing especially among younger females, thus linking awareness to age and educational level:

"And the awareness about breast cancer in Kuwait now it's increasing...there's more awareness in those girls, and also teachers." (Interviewee 11).

Yet, some disagreed and believed that awareness is still not up to the required levels and attributed social beliefs such as punishment from God, voodoo, and being secretive about it as the reasons behind this lack of awareness:

"People themselves they still think that whatever they have is related to a punishment from God"

"it's a combination of voodoo, not accepting it, they don't want to know about it, or they don't want anybody else to know about it. (Interviewee 12).

Finally, the issue of expats was raised, many of whom are females, and they constitute a high number of the residents in the Kuwaiti society, they too play a role in the awareness about breast cancer:

"But still we have also those who are non-Kuwaiti, and many of them are not educated, especially those housemaids. So, we are talking about a huge number of housemaids, especially coming from India, from Sri-Lanka, from South East Asia. And so we are talking about like 900,000, and most of them are females, and they might be affected at any stage of their life, of breast cancer." (Interviewee 9).

#### 7.5.2.3 Theme 3: Younger females

The interviewees noted observations about prevalence of breast cancer in younger females compared to global age figures. Few participants spoke about younger age incident rates. We know from the previous chapters that breast cancer in Kuwait affects middle-aged females, and it is a decade earlier than what it is in the western world. Females usually present at a younger age group, 55-59 years of age. "We are seeing actually more young ladies who are affected by the cancer of the breast...this is much younger than the breast cancer in the western culture" (Interviewee 3).

One interviewee who is a breast cancer oncology specialist explained that when younger females are diagnosed with cancer, they should not rely on the regular mammogram only because in that case the genetic factors play a role thus demanding further investigation like the MRI:

"There must be a high-risk screening, high risk population. Patients in younger age group developing cancer, or their families. Very strong family history. Some genetic mutation. They should go for a special screening program for high risk. And we don't depend only on the mammography in this situation. We do more. We do MRI for this type of young age group, high risk." (Interviewee 10)

Usually when younger females are affected with breast cancer, suspicion about genetic mutation rises and it is recommended to conduct screening for the whole family. He further explained that social factors hinder proper screening and diagnosis, since hiding diagnosis is a very common phenomenon in the society:

"Very common here in Kuwait and I know many families, sisters all together, having cancer. None of them knows about her sister or her daughter. They are hiding.... we can do proper screening program for them for early detection to detect the disease early because they are liable, they are at risk to have breast cancer." (Interviewee 10)

No clear reason why they keep it to themselves, but one thing might be fear, as outlined above in Section 7.5.2.1.

It has been noted by the interviewee that one of the health issues affected by breast cancer in younger females is fertility, thus, campaigns should address the issue of this matter as well:

"And even we sometimes feel shy to ask about certain side effects, which really disturb the quality of life between the patient and her husband, their families. And since we are seeing also younger patients, you know, the fertility issue will come up. Shall I get pregnant? I want to have a child. There is a lot of things really to be covered and this campaign." (Interviewee 10). Finally, another interviewee had a different note on age affected groups, and realized that older females were more encouraged to do the screening than younger ones:

"We also noticed that older women...this is strange; they are more encouraged to do it than younger women." (Interviewee 8).

#### 7.5.2.4 Theme 4: Late diagnosis

One of the most spoken about themes during the interviews was the late diagnosis among breast cancer patients. Indeed, this information was confirmed by the majority of the interviewees who spoke about late diagnosis. This theme was discussed in relation to other factors such as low levels of awareness and barriers to diagnosis.

#### i. Late presentation is common

The interviewees, being physicians, discussed their observation and input on late diagnosis. The majority discussed the late presentation of patients a lot in their interview. One interviewee stated that even though breast cancer is the most common female cancer in Kuwait, the stage of the disease at presentation is usually high, e.g., stage III or VI. Despite the introduction of the preventative and screening programs, the stage remained the same.

"However, the screening program started in 2014 and the stages did not change up until now. Now we are seeing more in situ lesions, but the stages are still high". (Interviewee 1).

However, another interviewee was the only one to claim that now it's improving and usually is being diagnosed at stage II. There has been a historical transformation of diagnosis, where there might be improvement in the diagnosis of cancer, as one interviewee said that in 1983 most of breast cancer patients had late presentation and the cancer stage used to be III or VI:

"in 1983, for example, about 70% of the people, of ladies diagnosed, were diagnosed with stage 3 and 4. Now, as I mentioned, most of the patients are diagnosed with stage 2. And we are seeing now more and more stage one" (Interviewee 3).

This observation was confirmed by several participants who stated that albeit females' presentation with breast cancer is usually late, only 4% of eligible females took the screening program; the stage of the disease at presentation is usually III or even VI. The type of cancer they present with is usually the aggressive type and at an age that is 10 years younger than those seen in the United States or Europe as mentioned earlier in chapter one.

"The age at which breast cancer occurs in Kuwait is ten years younger than the United States and Europe. Our breast cancer patients, they present with an advanced stage. Usually in stage 3 or 4 and they would have an aggressive cancer because of the young age. So, the reason why it's an advanced is because of the lack or the undertaking of screening program of breast cancer in Kuwait" (Interviewee 4).

One of the reasons behind late diagnosis is that most patients were diagnosed due to the presence of symptoms and not from screening thus making the stage of the disease usually advanced:

"The majority of the patients are diagnosed through symptomatic and not through screening. So, the majority of the people come to the clinic, because they felt a mass or the mass is locally advanced, and then they get the image done and the biopsy". (Interviewee 5).

During the interviews we tried to investigate with the interviewees the reasons behind the late presentation. Some attributed it to low levels of awareness, while others listed other barriers to early detection.

#### ii. Late presentation and awareness

Many interviewees linked late diagnosis to low levels of awareness. They believed that low levels of awareness did not facilitate seeking medical help early on and thus led to late presentation. One interviewee for example, related the late presentation of breast cancer to low awareness levels:

"Part of the delay of presentation of our breast cancer patients is the awareness of how serious this problem" (Interviewee 2).

Another interviewee believed the reason for that is the deficiency in advertising and campaigning breast cancer; he also spoke about low awareness levels among less privileged districts, thus presenting at a late stage of breast cancer: "So, for this district in areas like Jahra or Ahmadi or whatever, now they have big hospitals there. And they have X-ray machines there as well. And in the national screening program they have also one of these screening program there. But there is no awareness program. They don't know about it. Sometimes the polyclinic for screening is beside the house and they don't know about it. There is lack of information. A lot of lack of information, not reaching or letting patients know that we have a national screening program." (Interviewee 10).

Furthermore, one interviewee mentioned several reasons behind the late presentation and as a result the late diagnosis of breast cancer and one of them is that the campaigns couldn't deliver the required message to the population at risk and that their activities are very occasional:

"They do it once per year or maybe twice per year which is not enough. People will forget about it" (Interviewee 13).

#### iii. Barriers to Diagnosis

In addition to low levels of awareness, other barriers for the early detection of breast cancer have been discussed by the interviewees. One interviewee explained that a reason behind late diagnoses is the fear towards cancer which prevents them from seeking examination:

"...even some of them they come with a mass and I tell them you have to do a mammogram, she would say no I won't, I don't want to, I'm afraid of what might the doctor finds" (Interviewee 13).

He extended his analysis to blame healthcare workers by stating that the lack of communication skills in the health professionals and their inability to convince patients is a barrier against diagnosis:

"We need to improve the communication skills of the doctors,"

"It should be skilful way, because you want to convince them. Ok? they have some worries and maybe those worries are unrealistic and we have to address it" (Interviewee 13).

Finally, one interviewee related late presentation to social factors whereby hiding sickness between relatives and avoidance to tell each other about their diagnosis had prevented the early family screening which could be a lifesaving. Another reason for the late diagnosis, he claimed, is that most of the family in the Kuwaiti society have helpers at home who take care of the house and sometimes they hire special ones to take care of the old ladies:

"Parents are busy; they leave everything for the maids" (Interviewee 10).

#### 7.5.2.5 Theme 5: Approaches to raising awareness

Awareness was identified by the interviewees as being an integral part to the early diagnosis of breast cancer and addressing its risk factors. Thus, interviewees were asked about their opinion on an effective approach to raise awareness. Some interviewees spoke about the current approaches and highlighted areas of improvement, while others suggested new approaches for future awareness campaigns. These approaches were divided into sub themes depending on the sector that implement awareness activities, be it NGOs, the government, or the private sector.

#### i. Current campaigns

According to the interviewees many efforts have been taking place to raise awareness about breast cancer and early screening. These efforts have not been exclusive to the Ministry of Health or government agencies but are also extended to the NGO"s and the private sector.

#### ii. NGO

Nearly half of the interviewees spoke about CAN. They launched a campaign with a dedicated mission and a clear strategic plan for breast cancer awareness. The campaign runs activities year-round but with more emphasis on October. According to one interviewee the campaign also runs survey studies before and after each event to assess the level of improvement in awareness and the success of the campaign. The main activities they conduct range from giving lectures in school on how to examine the breast, to providing leaflets and books in the shopping malls. They also showcase different awareness programs on the TV screen in the waiting areas of the polyclinics. They broadcasted a breast cancer awareness advertisement on public TV however the interviewees did not mention how often they would run it for. One of CANs' most noticeable activities is teaching schoolgirls how to do BSE. One interviewee spoke more about their school campaigns:

"I heard that they go at the age of like 17 or 18 and they teach them how to do breast examination. And from that point they can teach their mothers, their daughters, for the future." (Interviewee 10).

Some of the Interviewees have been part of CAN campaigns and participated in their awareness campaigns held in shopping malls as a physician. They had a booth with brochures about breast cancer. There was also a room for examination. In the presence of a doctor and a nurse they offered to teach BSE to females who visited the booth and are interested in knowing more about breast cancer. One interviewee shared her experience:

"We have also the campaign they are doing, even in October, in malls. To get more of the normal population to see what we have as a service to give."

"They said any woman who would like to learn to do the breast examination, there is a doctor inside and a nurse, they will teach you." (Interviewee 6).

Being the most active NGO in the area of breast cancer awareness CAN also executed an advertisement campaign outside the city of Kuwait to raise awareness among the less privileged. During the interview, one interviewee mentioned some other initiatives done by NGOs:

"But if we are talking about the voluntary campaigns come from the NGOs like for example 'The social society for women", yes I'm aware that from time to time they would have campaigns, which target females and they are maybe doing it in big malls or maybe in shopping centres, they do it sometimes and mainly when there is a breast cancer day, they do that." (Interviewee 13).

No other NGO has been mentioned in terms of efforts of projects conducted in the area of breast cancer awareness or research in Kuwait.

#### iii. Government

As for governmental efforts, interviewees spoke about the 'Kuwait National Mammography Screening Program' which was established in 2014. This program invites women by SMS message to take part in the screening program. As part of this campaign each PHCC and governmental hospital work together hand in hand on this issue and you will find poster and TV adverts about the screening mammography which says:

"if you are from the Kuwaiti population, female. If you are above 40, and there is no history of breast cancer before and you want to do a mammogram, you have to register on this hotline. This is one type of increasing the awareness and the way to deliver the information." (Interviewee 6).

This program was established because of the low uptake of screening, a national

screening program was essential:

"There was a problem that females they don't accept or they don't come voluntarily for screening and there was a problem and for such a reason a national program for screening for asymptomatic females in Kuwait was established." (Interviewee 13).

Governmental organization is responsible for breast cancer screening and its role

to promote for screening of the breast:

"The Ministry of Health, we have an approved screening program for breast cancer, it has its own policy and procedure, it has its own wellstructured premises where the woman can go and do the screening and they have its own infrastructure resources and physician and staff." (Interviewee 14).

Activities are also done on the primary care side:

"Many polyclinics or primary care health centres will start to do a campaign in their clinic, just to promote for the awareness of breast cancer and for the screening and they will give ladies a referral, even in the hospital" (Interviewee 14).

#### iv. The Private Sector

A collaboration between the governmental and private sectors was established

to raise awareness towards breast cancer and offer screening through Hayat

Medical Centre:

"The aim of that was to screen ladies who are suspected to be affected by breast cancer" (Interviewee 9).

Media and social networks also participate in spreading awareness among females. Some efforts are individually done by healthcare workers. One interviewee spoke about his experience in "dewaniyya" which is a social gathering present in the Kuwaiti culture, where a number of males or females gather in the host house regularly and discuss many issues:

"I went to the 'dewaniyyas' and I was able to speak to so many people, and I gave the message, the health message, in a unique way and it was very successful. And we've seen that in the reach of vaccination for influenza, that the people who went, first were scared about influenza vaccination, but later on, when we started to talk with them, the vaccination rates increased. Also, smoking cessation. When we talk to them in these social gatherings, all smokers have started to think about the idea of quit smoking." (Interviewee 9).

Other activities to increase breast cancer awareness are through patient conferences, whereby both patient and physicians are present to share their experiences with breast cancer:

"Although we do group therapy to the Arab speakers and the English speakers, and I always do that once a month, both of them, and I always introduce someone who's finished and been cured for the past ten, 15 years to be there so they can ask her and tell her how she's doing and everything." (Interviewee 12).

Finally, different private sectors are also involved in breast cancer awareness activities and campaigns:

"Other than the government, we have so many initiatives from the non-governmental sector or from the community. We have so many, for example, banks or sometime college or a private clinic, private hospitals will take the opportunity to increase the awareness about breast cancer and some of the initiatives that they will give a special offer sometimes in the private, they would reduce the prices for the test, especially during the month of October, just to encourage more women and ladies to come and do the screening." (Interviewee 14).

#### v. Areas of Improvement

More than half of the interviewees criticized the current practices and believed that there are areas of improvement. One of the most recurring criticisms was that efforts are concentrated around October the month of breast cancer awareness, and little to null effort is being done all around the year. There are different parties: private, government, NGOs, societies, organizations and individuals sponsoring breast cancer awareness in many different ways, but the problem is that the activities occur during the month of breast cancer:

"There are a few campaigns. I mean, with CAN, different societies and different organizations are doing certain campaigns, mainly in October of every year. We see a lot of those campaigns annually, but between each October of every year, we don't really hear much about the disease. So usually, the campaigns occur from October 1st to October 31st..." (Interviewee 5).

The month of October has been heavily dedicated to breast cancer awareness that some people started to associate the screening with this period only. Activities about breast cancer increase during the month of October and as a result uptake of screening increases:

"Sometimes during the screening program, that is done every October, when it's the month of breast cancer, ladies are coming to ask us if they can do a screening test for it." (Interviewee 14).

Other areas of improvement have been tackled by other interviewees, for example one interviewee said the most famous campaigns are the National Screening Program and CAN. They both sponsor many awareness activities, yet it seems to be still insufficient:

"They are doing a great effort but still we need more awareness and effort to push women to participate in the screening program." (Interviewee 7).

The problem is convincing people to make the effort. Similarly, one interviewee also expressed the poor interest of the general public in this topic, he spoke about what he thought is the classical way of activities done in order to raise the awareness:

"The classical way for example when you go to the mall and you have a station where people can come to you only those who are motivated will come to you, but the majority will not come." (Interviewee 13).

#### vi. Suggestions for future campaigns

Among all the interviewees, only three suggested ways to do future campaigns. According to these interviewees, the best way to increase breast cancer awareness is the introduction of a health education program early in school life. Some interviewees believed that this would target the fear factor. It will educate them, and this will facilitate passing the message to their family which will in return change their perception towards breast cancer.

"So, if we start building this in schools, I think this will reflect on the society because every girl is a daughter of a woman. If the woman is afraid, her daughter can help her, so this is the way I see" (Interviewee 1).

Finally, one interviewee said that he's using Instagram as a way of advertising and educating people to raise their awareness, emphasizing the role of social media in raising awareness. Another interviewee (interviewee 2) on the other hand thought that all sorts of media could be part of spreading awareness whether it's TV, radio, Instagram and the rest:

"You need to approach them through media"

"I do it on my page on Instagram and I write it, I teach it to my students" (Interviewee 2).

#### 7.5.2.6 Theme 6: Cultural Issues

#### i. Taboo/Stigma

One of the major themes that came out of the interviews was about cultural issues that are reflected by a taboo and stigma of breast cancer. People's perception of breast cancer stands as a hurdle for early diagnosis, seeking medical care, voicing out the sickness, and disseminating proper awareness. The majority of participants in the interviews brought up the subject of taboo and stigma and spoke about the cultural barriers that face successful breast cancer awareness/ screening. The topics were broadly divided into two subthemes, one related to the perception of breast cancer and how people view it, and the second related to the impact of this perception on people's behaviour towards breast cancer.

#### a. Perception of breast cancer

Interviewees reflected on the perception of people towards breast cancer and how much of a taboo it is considered. In addition, once the sickness is made known, the person is stigmatized, and cancer is immediately linked to death. The first interviewee said that some people are afraid of cancer and think if they talk about it, they will become exposed. So, they would rather keep it as a secret.

Moreover, another interviewee mentioned that having breast cancer is considered a taboo among people living away from the capital district and as a result the CAN campaign had focused their activities more on these areas specifically. He also believed that the media has a role in supporting the idea that having breast cancer is a taboo. People in Kuwait consider cancer as a taboo and call it 'the killer disease. It was recalled that cancer continues to carry myths among females in our region and that is the reason behind its stigmatization:

"A lot of people, a lot of women in our country, in our background, in our education level, they have a lot of myths and they believe in the myths". (Interviewee 4).

It is very difficult to inform a female that she has cancer, the word itself is a taboo among the Kuwaiti population because there will always be a link between cancer and death. One interviewee mentioned that some people believed it is a punishment from God for wrongdoing, others believe it is a curse.

"Because our knowledge here in the community, this cancer, cancer is equal to death" (Interviewee 4).

Moreover, culture still controls people's perspectives towards certain issues especially relating to exposing parts of female body even for educational purposes:

"But actually, our culture, our religion right now, it's not acceptable to see a woman without any clothes, even for education purpose" (Interviewee 4).

People have even avoided using the word cancer from how deadly and cursed they think this disease is, a popular opinion as stated by an interviewee: "They think cancer is 'the thing', not cancer" (Interviewee 12).

#### b. Impact on breast cancer

The perception of breast cancer among the Kuwaiti population including the stigmatization of breast cancer patients and the taboo over the disease has without doubt affected people's behaviour towards breast cancer. The interviewees spoke about the impact of the cultural beliefs around breast cancer on people's reaction to it and the barriers it creates. One believed that because of the cultural myth and taboo surrounding breast cancer disease, many women seek to be silent and prefer not to talk about it:

"it's difficult in our population that somebody will come out and say that I have cancer" (Interviewee 2).

Thus, it is not uncommon for patients to hide their diagnosis because they don't want to be stigmatized:

"But the problem is there are lots of people they don't want others to know."

"I have two sisters, none of them wants the other one to know. They're living in the same house, they go to the same doctor, but they don't want anyone to know about it." (Interviewee 2).

As a result of this stigmatization breast cancer patients can act very secretively especially in front of relatives:

"They are not telling their relatives that they have cancer. They are hiding it. I don't know why" (interviewee 10).

The interviewees explained the issue of sickness in society and noted that people do not like to discuss their health issues in general, even people with chronic diseases like diabetes, hypertension refuse to speak about their disease because they don't want to be stigmatized and suffer the consequences of the taboo behind talking about such an issue:

"Here in Kuwait, even the people who has diabetes or hypertension will not go in the media to tell their story." (Interviewee 5).

The stigma against breast cancer females in Kuwait had obscured the transfer of knowledge and education about it and stood as a barrier against their willingness to increase awareness.

"So, women will avoid, when you mention the word breast cancer, they will avoid to educate or to know about it" (Interviewee 9).

One interviewee recalled a question from a survey study done by CAN whereby women were asked about their response when noticing a lump in their breast, 60% said they would be scared, and the rest pretended to be ok and will not seek medical advice. This reaction thought to be due to denial because having a lump might mean they have cancer which is a taboo in this culture or fear from cancer.

Interviewees were asked to comment on the storytelling adverts, when one interviewee saw the advertisement, his comments were as follows:

"I think you will find difficulty, a female who was diagnosed here with breast cancer, to come out in ad like that, and talk about their stories, and, you know, share their, either scar or their appearance, or the psychological effect on it. There is a lot of culture negativity towards that, so I don't think it will be applicable here." (Interviewee 5).

It is almost prohibited to talk about breast cancer among females in Kuwait because the culture believes that it is a taboo and female patients would be stigmatized as a result. One interviewee shared his experience from the west and compared both cultures by recalling that this behaviour was present a long time ago in the western world but nowadays; people perspectives had changed:

"When I used to treat patients with breast cancer in Canada, a lot of them even didn't want to wear a wig. They wanted to wear a scarf, they wanted to show that they were on chemotherapy, they had the disease and they were going to fight the disease and beat the disease. It's not the same here, again. So that, I don't think it's also applicable here. Maybe if you can change a few things on it, but not the way it is, like that." (Interviewee 5).

Being a cancer patient has led to some extreme behaviour from some people because of the pressure set by society on people suffering from this disease, some common reactions were described by the interviewees: "Patients come hiding their face to avoid anyone knowing them. And some of them they change their names. When the staff nurse is calling her, different name. Because maybe someone sitting will recognize her." (Interviewee 10).

Not only did the stigma push people to hide their identity but it also created important barrier to coping with the patients, whereby it prevented patients from receiving the support that is much needed in times of treatment:

"You need the family to be there to support each other. It will help them accept the cancer, and also it helps the cancer patient to feel better about themselves, and that will also give more power to fight the cancer." (Interviewee 12).

#### ii. Modesty

Among the few themes where a common agreement was reported among all interviewees, was their opinion on advertisements that demonstrated illustrations and drawings of breasts, including a Scottish advert demonstrating self-examination of breasts through a video showing women self-examining breasts. All interviewees agreed that albeit informative, showing such advertisement publicly or on television is not acceptable in Kuwait, for cultural and religious reasons. Modesty and covering up has been highlighted as a theme discussed by all participants.

In Kuwait, and most of the Arab world it is unacceptable to show body parts on national TV. It is part of the cultural and religious codes to cover the body in public:

"it's very difficult to put these pictures. Our social background is a bit conservative and they might not allow these pictures to be put on certain TV shows or some media...it's a bit over for our conservative...." (Interviewee 2).

Some participants did not like the last Scottish advertisement shown by the researcher claiming that using a video of a naked woman to advertise breast cancer was not a good idea nor an effective way to deliver the message:

"I mean, this is not the way, [not] the right way to convince the lady"

(Interviewee 3).

Interviewees expressed that as a middle eastern country and part of the Arab world; modesty code constitutes an important pattern of the culture in Kuwait and showing parts of a female body, is never acceptable.

"It won't be allowed...It is not possible...our problem because we are in the middle east, we have regulation, the scene of the breast itself is a taboo in Kuwait and in the Islamic world. And to show a breast on TV, it shall I say, it will be a disaster" (Interviewee 4).

One interviewee for example believed that people in Kuwait do not accept to see body pictures especially for females. It is against the culture even for educational purposes, he shared his experience:

"I once posted on Instagram about breast cancer. It was a diagram ... I used. A lot of people put comments, negative, that why did you put a picture of a breast? ...you don't need to...you can explain without the picture, you don't need that picture. Although it wasn't a picture, it was a diagram of a breast" (interviewee 6).

Although few of the advertisements do not respect cultural norms for example when showing a sensitive part of the body, participants thought that those kinds of adverts can be used in special places where the attendees are only females like in maternity hospitals, obstetrics and gynaecology clinics or to students for educational purposes:

"We can do it but in very, let's say small scale where females are there; in school, for females at school, we can do it...But in public there are males and we don't accept to see a naked woman" (Interviewee 9).

Interviewees offered alternative places where such adverts (advert 4) could be used:

"Going to group of ladies like teachers, is ok, banks, companies and different departments is ok, also group of staff nurses or to any group, but to 14 years old girls, no, definitely no." (Interviewee 10).

"This is an excellent ad, it's a short, educational video, especially if we keep them in the polyclinic and the hospitals, private hospitals, the private clinic, tertiary centres, they will target the right cohort." (Interviewee 14).

7.5.2.7 Theme 7: Reluctance to use emotional content to raise awareness Interviewees were asked to express their opinion on two types of advertisements. One which focused on emotions and showed the bond between a breast cancer patient and younger daughter, and another that used the story telling method of advertisement (a person with breast cancer or previous breast cancer talking about her experience), which also holds some emotional feel. Nearly half of the interviewees expressed their reluctance to use emotional content to raise awareness. They believed that such content masks the message behind the advertisement, and made the viewer think more about their emotions rather than their health. Whereas most of the interviewees agreed that the story telling advertising strategy would not be successful in a culture like Kuwait's since chances are you will not find women willing to speak about their breast cancer journey.

The interviewees' comments were divided into two sub themes, one about emotional content and the other about story telling content.

#### i. Emotional content

Usually, emotional ads are used to stimulate the feeling of the viewer in a way to convey the proposed message, however, one interviewee thought it would barely draw the attention to the delivered message and rather focus on the emotion per say:

"So, this advertisement is very emotional and in our Arab world we are very emotional people, so people will get more attached to the emotions rather than the message, so they will feel sad for the family, they will not focus on the message" (Interviewee 1).

Several interviewees believed that emotional adverts do not fit the Kuwaiti culture because people might miss the message hidden within the emotional content:

"I will understand it but maybe lay people might not get it" (Interviewee 4).

"I don't think it will help much. We need direct messages for women to participate in screening" (Interviewee 7).

When asked about the first emotional advert (the mother and daughter) an interviewee commented without any further explanation:

"No, I don't think it is valid here in Kuwait really. This is for a special culture, not for us. Not for us." (Interviewee 10).

The first advertisement may not be applicable in Kuwait because the relationship dynamic between the members does not resemble that in Kuwait; particularly the family size, the relationship between the mother, and daughter and the mother and her husband are very different. One interviewee pointed out that the message behind the advert wasn't clear enough for the people to understand it.

"Not be very applicable, because the picture of that as typically of a family here, is not the same as the picture that we have. So, you know, a mother with one child and a husband in a small house, it doesn't really reflect our dynamics or family dynamics in Kuwait, I would say, or our region. And even the relationships between the mother and the children, and the husband is not the same." (Interviewee 5).

Some interviewees viewed the emotional content as a negative and rather depressing way to convey a message which would not help in raising awareness. It would rather create fear or associate sickness with death or negative connotations. Having emotional messages in adverts may not be very effective because looking at the stages of treatment discourages the viewer and as a result prevents them from screening:

"Our ladies in Kuwait, they will get depressed by seeing it. The lady looks too sick, so it is not giving a positive impression of what we are talking about. If this lady, for example, if by the end they showed her as a healthy woman who has been cured, it will give a better impact. This will be negative for our ladies here in the Middle East, it's a negative impact." (Interviewee 8).

"I think it's more a scary advertisement for the public, rather than giving hope" (Interviewee 9).

However, some interviewees liked the content and believed it could be effective in delivering the message. One interviewee for example supported the idea of emotional adverts because she thought it would be more effective and touching at the same time:

"it's very much touching. It's beautiful" (Interviewee 2).

"it was very nice for advertising. So, we have this. In Kuwait we did this a lot of this." (Interviewee 3).

Another one was not against the emotional type of adverts, however; she

suggested to have some modifications to it:

"it's nice, I like it but we have to just modify it to be applicable to our culture." (Interviewee 6).

"For example, if a lady 60 and above watches this video it will not affect her like the young people who will understand the technology, especially here in Kuwait." (Interviewee 11).

Finally, when one interviewee saw the emotional advert (the mother and daughter) she liked it but she also suggested to modify the advert in order to fit the Kuwaiti culture:

"Very promising because at the end of the ad, there was a message, and they are trying to find a solution that will increase the survival rate and the survival from the breast cancer, and this is the job of the scientist and medicine and the health sector." (Interviewee 14).

## ii. Story Telling content

Females In Kuwait are unable to expose themselves and come out on public TV and express their feelings when diagnosed with cancer because of stigma and taboo that surround cancer:

"You will be very lucky if you find any patient who is willing to do that. If you do, then yes that will be very strong" (Interviewee 4).

Some people would reject such type of advertisements because not everyone agrees to tell their family about their sickness:

"She would say I don't want my parents to know, because if I tell them or they're aware of it they will die." (Interviewee 12). "This idea of fear of telling others is really stopping lots of awareness to be around." (Interviewee 12).

When talking about the storytelling kind of advert, interviewees thought it would be very difficult to have a female coming out loud and reveal her journey when diagnosed with breast cancer because of the Kuwaiti culture.

Since the storytelling advert is also an emotional one participant believed it would not be very successful since it also reflects images with negative connotations such as illness, death, depression:

"I think it's a little bit pessimistic" (Interviewee 9).

Another interviewee shared a similar experience where participants spoke about their journey with breast cancer:

"They gave a very nice presentation. And it was really very emotional. It touched the heart really of all the people inside. It is good." (Interviewee 10).

Some interviewees supported the storytelling type of advertisements:

"I feel this is the strongest one. It talks to our emotions, our feeling, so it will motivate the women more to go and screen for breast cancer. I think these are the strong tools you can use for awareness." (Interviewee 11).

Although some interviewees did not support emotional types of adverts, they suggested some changes such as paying actresses to do it or focus on the positive stories only rather than going through the bad journey of discovering the cancer diagnosis:

"This is a good idea. But concentrating on surviving is better than explaining, showing the shock and the grief they had for the exposure." (Interviewee 7).

"Either because the people themselves they're not coming up and talking about it, or they're not ready to pay for after actresses to do that. You can pay for actresses to do that; you can have somebody do it nicely." (Interviewee 12).

## 7.5.2.8 Theme 8: Education - Start Early

The theme of educating females about breast cancer at an early age has been brought up by almost half of the interviewees. Being a member of NGO, one interviewee appreciated the role of the ministry of education in facilitating access to schools to teach the schoolgirls on how to examine their breasts. The idea behind this is not only to increase the girls' knowledge and awareness but to educate their family as well. Schools represent a potential venue for cancer education and increasing cancer awareness among females:

"Starting from school, they need to be educated, they need to be taught about what cancer is. I don't think it's in the curriculum in Kuwait or in biology in early age, regarding cancer. So how to tackle this? Maybe campaigning is not enough but you need to educate, you need to inform and you need to correct the misleading information, the myths that exist." (Interviewee 4).

The use of the available technology is key to spreading the message of awareness to the older generation through younger people at home:

"And when you reach the younger population, even if they do not fit into the target population for screening, they definitely live in a household where they have at least members who fit into the target population". For example, if you have somebody who lives in a certain district, an older lady, she is 60 years old and she doesn't really use social media. But she has daughters or sons, and they follow certain celebrities. And those celebrities, or people, are regularly talking about important issues in society. One of them is breast cancer" (Interviewee 15).

Several interviewees believed that investing in female education at an early age

would have its rewards for the whole family:

"It needs to start from the education in schools, the girl in high school has to learn an idea about that. Every girl is going back to her home, and talks to her mother. So, she can help her understand, we need to use schoolgirls as transmitters of the health message, okay? And so that will be good in spreading the message." (Interviewee 7).

"Don't forget also the schoolgirls can also give or transmit the message to their housemaids" (Interviewee 7).

Some interviewees supported the introduction of education about breast cancer early in schools and as part of the educational curriculum, this is one of the ways to improve the awareness among women in general:

"...including breast cancer screening and its importance and the issues of breast cancer in the undergraduate curriculum. When we put for the girls in the high school or even in the secondary schools and also in the university, then in the future they can convince their parents, aunts and other relatives" (Interviewee 13).

"It should be part of the education, the Ministry of Education, for example, for the high school, they can do such encouragement, they tell them how to know this, how to do the screening, what's the age before and after, how to do the self-examination even, at home." (Interviewee 14).

Contrary to this support, one interviewee didn't like the idea of teaching schoolgirls how to examine their breasts due to cultural reasons, however, this participant did support introducing the subject in the school curriculum.

## 7.6 Discussion

The thematic analysis of 14 interviews with specialists working in the field of breast cancer in Kuwait resulted in the emergence of eight themes under which the qualitative data are presented and discussed. The identified themes were fear, low levels of awareness, perspective of younger women, late diagnosis, approaches to raise awareness, cultural issues namely taboo, stigma and modesty, reluctance to use emotional content for advertisement, and the need for early education.

While the results of the quantitative Chapter 6 Breast cancer knowledge and awareness among female residents of Kuwait. A quantitative study demonstrated the low awareness levels among the target population in Kuwait and highlighted the need to increase the levels of awareness, the importance of this study was to explore the best approach to increase the levels of awareness. Particularly the aim of this chapter was to evaluate the level of knowledge and awareness about breast cancer non-lump symptoms, risks, and screening programs in the general population of females in Kuwait attending general practice clinics in the five districts of the country. Whilst other studies have been predominantly quantitative, they have explored the incidence, morbidity and mortality of breast cancer in Kuwait, its impact on the quality of life, and the knowledge, awareness, and practices concerning breast cancer. (Alwahaibi et al., 2017, Al-Awadi and Khan, 2019, Alawadi and Ohaeri, 2009) This is the first qualitative study to explore the health professional's point of view about raising breast cancer awareness in Kuwait. Two previously published articles were identified where qualitative research on breast cancer has been used in Kuwait. The first one used a case study design where key informants from government and nongovernment institutions in Bahrain, UAE, Kuwait and Saudi Arabia were interviewed to review breast cancer screening, early detection practices in Gulf region, and outlined enablers and identified priorities for scaling up early detection programs (Fadhil, et al., 2018). The second was a qualitative study to determine Kuwaiti Women's knowledge of breast cancer and barriers deterring attendance at mammography screening where two focus groups with a total of 23 women were used (Marzouq & Floyd, 2019).

Henceforth, the uniqueness of this research was that: firstly, it is qualitative research involving interviews with health professionals while most of the published literature entailed systematic reviews, quantitative research method or qualitative research with female focus groups. Secondly, this research serves as a guide to inform future awareness campaigns that could be designed and tailored to best suit the Kuwaiti population and based on actual input from key stakeholders. The previous literature concentrated on highlighting the status and the problems associated with breast cancer, whereas this research had gone a step further into exploring the best approach in solving the problem of low awareness of breast cancer and consequently the low uptake for early screening. No published research has gone far into the analysis of existing awareness campaigns nor explored the best approach to educate women about breast cancer in Kuwait. Moreover, the use of the video demonstration of breast cancer advertisements was a novel approach in delving into the interviewees' preferred content to inform any future campaigns.

According to the interviewees, a considerable amount of effort has already been spent in the past years on awareness campaigns, yet the levels of awareness according to our findings are still low. Therefore, this chapter discusses the findings from the qualitative interviews to close the gap between the current efforts directed towards breast cancer awareness and what the population really needs to become more aware.

## 7.6.1 Comparison with previous literature

#### i. Fear

Fear was a central issue that many other themes revolved around, including late screening, low levels of awareness, social stigma, and the impact of media and awareness campaigns. One interviewee (interviewee 3) mentioned that he ran a survey study with his team. That survey composed of 3 questions. One of the questions was about the response from participants when noticing or finding a lump in their breast. It was found that more than half of participants (60%) were too scared to seek medical advice. Upon repeating the same survey again after 5 years, this seemed to improve with time. However, as mentioned earlier in the chapter this survey study was not published.

Fear from breast cancer comes with the risk of late detection or screening, a study sought to investigate the beliefs, fear and awareness about breast cancer and mammography screening practices of females in Iran (Emami et al., 2021). Results showed that just 38.2% of females (mean age 51.51 and SD 8.34) reported having a mammogram within the last 24 months; self-efficacy, susceptibility, motivation and lower perceived barriers were associated with being screened. Neither fatalistic belief nor awareness towards breast cancer were significantly associated with the screening behaviour (Emami et al., 2021). Although this was quantitative research, its results contradicted what our interviewees believed whereby they highlighted fear as being a major barrier for seeking screening. Another cross-sectional study conducted in Turkey on "The effect of women's breast cancer fear and social support perceptions on the process of participating in screening" found no statistically significant association between breast cancer fear, social support and the women's screening behaviour.

However, other research has suggested that breast cancer fear and the effect of social support on screening attitude may be important (Kissal et al., 2018). For example, a qualitative study conducted on females in Ethiopia concluded that according to patient's narratives, "fear of surgical procedures and lack of trusts on medical care were the major reasons for late presentation of breast cancer" (Tesfaw, et al., 2020). Another qualitative research conducted in Jordan using 26 focus groups of females with no previous history or symptoms of breast cancer mentioned that fear acted as a barrier that stopped women from practicing breast health examinations (Taha, et al., 2012).

Although all these studies associated fear as a barrier to seeking screening for breast cancer; the difference between the before mentioned research and our current research is that this qualitative study explored the health professionals' views and not that of patients or general female population; and expanded further to consider new approaches to awareness raising.

#### ii. Low level of breast cancer awareness

While fear was seen to discourage women from seeking medical attention, low levels of awareness was also thought to be a major reason for late detection of breast cancer.

According to the World Cancer Research Fund, breast cancer makes up 25% of cancer cases in women, with around 89% of females in developed western countries have a high survival rate due to awareness and early detection (World Cancer Research Fund, 2021, Dec 21). Unlike developed countries, in developing and underdeveloped countries, breast cancer is diagnosed in late stages due to lack of awareness about screening in women. Cancer Research UK has estimated that most cancer that is diagnosed early has a high chance of being treated; highlighting the importance of improving early detection in all countries, including Kuwait (Cancer Research UK, 2021). According to the interviewees in this study, the low level of awareness about breast cancer leads to low uptake of screening. A study in Iran, which is considered to have a lot of common cultural features with Kuwait, showed that late presentation and diagnoses of breast cancer is the usual occurrence, and that there is an utmost need to improve awareness about it (Tazhibi and Feizi, 2014). In the same study it was found that the knowledge about risk factors, screening and BSE were lacking among participants. There was also a noticeable distinction between the level of awareness of those in the capital compared to those who lived in other districts (Tazhibi and Feizi, 2014).

The findings of this study are consistent with what the interviewees in the current study. In fact, the interviewees also spoke about the difference in awareness levels among females between the capital and other remote districts in Kuwait. People living away from the capital have lower awareness levels compared to people living in the capital area. They believed that areas outside the capital are at a lower advantage in getting the required awareness program they need than those in the capital city. Moreover, a study conducted in Kuwait where knowledge, awareness and practice of 421 female Kuwaiti teachers working in schools in Al Jahra district were explored, showed that there is a lack of practicing self-examination due to either not being knowledgeable about it, not knowing how to do it or lack of motivation to do the practice. The study also showed how low participants understanding was about the importance of

mammography as a screening method for early detection, where results showed only 14.3% knew about it (Alharbi et al., 2019). Similarly, the interviewees in the current emphasized how there is a lack in consistency across different sectors in recommending women to screen, whether it is media or health professionals.

According to a survey done in Qatar, which is similar to Kuwait in many ways, low awareness in Arab females can be specifically explained due to lack of information given by the doctors and low encouragement to do clinical screening such as mammography or breast self-examination (Donnelly et al., 2015). This in turn contributed to low levels of participation in screening campaigns. In general, there is lack of national screening programs in the GCC countries that follows up and monitors patients, and instead relies on women to solely selfpresent (Donnelly and Hwang, 2015). The interviewees in this research thought that the messages being communicated to the population were not sufficient. While some interviewees thought the current campaigns were not enough; others believed that the tools used were insufficient.

#### iii. Younger females

In this qualitative study, the interviewees described the prevalence of breast cancer in younger females in Kuwait. In fact, a group of Arab physicians had the impression that breast cancer is more prevalent in younger females than older ones, but to be more precise about this, a literature review has been conducted in order to be able to prove this notion. Reports and articles were taken from several countries: Saudi Arabia, Bahrain, Qatar, Kuwait, Emirate, Oman, Yemen, Iraq, Syria, Jordan, Lebanon, Egypt, Libya, Algeria, Tunis, Morocco, and Sudan. It was shown that the average age in which Arab females were diagnosed with breast cancer was 10 years younger than females in western countries. This supports both the impression the physicians made about how breast cancer tends to present in younger women in Arab Countries (Najjar and Easson, 2010) and the claims of our interviewees.

To further investigate this finding, a study was done in the Sharjah Breast Cancer Centre at University Hospital Sharjah in the UAE, which is considered to have common aspects with Kuwait. The study was done on 1,048 females who have been patients at the University Hospital Sharjah before. A prominent finding of this study was that breast cancer was found in one of every 11 females, and one in every five was under the age of 40. The average age of breast cancer diagnosis, while similar with neighbouring GCC Countries, was 49 years, which is lower than that of developed countries such as Europe and the United States where is it 60 years (Bendardaf et al., 2020).

It is common for females in society in Kuwait and most Arab countries to be ashamed of getting breast cancer and a lot of females tend to hide the diagnosis from family members, which in turn is considered a barrier when trying to identify high risk females. This is shown in recommendations by Cleveland Clinic who states that females who are diagnosed with breast cancer tend to have a genetic mutation that classify them as high-risk patients, thus making them predisposed to getting breast cancer, and that it is recommended for females who have family history to get genetic counselling to identify the risk of being diagnosed. Also, although mammograms are recommended at age 40 and above, in women who are at high risk, it is recommended to start at age 25, and along with it, it is advised to also do breast MRI. Moreover, younger females getting diagnosed with breast cancer also face more challenges regarding fertility, sexuality and pregnancy after treatment, which is considered a worrisome matter for females and should be addressed in awareness campaigns.

#### iv. Late diagnosis

One of the major problems discussed in the interviews was the late presentation of breast cancer at stages III or VI instead of the early stages, leading to complications and serious consequences associated with late diagnosis, including death. The earlier breast cancer is discovered, the higher the chance of survival. When recovery occurs, it would be easier for females to regularly do screenings. This can be achieved by increasing awareness to convince and motivate females to do it, not only in breast cancer awareness month but throughout the year. One of the reasons why females tend to avoid early screening is because they lack awareness and knowledge about this disease and the impact of late presentation (Gulshan Karbani, 2011).

Another study done in the University of Hail in Saudi Arabia, aimed to test the knowledge of the residents of Hail about breast cancer. There was severe low

knowledge and low level of awareness among the people. They had no understanding of how breast cancer manifests, and most importantly, lacked the information that increased age is one of the major risk factors. Some females perceived that presenting late is associated with "fate" and "destiny", which indicates that there is somewhat a religious aspect in these communities that hinders women to seek medical advice early on. Moreover, fear is most definitely related to females being unwilling to seek medical help since they are scared of what they might discover (Hussein et al., 2013).

Descriptive research conducted in 327 female nurses involved in education and research at a hospital in Turkey concluded that participants knowledge levels of breast cancer were not related to fear levels, yet breast cancer fear level was high and knowledge level was moderate (Cal et al., 2018). This was consistent with our current research finding. However, as mentioned earlier in this chapter, it is commonly believed that low level of awareness is associated with a lower level of education, but from the experience of interviewees, it was noted that low levels of awareness can also be found among females with a high level of education, since knowledge of the consequences and treatment effects created more fear.

A study 19 females done in the UAE aimed to find the factors that lead to late presentation for breast cancer screening and treatment (Elobaid et al., 2016)A lot of the females in the study, although reported having a lump, they supposed that it was not serious since it was painless. The study also showed that there was fear from society among the females, which held them back from seeking medical advice. These findings agree with what our interviewees had reported whereby they considered lack of knowledge as a main barrier for seeking medical attention even among females who presented symptoms. The same study that was conducted in UAE showed that females who had regularly screened before their diagnosis aided in them taking their condition seriously, thus they sought medical advice before other women in the study (Elobaid et al., 2016).

It has been shown that some participants focus on getting screening from a female doctor, which can also delay the diagnosis. Others focus on the negative

aspects of the word cancer, where females avoid mentioning it to their families. According to an article about the Psychosocial Aspect of Female Breast Cancer in the Middle East and North Africa (Salem and Daher-Nashif, 2020) females might be more comfortable talking to strangers than their families about their diagnosis. A lot of females feared mentioning it to their husbands for fear of getting a divorce, while others avoided mentioning it to their friends due to the stigma of the disease or in order to not be a liability. This even affected the women's desire to get adequate screening or treatment (Salem and Daher-Nashif, 2020). A study based in Saudi Arabia reported that the female population had low awareness about how self-examination and seeking medical help can contribute vastly to the successful treatment of breast cancer along with selfexamination (Ramya Ahmad et al., 2019). A lot of obstacles in their way included "wrong health practices, social barriers, fear, social stigma associated with the disease, lack of knowledge, and level of education" (Ramya Ahmad et al., 2019).

#### V. Current approaches to raising awareness

There are many ways to raise awareness; some have been seen to be more effective than others in the Kuwaiti context. For example, in this study, media and advertisements seeking to raise awareness about breast cancer showed to play the opposite role they were created for as mentioned by the interviewees. Some advertisements were claimed to be insufficient and not encouraging for women. In fact, the finding from our interviews is supported by research conducted on Spanish women in 2009, which showed that females who had occasionally been exposed to breast cancer content in television news were 1.9 times (95% CI 1.1-3.4) more likely to be very afraid of breast cancer compared to those who had no exposure (Lemal and Van den Bulck, 2009). Thus, care must be taken when developing awareness raising media content to encourage females to seek medical attention rather than provoke additional fear. According to our interviewees many reported that the current effort done in raising awareness is insufficient, some claimed that it is concentrated in October, and others criticized the approach or content.

Many interviewees claimed that there is a need for awareness campaigns all year round and not only concentrated around the month of October. In addition, several interviewees highlighted the need to develop different approaches for raising awareness that should target different audiences in different ways. Three interviewees noted that the best way to increase breast cancer awareness is the introduction of a health education program early in school life. Some interviewees believed that this would target the fear factor. It will educate them, and this will facilitate passing the message to their family which will in return change their perception towards breast cancer. It was notable that targeting younger generations and schoolgirls could show a positive impact on women's awareness. In fact, the levels of breast cancer awareness in Saudi females in Taif City, was evaluated and showed adequate knowledge regarding the risk factors of breast cancer amongst the participants (Mohammed, et al., 2014). This was attributed to the increased campaigns in recent years done by the Ministry of Health in the city, where there was a focus on raising awareness in younger generations in order to highlight the importance of BSE and clinical breast examination from a younger age (Mohammed, et al., 2014). Participants in the study mentioned that electronic media was a major source of knowledge about breast cancer for them, but around half of them had poor knowledge regarding mammogram and its importance as a tool used to screen for breast cancer. The authors concluded that social media should be utilized more in order to spread more awareness to females in order to increase screening rates and decrease prevalence (Mohammed et al., 2014).

Also, a UAE based study found that despite many awareness campaigns done by the Ministry of Health and Prevention, governmental and NGOs, there was still a low number of females partaking in screening programs regarding breast cancer, but it noted that the higher the knowledge about the benefits of screening, the more likely females will take part in it (Rabbani et al., 2019). The study aimed to examine the effect of community based educational intervention on females and whether it increased their participation in screening. Post intervention showed a noteworthy progress in breast cancer knowledge, it also eliminated the negative aspects females had regarding breast cancer, suggesting that community-based educational programs can play a major role in increasing awareness in females towards breast cancer (Rabbani et al., 2019). Participants in the current research were also concerned about the content being presented at the campaigns. When designing any approach for breast awareness it is important to carefully study the content that needs to be displayed or information to be highlighted. Treatment has been described by participants in breast cancer research to losing valuables (by valuables they mean hair, breast or beauty). This created fear in them (Obeidat and Lally, 2014, Fearon et al., 2020). For example, females described losing their hair, a breast, a normal life, fertility, independence, autonomy, physical attractiveness and arm function (Obeidat and Lally, 2014, Fearon et al., 2020). These losses, especially hair loss and mastectomy, were perceived by respondents as negatively influencing their quality of life, physical wellbeing, body image and relationship with their husbands, if married (Fearon et al., 2020). For some females, losing a breast was as equally shocking as learning of their diagnosis (Jassim and Whitford, 2014) and findings of loss and the consequences of treatment were consistent between the literature and our current research. Therefore, this "loss" factor should be taken into account when designing a breast cancer campaign or advert. Whilst it is important to have strong content that is both attractive and informative, care must be taken in order to avoid creating fear among the target population since this might hinder their engagement.

Contrary to this research, a study in Jordan aimed to explore if there is a relationship between media marketing advertising and participation in early screening campaigns (Alhawamdeh et al., 2020). The study intended to compare the results with previous studies on the same topic. It stated that by marketing advertisements, we can spread awareness to other females. A big factor can be women who are survivors; they can persuade other females to do regular screening and encourage them to seek medical attention early. Depending on the society and approach, marketing awareness campaigns have been shown to have a positive effect on females to screen early, as it was shown that traditional and modern methods of marketing advertisements spread early awareness. New media technology, along with television, newspaper and radio can be very helpful in affecting females and increase their knowledge regarding this disease, its risk factors and importance of early detection. It also mentions

how important is to collaborate with celebrities that can influence females and raise awareness about the issue (Alhawamdeh et al., 2020)

One interviewee also expressed the poor interest of the general public in this topic, he spoke about what he thought is the classical way of activities done in order to raise the awareness where using new innovative ways could be useful. Finally, one interviewee said that he's using Instagram as a way of advertising and educating people to raise their awareness, emphasizing the role of social media in raising awareness. Other interviewees thought that all sorts of media could be part of spreading awareness whether, TV, radio, Instagram or other social media networks.

## vi. Cultural issues:

#### a. Social stigma/ taboo

Another cause for fear was the association of breast cancer with social stigma and taboo. Most of the participants in this study brought up the subject of taboo and stigma and spoke about the cultural barriers that surround breast cancer. The topics were broadly divided into two subthemes, one related to the perception of breast cancer and how people view it, and the second related to the impact of this perception on people's behaviour towards breast cancer. Previous research has shown that females often perceived themselves as minor to any treatment decisions, and occasionally underwent treatment against their expressed wishes (Obeidat, 2012).

In the middle east and gulf area, breast cancer is still seen as a taboo. Not only because breast cancer involves a perceived sexual part of a female but also the word cancer in itself is considered a taboo to be spoken about, that most of the time it is referenced as "that illness" as mentioned by one interviewee. Many diagnoses of breast cancer have been delayed because of this cultural factor (Elobaid et al., 2016). Studies present proof that there are misconceptions, stigma and taboo, which greatly affects the way members of the community view regular screening practices (Gulshan Karbani, 2011).

The cultural issues affecting Kuwaiti people's perception of breast cancer stands as a hurdle for early diagnosis, seeking medical care, and disseminating proper awareness. Arab females have been reported to describe breast cancer as a battle not just against sickness itself, but also against the stigmatisation they experienced which influence their perception about the sickness (Fearon et al., 2020). The finding of this study showed that people often try to hide their diagnosis because of the fear of losing their family where breast cancer is seen to affect marital life and leads to social isolation. A qualitative study on the psychosocial impacts of breast cancer on 19 Omani females reported that many women were reluctant to inform their friends about the diagnosis and they preferred to only share the news with close family members (Al-Azri et al., 2014). Another major concern observed in this study was "cancer stigma," which led to feelings of unattractiveness, self-consciousness, and solitude (Al-Azri et al., 2014). Some of the participants believed that society viewed them with pity, which in turn caused limited interaction and isolation from friends and family and the community as a whole.

Negative attitudes, stereotypes, and discrimination toward cancer patients are common in some societies where they were referred to as "victims" unable to make any contributions to the community and some people even avoid working with them (Al-Azri et al., 2014).

The perception and beliefs about a females' body as being private and should be conserved and that breast cancer leads to death have a great impact on the views of Arab men and females about breast cancer and the percentage of Arab women who undergo breast screening (Al-Azri et al., 2014). Adding to that is the fear of the negative reactions of society in case of being diagnosed with the disease. In Arab societies the role of females was primarily viewed as being a daughter, a wife or a mother. However, a diagnosis of breast cancer threatens these identities and roles (ALmegewly et al., 2019). The principal priority for many Arab females was considered to protect and promote their family's wellbeing. Females initially concealed their diagnosis so as to protect others from distress and sadness, especially their children (Jassim and Whitford, 2014b). This is an important factor to target in any future breast cancer campaigns, efforts must be directed towards normalising breast cancer and removing its association with stigma or shame.

#### b. Modesty

A number of health beliefs and sociodemographic characteristics are associated with mammogram participation among females including culture, religion, socioeconomic status, and education namely. Our qualitative data revealed that in Kuwait modesty was a central cultural code and it is not acceptable to show off nudity, real photos, or even diagrams of females' breasts. In fact, this finding is not unique to our survey as many studies have reported the impact of modesty due to culture or religion on both breast and cervical cancer (Padela et al., 2012, Dareng et al., 2015). A qualitative study on a sample of Iranian females aged 30 years and over to explore breast cancer-preventive behaviours in Iranian females concluded that among the barriers toward preventive behaviours are religious and cultural influences concerning femininity and modesty (Maryam Khazaee-Pool and Shojaeizadeh, 2014). Thus, considering women breasts as part of their sexuality and treating them as private parts that cannot be displayed in ads or breast cancer campaigns is an important consideration to be taken into account when developing any awareness campaign.

## vii. Reluctance to use emotional content

Stirring emotions to trigger knowledge and memory has long been a strategy used for branding, advertisement and media campaigns. While this is a proven strategy to transfer impactful information to the viewer in the healthcare sector (Abu Abed et al., 2014, McQueen et al., 2011) the interviewees did not agree that emotional stories would lead to improved breast cancer awareness in Kuwait. A randomized experiment done using moment-to-moment audience analysis methods, where researchers compared females' emotional responses with a narrative versus informational breast cancer video (Bollinger and Kreuter, 2012). A hand-held audience response device was used to report the intensity of their emotional reaction while watching one of the two videos. Both videos communicated three key messages about breast cancer: (i) understand your breast cancer risk, (ii) talk openly about breast cancer and (iii) get regular mammograms. Results showed that strong emotions were more likely to correspond to contextual information about characters in the video and less likely to correspond to health content among females who watched the narrative video compared with those who watched the informational video (p < 0.05) and

were more likely to report feeling attentive, inspired, and proud. Also, those females were less likely to feel upset (all p< 0.05) (Bollinger and Kreuter, 2012); however, this did not detract from obtaining health information. Findings suggest that stories can be used to communicate health information without distracting from core health content (Bollinger and Kreuter, 2012).

Another study which compared the effects of narrative and informational videos on use of mammography, cancer-related beliefs, recall of core content and a range of reactions to the videos showed that narrative forms of communication may increase the effectiveness of interventions to reduce cancer health disparities (Kreuter et al., 2010, McQueen et al., 2011). When shown international adverts containing emotional content, the interviewees in the current study commented on four main issues: nudity (or the need to have more modest content), displaying a local content (a family that would resemble a Kuwaiti family), adding more hopeful and less depressing content, and finally recruiting patients to share their story. Therefore, with the ample evidence on the effectiveness of emotional and narrative content for health-related videos, any future breast cancer campaign/ ad should be tailored to suit the Kuwaiti context taking into consideration modesty, local context, raising hope, and recruiting willing survivors to share their stories.

#### viii. Education- Start early

In our current research nearly half of the interviewed participants spoke about the importance of early education of females about breast cancer and its introduction in the school/university curriculum. Participants have highlighted the impact of younger females on their elder mother/ grandmothers/ or even house maids in raising awareness about screening. This reflects that young females are all a target population when it comes to any awareness campaign to be done.

A study conducted in the city of Riyadh, Saudi Arabia on females aged 18 and older showed that the sources of information for those who knew about breast cancer and self-examination were 22% only from school/ university (Al Otaibi et al., 2017). Breast cancer campaigns received a 39% as a source of information (Al Otaibi et al., 2017). Another study done in the UK titled Breast education for schoolgirls; why, what, when, and how? (Nicola Brown, 2018) conducted on 2089 schoolgirls (11-18 years) concluded that the preferred delivery format was age eleven (50%), girls only taught sessions (41%) with female teachers (43%) and thus a need for breast education and delivery preferences was identified. In fact, several other researchers have reported the benefits of early education of female about breast cancer (Omrani et al., 2020).

# 7.7 Strengths and Limitations

## 7.7.1 Strengths

The study by itself is unique. It is the first qualitative study conducted in Kuwait that discussed the best approaches to improve breast cancer and screening awareness among the Kuwaiti population from a professional perspective. It was a success to have 14 interviewees participate in this study because data collection happened during the peak time of COVID-19 pandemic which was a very busy period, and it was hard to find such participants. Having participants from different backgrounds but interested in breast cancer and breast cancer screening gave a diverse and knowledgeable view to the subject and helped in collecting the data from a variety of angles.

## 7.7.2 Limitations

English is the second language for the researcher and the interviewees and sometimes it was difficult for the participants to express what truly they wanted to say or to give the full picture. The amount of data that need to be collected; their perspectives, opinions or experiences required a longer time than what participants could accommodate. It was intended to have focus group discussions instead of individual interviews however, due to COVID-19 pandemic it was difficult to have groups of people physically together on one table at that time. The researcher planned to have a larger number of interviewees but again due to the effect of the pandemic it was difficult to find participants willing to give some of their time for that interview. However, even with these limitations, the data collected is rich and informative.

While including breast cancer survivors would undoubtedly provide an additional important dimension to the study there were practical reasons for not doing so. First the restrictions imposed by Covid would have impeded sampling and

recruitment significantly. Moreover, the obvious stigma and taboo surrounding breast cancer in the community suggested that recruiting a sufficient sample of women willing to share their experience would have been challenging.

# 7.7.3 Implications

Having known that awareness and screening uptake is low, several barriers were identified as being responsible for the gaps in knowledge. Attention should be directed towards educating the Kuwaiti population about cancer and its screening methods. A collaboration between all sectors is important to reach our target, including healthcare professionals, policymakers, and researchers. Since Kuwait is a Muslim and Arab country it has a specific cultural structure and with some groups of people you need the support from the religious and elderly people as well to have the required message delivered to them.

# 7.8 Summary

In this chapter, the interviews discussed the reasons behind the low awareness of breast cancer and screening program and the possible ways to improve it. More details and a deeper discussion will be provided in the following chapter, bringing together the findings from this study with those of the systematic review (Chapter 5 Understanding awareness, beliefs and attitudes towards breast cancer and breast cancer screening behaviour in the Gulf region) and cross-sectional survey (Chapter 6 Breast cancer knowledge and awareness among female residents of Kuwait. A quantitative study).

# Chapter Eight: Synthesis of findings, discussion, and future recommendations

# 8.1 Introduction

A multi-method approach was used in this thesis to explore breast cancer awareness among women in the GCC countries in general and among the Kuwaiti female population, in particular. Results were obtained from three distinct research methods: systematic review, quantitative, and qualitative studies and in this chapter the findings from all three will be compared and integrated. A comparison of the results with the literature will be discussed, and the strengths and limitations of this thesis will be presented. Finally, future research recommendations and policy implications will be outlined.

# 8.2 Synthesis of the findings

The aim in this thesis was to provide a comprehensive insight into breast cancer awareness and its screening methods among females in Kuwait. As such, a multimethod programme including a series of studies was carried out to enable a holistic picture not only of awareness but also to offer potential solutions for policy and practice.

This aim was addressed through three specific objectives:

- 1. To provide an understanding about the awareness of, and beliefs and attitudes towards breast cancer and breast cancer screening behaviour in the GCC countries (Systematic review Chapter 5). More specifically
- i. To capture the level of breast cancer awareness among the general female population in GCC countries.
- ii. To describe the beliefs/ attitudes towards breast cancer among women in GCC countries.
- iii. To describe attitudes, beliefs and awareness of breast cancer screening among women in GCC countries.
- 2. To assess breast cancer knowledge and awareness among female residents of Kuwait (Epidemiological study, Chapter 6).
- To describe BCAM domains (sociodemographic factors, breast cancer symptoms and signs, confidence skills and behaviour in relation to detecting breast change, knowledge of the national screening program

in Kuwait, anticipated delay in contacting the doctor, barriers to seeking medical help, knowledge of age-related lifetime risk and knowledge of risk factors), in the study population.

- ii. To summarize the relationship between awareness of non-lump symptoms with the BCAM domains (sociodemographic factors, confidence skills and behaviour in relation to detecting breast cancer change, knowledge of the national screening program in Kuwait, anticipated delay in contacting the doctor, barriers to seeking medical help, knowledge of age-related lifetime risk and knowledge of risk factors).
- iii. To investigate sociodemographic factors associated with awareness of non-lump symptoms and breast cancer knowledge (knowledge of the national screening program in Kuwait/ confidence, skills and behaviour in relation to detecting breast cancer change).
- iv. To investigate the relationship between awareness of non-lump symptoms and breast cancer knowledge (knowledge of the national screening program in Kuwait/ confidence, skills and behaviour in relation to detecting breast cancer change).
- 3. To identify the best approaches to improve breast cancer awareness in Kuwait (Qualitative study, Chapter 7)

The results are mapped according to common themes within the individual study findings and compared across the three studies. Findings are divided into three main themes: breast cancer, breast cancer screening, and improving breast cancer awareness. Both breast cancer and breast cancer screening activities were explored considering awareness, beliefs, and attitudes. Table 8.1. provides a summary of the synthesis.

Table: 8.1 Sun	nmary of the fi	ndings from th	e three studies

	Systematic Review	Quantitative study	Qualitative study
	Studies indicated that the level of	There is a lack of knowledge	Key informants perceived a lack
	knowledge and awareness in the GCC	about breast cancer and the	of knowledge about breast cancer
	regarding symptoms, BSE and screening were inadequate.	<ul><li>screening program in Kuwait.</li><li>The awareness about signs and</li></ul>	and the screening program amongst females in Kuwait.
Breast Cancer- Awareness	<ul> <li>The main symptoms mentioned bloody discharge, breast mass, abnormal arm swelling, nipple retraction, and discoloration.</li> <li>Some studies indicated good knowledge of breast cancer symptoms.</li> </ul>	symptoms of breast cancer was generally low particularly for non-lump symptoms.	• Low uptake of breast cancer screening in Kuwait and the late presentation of breast cancer patients with low levels of awareness, which is thought to be lower in Kuwait than other countries.
			• Younger females have an impact on their elder mother/ grandmothers/ or even house maids in raising awareness about screening. Young woman should be targeted in awareness campaigns.

Breast	• Low to moderate level of knowledge	• Middle income family, area of	People living away from the
Cancer-	was found regardless of the female's	residence and confidence in	capital have lower awareness
Factors	educational status, marital status, and	checking the breast was	levels compared to people living ir
associated with	their family history of breast cancer,	significantly associated with	the capital area.
awareness	although education was the biggest	awareness of non-lump	
awareness	determinant of awareness.	symptoms.	Awareness is now increasing
			especially among younger females
	Age was not a statistically significant	• Kuwaitis' nationals were less	thus linking awareness to age and
	factor when relating to knowledge	aware of breast cancer non-lump	educational level.
	about breast cancer.	symptoms than other	
		nationalities.	<ul> <li>Socio-cultural factors play a role</li> </ul>
	<ul> <li>Women aged (30-40-50) that were</li> </ul>		in spreading the awareness,
	educated, married, and had an		heredity could also play a role.
		<ul> <li>Participants who had above</li> </ul>	neredity could also play a fole.
	occupation, had better knowledge	secondary level of education	
	about breast cancer awareness.	but lower than university level	<ul> <li>Expat females constitute a high</li> </ul>
		were more likely to be aware	number of the residents in the
		than those with university and	Kuwaiti society, they too play a
		above level of education or	role in the awareness about breas
		secondary education.	cancer.
		<ul> <li>Middle class (income between</li> </ul>	
		500-1500 k.d) participants were	
		more likely to be aware than	
		other socioeconomic classes	
		compared.	

Beliefs	Risk factors included: not breast	Identified risk factors were:	Some believed that awareness
and Attitudes- Causes of breast cancer	<ul> <li>feeding, family history of breast cancer, hormone replacement therapy, radiation, unhealthy diet and overweight, tight bras, trauma, smoking, pollution, perfumes, creams, mental stress and envy and evil eye.</li> <li>People believed that cancer is from God, that chemotherapy would kill them and that it would be a punishment.</li> </ul>	<ul> <li>stress and psychological tension (64.3%), having a personal history of breast cancer (57.8%), having family members with history of breast cancer (55.3%) and consuming a lot of fatty food (51.7%).</li> <li>The rest of risk factors were only known to less than 50% of participants.</li> </ul>	was not up to the required levels and attributed to social beliefs on causes of breast cancer such as punishment from God, or evil eye.
	<ul> <li>Old age at pregnancy was found to be the least known risk factor to participants.</li> </ul>	• The discrepancy found in the responses received from participants suggests that the knowledge of risk factors was still weak and there was no common widely known risk factors identified by women.	
Beliefs and Attitudes- Prevention	<ul> <li>Nearly two third they didn't believe to be affected by cancer one day and one third were not sure about that.</li> </ul>	This theme was not tackled in the BCAM.	<ul> <li>Half of the interviewed participants spoke about the importance of early education of females about breast cancer and</li> </ul>

of breast	Only one third perceived cancer as a		its introduction in the
cancer	serious disease and nearly half not sure		school/university curriculum.
	about its seriousness.		
	Few participants thought if their		
	destiny to have breast cancer, they		
	would have it.		
	Few thought their chances of getting		
	breast cancer would be very low.		
	• Few others belief they were too old to		
	get breast cancer.		
	• Less than one third believed that death		
	from breast cancer is inevitable even if		
	discovered early. They didn't want to		
	know about it even if were diagnosed		
	with it.		
Beliefs	<ul> <li>Participants believed treatment was</li> </ul>	<ul> <li>Unaware participants were</li> </ul>	This theme was not tackled in the
and	successful, but poor outcome was	more likely to use herbal	qualitative interviews.
Attitudes-	because of late-stage diagnosis of	treatment/ do nothing or don't	
Treatment	breast cancer.	know what to do when noticing	
of breast		changes in their breast.	
cancer	<ul> <li>Several other traditional treatments</li> </ul>		
	were reported: herbal medicine,		
	cauterization, and religious practices		
	including drinking Zamzam water, then		

<ul> <li>Participants had a very pessimistic view about it causing pain, disfiguration, endless treatments, disasters, and death.</li> <li>The majority knew that if detected early, it can be treated.</li> <li>Screening-Awareness</li> <li>Women have become more optimistic about breast cancer as it could be prevented with the practice of</li> <li>Most participants knew about the screening program.</li> <li>Very few practiced BSE and less</li> </ul>		<ul> <li>view about it causing pain, disfiguration, endless treatments, disasters, and death.</li> <li>The majority knew that if detected early, it can be treated.</li> <li>Women have become more optimistic about breast cancer as it could be prevented with the practice of screening methods.</li> <li>Knowledge about all the available breast cancer screening methods was very low.</li> <li>Most participants believed that screening methods (BSE and mammography) can prevent cancer and</li> </ul>	Most participants knew about the screening program. Very few practiced BSE and less than one third of the eligible females took part in the screening program. The frequency of checking the breast is unaffected by the awareness knowledge. Participants who were checking	Participants linked the low uptak of screening and the late presentation to the low awarenes about the screening methods.
--	--	---	---	--

Screening- Barriers• Fear and shyness being the topmost frequently reported barriers to screening. • Participants believed that mammography is painful and exposes• The foremost obstacle preventing participants in this study from seeking medical help was fear.• Females were still uptake screening were too afraid to find were sick.	
<ul> <li>Participants to radiation.</li> <li>Participants found screening for breast cancer to be shameful, a significant barrier for engaging in screening.</li> <li>Most participants would perform mammography if their doctor talked them into it but only half would engage if they received an invitation to screening.</li> <li>Half of participants perceived the importance of breast self-examination, but the majority believed in doing tests from time to time, nevertheless.</li> <li>Fear was reported in many forms including: general fear from breast cancer screening, fear from what they might discover, fear from cancer, fear from gossip, husband and social stigma, and fear from death.</li> <li>Fear vasi associated wi knowledge or lack of it, social stigma, body image media and advertisement women would fear cancer women would fear cancer is not a matter that affee the patient but also othe in her family.</li> <li>Social factors hinder pu screening and diagnosis.</li> <li>Lack of communication the health healthcare was</li> </ul>	ith with ge, and nts. n why er. n of diagnosis ects only er women oroper ss are a

The lack of knowledge second most	their inability to convince patient
frequently mentioned barrier to	was a barrier against diagnosis.
screening.	
<ul> <li>Participants mentioned shyness as</li> </ul>	Fear of losing their family where
being a concern especially by not	breast cancer is seen to affect
wanting to be examined by a male	marital life and leads to social
physician.	isolation.
<ul> <li>Lack of infrastructure was mentioned</li> </ul>	<ul> <li>Modesty was a central cultural</li> </ul>
as a barrier it includes absence of	code, and it was not acceptable
health facilities to do screening,	to show off nudity, real photos, or
difficulty access appointment, and	even diagrams of women breasts
inconvenience of timing and	
logistics/transport.	
• Other barriers: doubting the benefit	
of CBE, having a non- supporting	
husband, family/social gossip, distrust	
with the healthcare staff and preferred	
to have it done somewhere abroad,	
seeking traditional or herbal type of	
medication instead of performing	
screening, lack of knowledge in	
disabled people due to sign language,	
lazy about it, preferred a female	
doctor, the stigma about breast cancer	
within the society, religious beliefs	
forgetting, lack of support from others,	
and health insurance and its cost.	

	<ul> <li>Women preferred being examined by doctors because they either did not know how to or lacked the confidence to perform BSE.</li> <li>More barriers: family refusal of being examined, pain from the examination, being busy with their children.</li> </ul>		
Improving breast cancer awareness	<ul> <li>Internet, media, and television were the main sources for their awareness, followed by health care providers.</li> <li>women aged below forty said they preferred awareness campaigns and interactive sessions in health-care facilities.</li> <li>Older women in the groups aged fifty and above preferred a variety of methods to acquire knowledge and awareness such as programs disseminated by the media and TV shows.</li> </ul>	This theme was not tackled in the BCAM.	<ul> <li>Media presented cancer as a killer disease which affected females' perception of the sickness and created fear.</li> <li>Current campaigns are not enough; others believed that the tools used are insufficient.</li> <li>Awareness activities, be it NGOs, the government, or the private sector.</li> <li>Efforts are concentrated around October the month of breast cancer awareness.</li> <li>The best way to increase breast cancer awareness is the</li> </ul>

introduction of a health education
program early in school life.
Instagram as a way of
advertising and educating people
to raise their awareness,
emphasizing the role of social
media in raising awareness.
Care must be taken when
developing awareness raising
media content in order to
encourage females to seek
medical attention rather than
provoke additional fear.
Females' breasts should be
treated as private parts that
cannot be displayed in ads or
breast cancer campaigns is
important consideration.
The interviewees did not agree
that emotional stories would lead
improved breast cancer awareness
in Kuwait

# 8.3 Synthesis of the findings

## 8.3.1 Awareness on breast cancer

All three studies confirmed that the level of awareness about breast cancer in Kuwait was low, which reflects the overall picture in GCC countries. The quantitative BCAM study revealed 35% overall awareness of non-lump symptoms, though interviewees perceived improvements in awareness among Kuwaiti females across the last decade, low screening uptake and the later symptomatic presentation suggest continued sub-optimal awareness.

Awareness of the signs and symptoms of breast cancer was low; although collectively half of the studies included in the systematic review concluded that knowledge of symptoms was good. Similarly, the results from the BCAM in Kuwait found that only 55% of participants considered a lump to be a sign of breast cancer, and lower still for non-lump symptoms. The overall awareness of breast cancer non-lump symptoms amongst participants in this research was low (35%); a similar result (38%) was found among female participants at Sharjah university where participants were students, aged 18 years and older (Rahman et al., 2019a). Another study conducted in Mumbai, India found that around half (49%) of the females were aware of breast cancer (Prusty, et al., 2020). The females who were aware of breast cancer considered lump in breast (75%), change in shape and size of breast (57%), lump under armpit (56%), pain in one breast (56%) as the important and common symptoms (Prusty, et al., 2020). The most common symptoms recognised by the participants in this thesis however were the breast cancer lump symptoms (56%), a finding that is common among women in general. More recently a study conducted in Palestine, which has a similar culture to Kuwait, found that women had a good awareness of breast cancer symptoms (41.7% of the participants) (Elshami, et al., 2022). Similarly, a study conducted in Africa concluded that women had adequate knowledge, favourable attitudes, and performed BSE (Asmare, et al., 2022). The findings suggest that although awareness of breast cancer has become more widespread, especially in recent years, specific knowledge about the symptoms of breast cancer could be improved and moreover indicate a potential focus for future awareness campaigns.

## 8.3.2 Factors associated with awareness

The systematic review of the literature showed that the awareness of breast cancer was significantly correlated with age, marital status, and level of education in the GCC countries. The level of education, employment status, socioeconomic class, age, marital status, and family history of breast cancer have been identified as factors associated with awareness (Kissal, et al., 2018). The systematic review also found that while age alone was not a statistically significant factor in relation to knowledge about breast cancer, it was important when considered alongside education level and marital status. The findings further indicated that there is low to moderate level of knowledge, regardless of the female's educational status, marital status, and their family history of breast cancer. Evaluation of the level of breast cancer awareness was adopted from Linsell et al., 2010 which was mentioned earlier in chapter six. The results also showed that Kuwaiti nationals were less likely to be aware of breast cancer non-lump symptoms than other nationalities although the number of Kuwaiti participants constituted the majority (84.5%) of participants.

Further, an additional finding which was in convergence among all three methods of research was the significant association between the level of awareness and area of residence. The BCAM showed that area of residence was significantly associated with participants awareness, with those living in the capital area more likely to be aware of non-lump symptoms. Stakeholders in the qualitative interviews believed that those living outside of the capital Kuwait namely in rural areas (Al Jahra/ Al Ahmadi) were less likely to be aware of breast cancer nonlump symptoms since they have limited access to awareness campaigns. Additionally, the systematic review revealed that participants living in urban or semi urban area had better knowledge about breast cancer and better screening uptake. Indeed, many studies have reported a better association with breast cancer knowledge in the population living in urban and semi urban areas (Abdou, et al., 2020)

Finally, the qualitative interviews also highlighted that although non-Kuwaiti nationals were thought to be more aware of breast cancer, expats constitute a huge number of residents in Kuwait, especially home helpers who take care of elderly. Thus, any future campaigns should take that into consideration since most participants in this study were Kuwaitis the results might not accurately reflect expat women's knowledge.

Therefore, combining the results of all three studies reveals that females who were less likely to be aware of breast cancer are:

- Unmarried
- Young 21-30 years old
- Kuwaiti nationals
- Living in Al Jahra and Al Ahmadi (outside the capital area and most rural areas)

With the exception of marital status, these results were confirmed by the qualitative interviewees as being the appropriate target populations for future awareness efforts.

# 8.3.2.1 Beliefs and Attitudes

## i. Causes of breast cancer

Breast cancer beliefs and attitudes were explored within the three studies included in this thesis, including females' perceptions of the causes and risk factors associated with breast cancer. The systematic review of the literature identified several studies that described females' perception of the wide range of aetiological explanations. The literature review revealed many causes and risks thought to be associated with breast cancer, namely: alcohol, radiation, family history, hormonal medication, stress, evil eye and envy, smoking, trauma, overweight, old age, as well as God and religious beliefs. Yet in the primary data collection studies the participants reported a narrower list of causes and risk factors of breast cancer. Responders to the BCAM mentioned: stress, family history, and unhealthy eating habits as the main causes and risks. It should be noted that there was a discrepancy in the responses among participants, that is no single risk factor was widely known by most women, which suggested that common knowledge about causes and risk factors of breast cancer is not widespread among the Kuwaiti female community. The qualitative interviews did not offer detailed reflection on the causes and risk factors, but they did emphasise the importance of religious beliefs and myths as perceived causal factors in Kuwaiti society where people regard the evil eye, voodoo, and envy as possible explanations for breast cancer. A Turkish study exploring female's perception of breast cancer suggested that the degree of fatalism experienced, and the influence of religion do not change significantly between generations (Kissal, et al., 2018). Such views underline the continued social stigma and taboo which are identified as significant barriers to learning more about the breast cancer and help-seeking for breast cancer symptoms.

The findings of this thesis are in line with published literature where several other studies (including recent ones) reflect poor knowledge of the risk factors associated with the development of breast cancer (Al-Zalabani et al., 2018, Jones et al., 2014, Boulos and Ghali, 2013). A study of female healthcare professionals in Saudi Arabia designed to explore their knowledge, attitudes, and practices related to breast cancer screening found poor knowledge of the risk factors, which suggests that awareness campaigns should equally target both the general public and health professionals (Heena, et al., 2019).

# ii. Prevention of breast cancer

While breast cancer prevention was not explored via the BCAM, several studies included in the systematic review reported that many women in GCC countries were inclined to accept breast cancer as destiny rather than identifying any medical or lifestyle changes that may help them reduce their risk of breast cancer. Studies report that many participants did not believe they were at risk of developing breast cancer with those that did feel at risk being more likely to perform BSE. Fear was a recurring theme in the systematic review and most participants preferred not to consider breast cancer or indeed wish to know that they had breast cancer. In the qualitative interviews stakeholders discussed the importance of prevention and particularly for prevention to begin at a young age. Many recommended including breast cancer awareness content in school and university curricula.

# *i*. Treatment of breast cancer

Females' beliefs about breast cancer treatment was a major driver in screening participation. Findings from the systematic review are replete with information on females' perceptions of breast cancer treatment. While some believed that successful treatments existed, others were pessimistic about treatment believing that it caused pain, disfiguration, disaster, and death. Conversely some studies concluded that many females accepted the value of early detection. As previously highlighted, many of the included studies reported that breast cancer

explanations were rooted in religious beliefs and, consequently, studies also showed that for some females', breast cancer treatment centred on religious practices such reading Qur'an, Ruqia, consuming Zamzam water or herbal medicine. Such findings align with the findings of the BCAM study which demonstrated that those patients with lower levels of awareness were more likely to drink herbal tea or do nothing when noticing a change in their breast. The connection between religious beliefs, such as fatalism and breast cancer cause and treatment has been reported by other studies where (Kissal, et al., 2018) reported a high degree of fatalism among Turkish females. Fatalism was higher when self-efficacy was lower and that the belief that the cancer could not be prevented was high among females with a greater fear of cancer.

# 8.3.2.2 Screening for Breast Cancer

# i. Awareness of Screening

Many of the studies included in the systematic review examined breast cancer screening. Using both qualitative and quantitative methods the studies sought not only to measure screening participation and practice but also awareness of screening more broadly. Overwhelmingly the studies concluded that while most participants had some awareness of breast cancer, knowledge of screening availability and screening practice was low. In fact, a global perception of females on breast cancer and barriers to screening reported similar results, stating that low awareness is not limited to areas of the world which lack national breast cancer screening programmes, and that misinformation and lack of awareness remain a vital concern for breast cancer screening participation across the world (Mascara & Constantinou, 2021).

Detailed understanding of the starting age for screening, frequency, and screening methods was lacking, although more recent evidence suggests an overall improvement in awareness. Moreover, knowledge of breast cancer screening did not necessarily lead to screening participation and typically knowledge about BSE and CBE was greater than knowledge of mammography.

The BCAM study revealed that screening activity was associated with several common predictors, namely: knowledge and awareness about breast cancer, its symptoms, and risk factors, being employed, living in semiurban areas, having ten or fewer visits to the clinics, married women, those having a positive family

history, higher level of education, higher husband's educational level, higher income and being aged 30-49 years old. Finally, a third of participants who had university degrees believed that clinical breast examination and mammography were only important for older aged females.

Again, systematic review findings aligned with BCAM responses in Kuwaiti females. Although most participants (82%) knew about the Kuwaiti screening program, only 8% practiced BSE and only 24% of the eligible females participated in the screening program. The frequency of self-examination was unaffected by the awareness; those who checked their breasts monthly were not more likely to be aware of nonlump symptoms than those that never or rarely engaged in self-examination. Thus, there was no significant relationship between screening programme knowledge and awareness.

# ii. Barriers to screening: fear, shyness, infrastructure

Agreement on the major barriers to screening was found across the three studies. Fear was frequently cited as a major barrier together with social stigma and taboo, shame, and shyness from family members. While stakeholders in the qualitative study acknowledged that improvements had been made in awareness, most recognized that fear and stigma continue to have a significant impact on screening uptake and that breast cancer has long been associated with social stigma and taboo. Some studies have suggested that religious beliefs could be a root cause for this stigma, yet there is a need for studies that provide solid evidence that fatalism and fear are barriers to participating in cancer screenings (Kissal, et al., 2018). Some societies, such as the Kuwaiti, are more conservative than others, especially in relation to the reputation of its females. Breast cancer diagnosis is not a matter that affects only the patient but also other females in her family. Finally, another factor that complimented the knowledge attained from the systematic review was mentioned by some interviewees, which was the lack of communication skills among the health professionals. Stakeholders believed that healthcare professionals' inability to convince patients is a major barrier to early diagnosis. Since many females in the systematic review reported that they would accept invitations to screening from health professional, many thought that the important role played by healthcare professionals should feature when designing screening awareness campaigns. The findings from this study were in line with the

available information published in recent literature, where barriers to screening were related to lack of knowledge about screening activities and scientific information, social and psychological factors dominated by fear, and geographical barriers related to infrastructure and availability of information and screening services (Mascara & Constantinou, 2021).

# 8.4 Strengths and Limitation

This study explored females' awareness, attitudes and beliefs towards breast cancer and breast cancer screening in Kuwait and explored the most appropriate methods to improving breast cancer awareness. No study of this kind has previously been conducted in Kuwait. The tools used were a combination of a validated and reliable quantitative tool (BCAM) and qualitative interviews. Although the BCAM was adopted from a previous study, the particular novelty of the current research was the use of qualitative interviews and the use of videos to elucidate and probe further information from the participants.

One of the possible limitations to this study is that there was not the opportunity to speak to females themselves and explore their views on the best ways to improve awareness, which would further add to recommendations for future campaigns. The design of future breast cancer awareness raising campaigns in Kuwait should have a general population/patient perspective included in the advisory group.

## **Researcher's reflection statement**

As I am writing these words, I am overthrown with a huge influx of mixed feelings. On the one hand I feel grateful and proud to have reached the end of this bumpy ride, yet I can't but recall all the obstacles that I had to go through to reach this date. This PhD journey, albeit fulfilling, was indeed one the biggest challenges in my life. Let's begin by introducing myself: I'm a female physician from Kuwait and my first language is Arabic. Coming to the UK to pursue my PhD was not an easy thing to do as I had to leave my children and family for a long period of time, adapt to a new country and face a cultural shock, and acquire new skills that I had never been trained on before. It took a lot of effort, determination, sleepless nights, long hours, and many times after the office hour, in front of the screen to achieve what I was meant to achieve. I had to adapt, and find my way through it, and I did, with the help of the amazing people who stood by me all along. Learning and doing something new was not easy. However, patience was the key, because repetition was something that could not be avoided to have the work completed in the best professional way. I realized that for me to be able to achieve my goals, I had to compromise, and this compromise was shutting the door to the outside world. I literally spent days on end with myself and the screen, and this was the only way for me to be able to have a clear mind and think straight.

# **Research reflection**

It is important to reflect on my own role in the research. My rationale for focusing on breast cancer in Kuwait flowed directly from my role as a public health planning professional in Kuwait. However, despite my professional role, the fieldwork for this study illuminated some major differences between myself and many of the women in Kuwait, particularly those residents in rural communities. Given cultural differences I was unable to drive myself to clinics to collect data and instead had to rely on my husband as chaperone. There is a general distrust of outsiders and I was met with resistance when collecting data, which required a change to the data collection schedule. Engaging women in the study and encouraging them to complete the BCAM in my presence was also challenging at times, particularly as this cohort is largely unaccustomed to research participation. Despite these challenges, I learned to be patient and tolerant and persevered with the data collection and I managed to access a representative sample of Kuwaiti women.

Just as my professional role did not ease access to the women in my quantitative study, during the qualitative interviews with key stakeholders, I have no doubt that my professional background assisted in accessing stakeholders. They were outspoken without needing to be careful about what they want to say because they knew that I'm not just a researcher but also clinician and that facilitated the interviews.

# **Personal reflection**

After achieving good milestones in my journey, and because of an exceptional medical reason I had to discontinue my research for a period and go back home. It took me a while to recover, but I insisted on coming back. Unfortunately, the pandemic happened one month after that. With all the lockdowns and restrictions, I was unable to conduct my qualitative study as planned and had to change it. It was difficult to adapt to the new situation with the presence of other responsibilities, but these hurdles soon unveiled hidden strengths that I discovered about myself.

The determination I had and the motivation to keep going was something I never experienced before about any other challenge in my life, not even medical school. I typically try not to think about the difficulties I faced during my PhD journey as something bad, because those challenges drove me towards the end of my journey. Here I am now, writing my final words for this long journey that will forever be one of my greatest lifetime milestones.

# 8.5 Recommendation of how to improve breast cancer awareness

systematic review of the literature and the qualitative interviews. The systematic review showed a difference in preference for main sources of information about breast cancer where younger females preferred awareness campaigns and interactive sessions in healthcare facilities, while older females in the groups aged fifty and above preferred a variety of methods to acquire knowledge and awareness such as programs disseminated by the media and TV shows (Nageeti et al., 2017). The interviews conducted in this study highlighted several issues related to both the approach and content of the breast cancer campaigns:

- Fear was the main barrier for not screening for breast cancer. Given such attitudes, campaigns containing fear-provoking content are at odds with appropriate methods to raise awareness. Fear means that females tend to avoid listening to the word 'cancer' itself or watching TV content about breast cancer or even looking at breast cancer adverts. Such reactions reflect an inner anxiety. Therefore, even though breast cancer campaigns seek to educate females about breast cancer and convince them to engage in preventative measures, fear provoking content has the opposite effect. Presenting cancer as a killer disease reinforces perceptions and creates fear.
- For some females, losing a breast is as equally shocking as learning of a diagnosis (Jassim and Whitford, 2014) and such findings resonate with the findings of this thesis. Therefore, this "loss" factor should be considered when designing breast cancer campaigns. Whilst stakeholders recognised the need to have powerful content that is both attractive and informative, care needs to be taken to avoid creating fear among the target population since this might hinder their engagement.
- Given the importance of modesty, an important consideration was the appropriateness of openly displaying breasts in breast cancer campaigns.
- The interviewees did not believe that emotional stories would lead to improved breast cancer awareness in Kuwait, instead more factual and scientific
- information was favoured.

# Tools

- The interviewees highlighted the importance of media campaigns in raising awareness. Many thought that there were simply too few campaigns while others believed that the tools used were insufficient. One interviewee believed that people's awareness could be increased using social media; however, its reach can be limited especially for people who do not have digital access, such as the elderly and those lived in rural areas.
- According to the interviewees, the best way to increase breast cancer awareness was the early introduction of health education programmes in school. Some interviewees believed that this may help overcome fear.

Young women would be educated and they could then pass information to family networks, which in turn could change perceptions by normalising discussions of breast cancer. A recent global review of barriers to screening found that health educational interventions show promising results (Mascara & Constantinou, 2021). This review also concluded that healthcare professionals should discuss breast cancer more, a finding echoed by stakeholders in this thesis who felt that healthcare providers are trusted information sources (Mascara & Constantinou, 2021).

Including women's voices

Additional research that seeks to include the perspectives of women would no doubt add value to this work. Accessing their views and responses to breast cancer awareness campaigns and programmes would provide the views of research-users and the target audience. The importance of social networks as a vehicle for dissemination is clear, and approaching this from the perspective of a survivor may help reduce taboo and stigma. The inclusion of their voices would ensure more robust and valid campaigns. While stigma and taboo remain key issues in the Kuwaiti context, the value of social networks as a vehicle for the dissemination of information required exploration. Undoubtedly approaching this from the perspective of a survivor may ultimately help reduce taboo and stigma.

# Duration

 One of the most recurring criticisms was that efforts were concentrated around October the month of breast cancer awareness, and little to null effort is being done during the rest of the year.

# 8.6 Conclusion and summary

After assessing breast cancer awareness and breast cancer screening behaviours, evaluating the level of knowledge and awareness about breast cancer in the general population of females in Kuwait, and exploring the factors associated with their awareness of symptoms and breast cancer knowledge; the findings in this thesis indicate that there is an urgent need for targeted breast cancer awareness raising activity directed at Kuwaiti women. The views of key stakeholders provide a valuable insight into how best to approach awareness campaigns. Their views offer a guide for decision makers to help channel the resources and focus on priority areas. Moreover, including breast cancer survivors in decision making can make a valuable contribution to the design of interventions and policy.

According to this research the first fundamental step towards increasing female awareness about breast cancer in Kuwait is to devise intensive educational programmes for healthcare professionals, especially family physicians who routinely see women for a range of health-related issues. Family physicians should act as a gateway for preventative care. Therefore, the introduction of a national health policy that mandates family doctors to discuss breast cancer and breast cancer screening with all women over 40, regardless of their presenting complaint. Women will be informed of their age-related risk and the availability of screening. Another step towards better awareness of breast cancer is the introduction of a mechanism to discuss women's' health within the school curriculum. The results if the BCAM identified low levels of awareness amongst women who have a secondary education and under degree. Therefore, it is important to start teaching young women about breast cancer and the importance of screening and early detection.

Awareness campaigns are commonly used internationally as a tool to provide information. The stakeholders interviewed in this thesis highlight the need for campaigns designed to be cognisant of the cultural context of Kuwait. The BCAM results highlight awareness gaps among certain sub-groups of women and campaigns should prioritise reaching these groups. Additionally, future campaigns should make use of a variety of tools to deliver the awareness message, including social media. Campaigns should be planned by all stakeholder groups, the Ministry of Health, NGOs, Government Institutions (healthcare centres), and the private sector; and consider the use of champions (such as celebrities or famous healthcare professionals) as figureheads. As to the content of future campaigns, it is also recommended that it features the following:

- Informative factual content about risk factors, symptoms, prevention and treatment, and screening methods.
- Language appropriate for *all* sectors of the population.
- Culturally sensitive, modest: no provocative scenes of female body, attempt to minimise fear.
- Neutral and not emotional yet emphasizes the importance of support to remove social stigma barriers (the literature specifically highlighted the role of husbands (Sabgul, et al., 2021).

Finally, even though efforts are concentrated around October the month of breast cancer awareness, campaigns must be sustained across the year.

# Dissemination of information

Effective dissemination of research findings is key, if the findings are to have the desired impact. Moreover, is important to help raise awareness of breast cancer and breast cancer screening among females in Kuwait. It is essential that all relevant stakeholders and audiences are considered when developing dissemination plans. Different approaches tailored to specific groups are required:

1. Conventional Academics outputs: Several peer reviewed publications are planned covering the systematic review, the BCAM survey and the qualitative findings. Abstracts will be submitted to national and international conferences, and in particular opportunities to formally present findings in Kuwait and the gulf region will be sought

2. NGO: Cancer Awareness Nation (CAN) had already offered to adopt the recommended approaches to increase breast cancer awareness. They are a main stakeholder than are heavily involved in spreading awareness about breast cancer in Kuwait, and therefore, the research findings are key in improving their approach into a more robust evidence-based approach. The findings of this research will be communicated to them in through proper means such as a briefing

paper that highlights the main findings and recommendations, where they will be encouraged to take them into consideration in their next awareness campaign.

3. Social media: Posting through social media would be as important as other approaches since it is simple and accessible to all the population. Social media plays a huge role in introducing trends and normalising things that could otherwise have been considered alien in the society. Thus, social media can be used for both disseminating the findings of this study and preparing content for future campaigns. An event can be organised where influencers on social media, particularly those who have most female followers in the gulf region could be invited where the findings of the study will be displayed. Each influencer will post about the event on their personal page and in return share the findings of the study. This will work as a corner stone to encourage survivors of breast cancer to speak up and voice out their experience by normalising talking about it and showing it on social media. Also, the event can be used to recruit influencers for future campaigns.

4. Communication: Establishing a link with breast cancer survivors through channels (NGOs, clinics) would be a useful way to involve them in future studies. The publication, social media event, and the dissemination of a briefing paper with all the recommendations will highlight the importance of sharing the experiences of breast cancer survivors. This emphasis may encourage survivors close to the stakeholder network to voice out and open communication channels with possible future candidates that could be recruited for future studies or campaigns.

# Appendix 1: Ethical Approval- Kuwait Ministry of Health (Arabic version)

State Of Kuwait Ministry Of Health Asst. Undersecretary for Planning & Quality



دولة الكويت وزارة الصحة وكيل الوزارة المساعد لشئون التخطيط والجودة

> التاريخ : <u>۹ الا الار</u> الرقع : \_\_\_\_\_

المحترم

Hassan

*السيد الفاضل / د. وكيل الوزارة* تحية طبية وبعد،،،،

الموضوع / تسهيل مهمة الباحثة / د. حنان معتوق الماجد وآخرون (رقم البحث 591 /2017) لأجراء البحث تحت عنوان:

<u>Breast Cancer Knowledge and Awareness Among Female Residents of</u> <u>Kuwait</u>

يرجي التفضل بالإحاطة بأن اللجنة الدائمة لتنسيق البحوث الطبية والصحية المشكلة بموجب القرار الوزاري رقم 207 لسنة 2012 قد أوصت باجتماعها السادس والثلاثون (5 / 2017) المنعقد يوم الثلاثاء الموافق 4 / 7 /2017 بالموافقة (بعد إجراء التعديلات المطلوبة) على إجراء البحث رقم (591 / 2017) المقدم من الباحثة / د. حنان معتوق الماجد وآخرون بتاريخ 7 /6 /2017 تحت عنوان:

Breast Cancer Knowledge and Awareness Among Female Residents of Kuwait

وذلك بعد أن قامت اللجنة استنادا للقرار الوزاري رقم 207 لسنة 2012 والتعميم الصادر من السيد / وكيل الوزارة برقم 156 لسنة 2012 باستطلاع آراء الجهات ذات العلاقة بموضوع البحث حيث رد السيد / الوكيل المساعد للشئون القانونية بالكتاب رقم 478 بتاريخ 21 / 6/ 2017 كما وافق السيد / د. رئيس مجلس أقسام الجراحة بالكتاب رقم 484 بتاريخ 2017/6/22 (متضمنا بعض الملاحظات) .

State Of Kuwait Ministry Of Health Asst. Undersecretary for Planning & Quality



دولة الكويت وزارة الصحة وكيل الوزارة المساعد لشئون التخطيط والجودة

التاريخ: ٢-٧-٧

برجاء التفضل بالاطلاع والتوجيه بما ترونه مناسباً نحو اعتماد توصية اللجنة والموافقة على مخاطبة الجهات ذات الصلة بموضوع البحث (السادة / مدراء المناطق الصحية والمستشفيات / السيدة د. مدير الإدارة المركزية للرعاية الصحية الاولية) بهذا الشأن للعمل على تسهيل مهمة الباحثين لإجراء البحث.

مع مراعاة التزام الباحثين بالمحافظة على حقوق المشاركات بالبحث بالخصوصية وسرية المعلومات وعدم تداولها خارج إطار البحث والحصول على الإقرار المستنير Informed Consent من المشاركات بالدراسة والتنسيق مع رؤساء الأقسام التي ستجري بها الدراسة وفقا للضوابط المنظمة لذلك.

وتفضلوا بقبول فائق الاحترام،،،،

2

الدكتور / محمد جاسم الخشتي الوكيل المساعد لشئون التخطيط والجودة رئيس اللجنة الدائمة لتنسيق البحوث الطبية والصحية

المتخطيعة والبساعد للم

Hassar

يوسف صراح الدويري وكمل وزارة الصحة بالإناب

264

# State of Kuwait Ministry of Health Asst. Undersecretary for planning & Quality

Date: 09/07/2017

No. 1822

# Respected/ Mr. Undersecretary of the Ministry

Greetings,

# Subject / Facilitating the task of researcher / Dr. Hanan Maatoug Al Majed.. and others, to conduct the research (number 591/2017) under the title:

Health Research, which was formed pursuant to Ministerial Resolution No. 207 of Kindly be informed that the Constant Committee for the Coordination of Medical and 04/07/2017 to approve (after performing the required amendments) to conduct the 2012, recommended during its thirty-sixth meeting (5/2017) held on Tuesday research No. (519/2017), submitted by the Researcher / Dr. Hanan Maatouq Al Majed & others On 07/06/2017

<u>Breast Cancer Knowledge and Awareness Among Female Residence of</u>

Under the title:

Kuwait

dated The research based on the Ministerial Resolution No. 207 of 2012 and the Circular After the Committee has implemented a survey to the relevant authorities to the 21/06/2017 and the Chairman of the Board of Surgery Departments has approved, issued by the Undersecretary of the Ministry No. 156 for the year 2012. 478 No. responded by letter in letter No. 484 dated 22/06/2017. (Including some observations). of Legal Affairs Assistant Undersecretary

of The study is conducted using a questionnaire for collecting the data of female Kuwaitis included in the study according to the research protocol (duration research is one year).

the authorities (Messrs./ Directors of Health Areas and Hospitals/ Mrs. Dr. Director of concerned The research does not include any medical experiments, medications or biopsies. 9 convenient with reference and approve to address the advise what you find committee recommendation of the and review Please

Central Department for Primary Health Care) in this regard to facilitate the task of researchers to conduct the research.

Taking into consideration the commitment of researchers to maintain the rights of participants for privacy and confidentiality of information and non-circulation outside the framework of research and obtaining informed consent of the participants study and coordination with the heads of departments in which the study will be conducted in accordance with the regulations.

Best Regrds,,

Dr/ Jasim Al-Khashti

Assistant Undersecretary for

Planning and Quality Affairs

Chairman of the Constant Committee

for Coordination of Medical and Health Researches

(Signed & Sealed)

Yousef Al-Duary For Undersecretary of Ministry of Health (Signed)



دولة الكويت وزارة المصحة وكيل الوزارة المساعد لشئون التخطيط و الجودة



المحترم

السبيد الفاضل / د. وكيل الوزارة

تحية طبية وبعد،،،،

# الموضوع / تسهيل مهمة الباحثة / د. حنان الماجد وآخرون – طالب دكتوراه في جامعة جلاسكو - المملكة المتحدة (رقم البحث 2018/853) تحت عنوان: How to imrprove breast cancer awareness among the female <u>residents of Kuwait</u> كيف نزيد الوعي بسرطان الثدي لدي الاناث في الكوي<u>ت</u>

يرجي التفضل بالإحاطة بأن اللجنة الدائمة لتنسيق البحوث الطبية والصحية المشكلة بموجب القرار الوزاري رقم 207 لسنة 2012 قد أوصت باجتماعها السابع والاربعون (6 / 2018) المنعقد يوم الثلاثاء الموافق 26 / 6 /2018 بالموافقة ( بعد استكمال الردود )على إجراء البحث رقم ( 853 / 2018) المقدم من الباحثة / د. حنان الماجد وآخرون – طالب دكتوراه في جامعة جلاسكو - المملكة المتحدة بتاريخ 2/26/2018 تحت عنوان:

<u>How to imrprove breast cancer awareness among the female</u> <u>residents of Kuwait</u> کیف نزید الوعی بسرطان الثدی لدی الانات فی الکویت

وذلك بعد أن قامت اللجنة استنادا للقرار الوزاري رقم 207 لسنة 2012 والتعميم الصادر من السيد / وكيل الوزارة برقم 156 لسنة 2012 باستطلاع آراء الجهات ذات العلاقة بموضوع البحث حيث وافق السيد / وكيل الوزارة المساعد للشئون القانونية بالكتاب الوارد برقم 914 بتاريخ 2018/7/8 ووافق السيد / د. رئيس مجلس اقسام الجراحات التخصصية بالكتاب رقم 935 بتاريخ 2018/7/11.

1

P.O. Box (5) 13001 Safat, Kuwait Tel : 24622228 - 24622230 Fax : 24866514 ص.ب : (٥) الرمزالبريدي ١٣٠٠١ الصفاة – الكويت تلفون : ٢٤٦٢٢٢٣٠ – ٢٤٦٢٢٢٢٨ – فاكس : ١٤٨٦٦٦٦٢

# Appendix 2: Ethical Approval- University of Glasgow



Dr Dorothy McKeegan College Ethics Officer 10<sup>th</sup> October 2017

Dr Dorothy McKeegan Senior Lecturer R303 Level 3 Institute of Biodiversity Animal Health and Comparative Medicine Jarrett Building Glasgow G61 1QH Tel: 0141 330 5712 E-mail: Dorothy.McKeegan@glasgow.ac.uk

Dear Dr Nicholl

## **MVLS College Ethics Committee**

Project Title: Breast Cancer Knowledge and Awareness among Female Residents of Kuwait Project No: 200170015

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project, subject to the following conditions:

- Project end date: 31 October 2018
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research:

(http://www.gla.ac.uk/media/media 227599 en.pdf)

- The research should be carried out only on the sites, and/or with the groups defined in the
  application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

# **Appendix 3: Consent Form (Quantitative Study)**



General Practice & Primary Care 1 Horselethill Rd Glasgow, UK, G12 9LX

Clinic ID

Participant's ID

### **Consent Form**

Title of project: Breast Cancer Awareness & Knowledge among Female Residents of Kuwait

Name of Researchers: Dr. Hanan Almajed, Dr. Barbara Nicholl & Dr. Sara Macdonald

### Please initial box

- I have read the participants' information sheet provided by the researcher for the <u>above mentioned</u> study.
- 2. I have a clear understanding about the <u>above\_mentioned</u> study and I had the opportunity to ask questions related to it.
- 3. I know that enrolment is <u>voluntary</u> and I can opt to withdraw at any time of the questionnaire completion.
- I know that this study is not a clinical trial and does not include drugs or invasive procedure.
- I know that the information I provide will be anonymous and confidential and will not be shared outside the study spectrum.
- 6. I wish to participate

Name of Parti	cipant	Date	Signature
Researcher's	Name	Date	Signature
	1 original fo	or participant, 1 origi	nal for researcher
1 Dr.o.	art Canaar Kaawlada	and Automotion and	ng Formale Desidents of Kunusit

 Breast Cancer Knowledge and Awareness among Female Residents of Kuwait University of Glasgow



General Practice & Primary Care 1 Horselethill Rd Glasgow, UK, G12 9LX

This study is part of a broader project around breast cancer awareness; if you think you might wish to be contacted in the future to participate in further studies in this area, please indicate below (This information will be kept separate from the questionnaire so that data collected in the questionnaire remains completely anonymous).

Yes	
No	
If yes, please provide:	
Name:	
Contact number:	
Signature	

Please note, this page will be kept separate from your survey responses.



Breast Cancer Knowledge and Awareness among Female Residents of Kuwait University of Glasgow

V2.0\_26.9.17

# **Appendix 4: Consent Form (Qualitative Study)**



Project Title:

Name of Researchers: Dr. Hanan Almajed Dr. Barbara Nicholl Dr. Sara Macdonald

CONSE	NT FORM		Please initial box
I confirm that I have read and unde Sheet.	rstood the Participant Informa	tion	
I have had the opportunity to think a <u>questions, and</u> understand the answ			
I agree to my interview/focus group	being audio-recorded.		
I understand that the recorded inter word by word and the transcription facilities in accordance with Data P	stored in the University archiv	ing	
I understand that my participation is withdraw at any time, without giving being affected.			
I know that this study is not a clinical procedure or drugs.	al trial and does not invasive		
I understand that all data and inform confidential and will be seen only by whose job it is to check the work of	y study researchers and regul	ators	
I agree that my name, contact detain information sheet will be kept for the		oject.	
I understand that if I withdraw from point will be retained and used for t		ip to that	
I agree to take part in the study.			
Participant's Name:	Date	Signature	
Researcher's Name:	Date	Signature	

# Appendix 5 : Participants Information Sheet (Quantitative Study)



General Practice & Primary Care 1 Horselethill Rd Glasgow, UK, G12 9LX

### Participants Information Sheet

Study Title: Breast Cancer Awareness & Knowledge among Female Residents of Kuwait.

Principal Researcher: Dr. Hanan Almajed

### Please read the below information before agreeing to participate in the survey

### The Purpose of the Study:

The aim of this study is to describe the level of breast cancer <u>awareness</u>; its risks, symptoms, and access to screening programs, among the female population of Kuwait. Conclusions drawn from the study will help researchers to develop measures suitable for females to increase their awareness and knowledge about breast cancer and breast cancer screening.

You are invited to take part in this survey. Your participation will help researchers to achieve their goals; however, you are under no pressure to participate, you do not have to participate unless you want to.

Dr Almajed is undertaking this survey as part of her PhD study at University of Glasgow (UK), funded by Kuwait Civil Service Commission. Her research is supervised by Drs Macdonald and Nicholl.

### What are you being asked to do?

We would like you to complete a survey asking questions about your knowledge of breast cancer. The time required to fill out the questionnaire will be 10-15 minutes, if you prefer, I can ask you the questions directly. You have been randomly selected to participate in this study.

There is no cost to participation in the study and no drugs or invasive procedure will be used.

Whether you decide to take part in this survey or not, will have no impact on the healthcare you receive, either today or in the future.

If you are happy to participate, you will be asked to complete and sign two copies of the consent form before starting to complete the questionnaire, one for you to keep as a record and the second for the researcher to store. However, participant's personal information given in the consent form will be kept strictly confidential and will be kept separate to the survey responses. Data from this study will not be shared outside of the study team.

Please ask me if you have any questions about the study or your participation in the study. If you change your mind and would like to withdraw from the study at any time, please contact the principal researcher Dr. Hanan Almajad on +965 97533033 or in writing by email to h.almajed.1@research.gla.ac.uk or by post to the address above.

V5.0 26.9.17

# Appendix 6 : Participants Information Sheet (Qualitative Study)



General Practice & Primary Care, University of Glasgow, 1 Horselethill Rd, Glasgow G129LX

### Participants Information Sheet

Study Title: How to improve breast cancer awareness among female residents of Kuwait

Principal Researcher: Dr. Hanan Almajed

Please read the below information before agreeing to participate.

### The Purpose of the Study:

The aim of this study is to inform the development of an intervention aimed at improving breast cancer awareness and knowledge, screening uptake, and early presentation in Kuwait. This will be done by reviewing and evaluating previous breast cancer interventions conducted in the region with those involved in breast cancer management, advocacy, control and prevention in Kuwait.

You are invited to participate in a focus group/ individual interview to review and discuss previous successful and failed interventions and gather exhaustive data on\_\_\_\_\_\_breast cancer awareness. Topics that will be explored include; weak and strong approaches adopted in previous interventions which led to their success or failure, potential areas for future interventions development, areas for improvement in the future interventions, primary components of a successful intervention in Kuwait and finding ways of reaching as much of the Kuwaiti population as possible. The session will last between 60-90 minutes. The discussion will be directed by a topic guide, held by the investigator. Field notes will be kept by the investigator. Those report and cover any changes in the list of questions, themes and sub-themes emerging from the discussion. The session will also be digitally audio-recorded. The data provided will not be shared outside the study team and that confidentiality will be respected. The

V3.0 03.09.2018

HOW TO IMPROVE BREAST CANCER AWARENESS AMONG FEMALE RESIDENTS OF KUWAIT

data will be stored in the researcher's office securely at home. The data will be transcribed and will be stored on the university J drive. Access to the data will be restricted to the researchers. However, the data provided will be analyzed in order to consider the development of a suitable intervention to improve breast cancer awareness and knowledge amongst the female adults of the Kuwaiti population.

Your participation will add valuable inputs to the study which will help to improve breast cancer awareness among the female residents of Kuwait. However, you are under no pressure to participate, you do not have to participate unless you want to.

Dr Almajed is undertaking this study as part of her PhD at University of Glasgow (UK), funded by Kuwait Civil Service Commission. Her research is supervised by Drs Macdonald and Nicholl.

### What you are being asked to do?

If you decide to participate you are required to sign two copies of the consent form to approve your participation, one for you as a record and one for the researcher to store.

You will be invited to attend a focus group with stakeholders from different organizations, or individual interview to discuss breast cancer <u>awareness</u>. You will be asked to discuss breast cancer awareness campaigns that you are aware of. You will also be asked to comment on a range of international campaigns and discuss the suitability of such approaches in Kuwaiti context. Each participant will take part in a focus group or an interview once. Interviews/ focus groups will be recorded but there will be no further contact with you. The researcher will, when data are analysed and written up for publication send a copy of the paper.

There is no cost to participation in the study and no drugs or invasive procedure will be used.

Please ask me any question regarding the study or your participation in the study. If you change your mind and would like to withdraw from the study at any time, please

contact the principal researcher Dr. Hanan Almajed on +965 97533033 or in writing by email to : <u>h.almajed.1@research.gla.ac.uk</u>.

You may also contact Dr. Sara Macdonald who's supervising the study, in writing by email to:

sara.macdonald@glasgow.ac.uk

HOW TO IMPROVE BREAST CANCER AWARENESS AMONG FEMALE RESIDENTS OF KUWAIT

V3.0\_03.09.2018

# **Appendix 7: Systematic Review Search Strategy**

# Systematic review search strategy

# Database: Medline search (1946- October 2016)

1- Keywords --- > cancer--- > map term to subheading --- > gives exp.
 Neoplasm

--- > 2919560

- 2- Cancer (with no mapping of term) --- > 1187126
- 3- Cancer \*OR tumour\* OR Neoplasm\* --- >3076191
- 4- 1 OR 2 OR 3 --- > 3441013
- 5- Awareness (map term to subheading) --- >explodeExp. Awareness --- > 16807
- 6- Health knowledge (map term to subheading)

(health knowledge, attitude, practice, health education, health behaviour

--- > explode)

--- > exp. Health education/ or exp. Health knowledge, attitude, practice/ Or exp. Health behaviour --- > 338471

- 7- Health promotion (map term to subheading)Exp. Health promotion --- > 64803
- 8- Campaign (map term to subheading)
  - --- > health promotion exp.
  - --- > health education exp.
  - --- > exp. Health promotion/ or exp. Health education
  - --- > 203467
- 9- Understanding (map term to subheading)
  - --- > comprehension (explode)
  - --- > 10515
- 10- Belief (map term subheading)

Explode --- > culture

- 11- Screening (map term)
  - --- > explode mass screening
  - --- > 112024
- 12- Mammography (map term to subheading)
  - ---- > explode ---- > 26784

13- Kuwait (map term to subheading)

--- > 2659

14- Oman\* OR Saudi Arabia\* OR Qatar\* OR United Arab Emirates\* OR Bahrain\*

(map term to subheading)

--- > 15939

- 15- 5 10 --- > 519175
- 16- 11 OR 12 --- > 132103
- 17- 13 OR 14 --- > 18458
- 18- 15 OR 16 --- > 638348
- 19- 4 and 17 and 18 --- > 159
- 20- Limit to humans --- > 157

# Database: Embase search 7/11/2016

# 1947- Present, updated daily

- 1- Cancer --- > map terms to subheading
  - --- > explode (neoplasm)

--- > 4111054

- 2- Cancer (no mapping of subheading)--- > 2762943
- 3- Cancer \*OR tumour\* OR neoplasm\*
   --- > 4177181
- 4- 1 OR 2 OR 3 --- > 4938921
- 5- Awareness (map term to subheading)

---- > explode ---- > 47403

- 6- Health knowledge (map term to subheading)
  - --- > health --- > explode

Exp. Health --- >843763

7- Health education (map term to subheading)

---- > explode ---- >281816

8- Health attitude (map term to subheading)

---- > explode ---- > 91097

9- Health practice (no mapping of term to subheading)

10- Health behaviour (map term to subheading)

Health behaviour --- > explode --- > 335752

- 11-Health promotion (map term to subheading)
  - --- > health promotion + health education

---- > explode ---- > 281816

12- Understanding (map term to subheading)

--- > comprehension --- > explode --- > 27339

13- Belief (map term to subheading)

Health belief + attitude to health + health behaviour --- > explode

--- > 33575

- 14- Screening (map term to subheading)
  - --- > screening / mass screening --- > explode

--- > 676857

- 15- Mammography (map term to subheading)
  - --- > mammography --- > explode

--- > 49024

16- Kuwait (map term to subheading)

---- > explode ---- > 4304

17- Oman\* OR Saudi Arabia\* OR Bahrain\* OR Qatar\* OR UAE (map term to subheading) --- > 26798

- 18-5-13--->1371404
- 19- 14 OR 15 --- > 708806
- 20- 16 OR 17 --- > 30524
- 21- 18 OR 19 --- > 2012671
- 22- 4 and 20 and 21 --- > 590
- 23- Limit to human --- > 567

# Database: Web of science search (now incorporates web of knowledge) 8/11/2016

(1947 – 2016)

- 1- Cancer --- > 1822214
- 2- Neoplasm --- > 143210
- 3- Cancer\* OR tumour\* OR neoplasm\* --- > 1966196
- 4- 1 OR 2 OR 3 --- > 1996196
- 5- Awareness --- > 155295
- 6- Health knowledge --- > 101106
- 7- Health education --- > 136811
- 8- Health attitude --- > 54589
- 9- Health practice --- > 171707
- 10- Health behaviour --- > 150959
- 11- Health promotion --- > 38411
- 12- Understanding --- > 1664071
- 13- Belief --- > 143574
- 14- Comprehension --- > 50468
- 15- 5 14
  - Or
  - --- > 2324996
- 16- Screening --- > 677476
- 17- Mammography --- > 28941
- 18- 16 OR 17 --- > 693099
- 19- 15 OR 18 --- > 2952325
- 20- Kuwait --- > 6801
- 21- Oman\* OR Saudi Arabia\* OR Qatar\* OR Bahrain\* OR United Arab Emirates\*

- 22- 20 OR 21 --- > 40878
- 23- 4 and 19 and 22 --- > 354

# Database: CINAHL

# On the 8/11/2016

- 1- Cancer (suggest subject term)
  - ---- > use neoplasm (MH) --- > explode

--- > 207074

2- Cancer (with no suggest subject term)

--- > 155576

3- Cancer\* OR tumour\* OR neoplasm\*

--- > 241600

- 4- 1 OR 2 OR 3 --- > 265409
- 5- Awareness (suggest subject term)

Tx Awareness --- > 28819

- 6- Health knowledge --- > 21732
- 7- Health education --- > 45844
- 8- Health attitude --- > 40547
- 9- Health practice --- > 17432
- 10- Health behaviour --- > 34238
- 11- Health promotion --- > 39868
- 12- Understanding --- > 80232
- 13- Belief --- > 27664
- 14- Comprehension --- > 4094
- 15-5-14

Or

- --- > 272388
- 16- Screening --- > 72911
- 17- Mammography --- > 7117
- 18- 16 OR 17 --- > 76104
- 19- 15 OR 18 --- > 336818
- 20- Kuwait --- > 477
- 21- Oman OR Saudi Arabia OR Qatar OR Bahrain OR United Arab Emirates--- > 3423
- 22- 20 OR 21

--- > 3858

23-4 and 19 and 22

# **Psyc INFO**

# Search done on 10/11/2016

- 1- Cancer (suggest subject term)
  - --- > neoplasm --- > explode
  - --- > 42958
- 2- Cancer --- > 65194
- 3- Cancer\* OR tumour\* OR neoplasm\*--- > 81400
- 4- 1 OR 2 OR 3
  - --- > 81847
- 5- Awareness --- > 87015
- 6- Health knowledge --- > 33148
- 7- Health education --- > 48105
- 8- Health attitude --- > 80638
- 9- Health practice --- > 47735
- 10- Health behaviour --- > 61744
- 11- Health promotion --- > 76880
- 12- Understanding --- > 317001
- 13- Belief --- > 116328
- 14- Comprehension --- > 52575
- 15-5-14

Or

--- >703765

- 16- Screening --- > 67495
- 17- Mammography --- > 1920
- 18- 16 OR 17 --- > 67829
- 19- Kuwait --- > 1246
- 20- Oman\* OR Saudi Arabia\* OR Qatar\* OR Bahrain\* OR United Arab Emirates

- 21- 19 OR 20 --- > 6930
- 22- 18 OR 15 --- > 754570
- 23- 4 and 22 and 21 --- > 70

# Database: International bibliography of social science (IBSS)

# (1946-2016)

# Search done on 14/11/2016

- 1- Cancer --- > 3901
- 2- Neoplasm --- >
- 3- Cancer\* OR tumour\* OR neoplasm\* --- > 3985
- 4- 1 OR 2 OR 3 --- > 3985
- 5- Awareness --- > 9924
- 6- Health knowledge --- > 6161
- 7- Health education --- > 12182
- 8- Health attitude --- > 4334
- 9- Health practice --- > 11749
- 10- Health behaviour --- > 12538
- 11- Health promotion --- > 3792
- 12- Understanding --- > 76134
- 13- Belief --- > 32429
- 14- Comprehension --- >2985
- 15-5–15 OR
  - --- > 147836
- 16- Screening --- > 3125
- 17- Mammography --- > 102
- 18- 16 OR 17 --- > 3163
- 19- 15 OR 18 --- > 150139
- 20- Kuwait --- > 1036
- 21- Oman\* OR Saudi Arabia\* OR Qatar\* OR Bahrain\* OR United Arab Emirates\*
  - --- > 4045
- 22- 20 OR 21 --- > 4849
- 23- 4 and 19 and 22 --- > 3

# **Appendix 8: Data Extraction Form**

Data Extraction Form

Reference ID	
Title	
Source	
Year Volume Issue Page	
Study Design	
Study Location (city; country)	
Participants	
Setting	
Population	
Sample size	
Intervention (if present)	
Questionnaire used	
Study Objectives	
Study Outcome (or Statistical Result)	
Ethical Considerations	
Conclusions	

# Appendix 9: Quality Appraisal Tool (Quantitative Study)

# JBI Critical Appraisal Checklist for analytical cross-sectional studies

	ver				
Date					
	-		_Year		_ Record
NUMDE	er				
		Yes	No	Unclear	Not applicable
1.	Were the criteria for inclusion in the sample clearly defined?				
2.	Were the study subjects and the setting described in detail?				
3.	Was the exposure measured in a valid and reliable way?				
4.	Were objective, standard criteria used for measurement of the condition?				
5.	Were confounding factors identified?				
6.	Were strategies to deal with confounding factors stated?				
7.	Were the outcomes measured in a valid and reliable way?				
8.	Was appropriate statistical analysis used?				
Overall	appraisal: Include 🗌 Exclude 🗌	Seek fur	ther in	fo 🗌	
Comme exclusio	nts (Including		reaso	n	for

# Appendix 10: Quality Appraisal Tool (Qualitative Study)

# JBI Critical Appraisal Checklist for Qualitative Research

ReviewerDateDate						
AuthorRecord Numb		ord Numb	er			
			Yes	No	Unclear	Not applicable
philosop research	congruity between the hical perspective and methodology?	d the				
	congruity between the ro plogy and the research q tives?					
	congruity between the ro plogy and the methods u data?					
method	congruity between the re plogy and the representat of data?					
5. Is there	congruity between the re plogy and the interpreta					
	e a statement locatir ner culturally or theoretic	-				
	fluence of the researcher n, and vice- versa, address					
adequat	rticipants, and their ely represented?					
current and is th	research ethical accord criteria or, for recent s nere evidence of ethical a opropriate body?	studies,				
report	conclusions drawn in the reference of the flow from the analystation, of the data?					
Overall app Comments	raisal: Include  Excluc	le 🗌 🤅	Seek fur	ther in	fo 🗌	

# Appendix 11: Quality Appraisal Tool (Mixed Method Study)

# Checklist for Assessing Mixed Methods Studies Adapted from:

O'Cathain et al. The quality of mixed methods studies in health services research. Journal of Health Services Research and Policy 2008; 13: 92. Pluye et al. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. International Journal of Nursing Studies 2009; 46: 529.

Justification for a mixed methods approach	
Was there a clear statement of the aims of the research?	Yes; Can't Tell; No
	Yes; Can't Tell; No
Was a mixed methods approach appropriate?	
Was there a clear description of the design for mixing methods?	Yes; Can't Tell; No
E.g., A clear description of the priority of methods (Was	
one given more prominence than the other)?	Vac Can't Tally No.
Was there a clear description of the sequence of	Yes; Can't Tell; No
methods?	
E.g., Did qualitative follow quantitative or vice versa:	
Were they carried out simultaneously?	Vac Cart Tally Na
Was there a clear description of the stage at which	Yes; Can't Tell; No
integration occurred e.g., at data collection; analysis?	Vac Carlt Talls Na
Was there a clear description of how the team worked to	Yes; Can't Tell; No
integrate methods?	
E.g., Was one team responsible for both approaches? If	
not, was there communication across the teams?	
Quantitative Component	
Was there a clear question answerable by quantitative	Yes; Can't tell; No
approaches?	
For observational studies/record review/routine data:	
Was sampling and the sample appropriate?	Yes; Can't Tell; No;
	N/A
Was source and type of routine data well described?	Yes; Can't Tell; No;
	N/A
What percentage of selected individuals agreed to	80-100%; 60 - 79%;
participate?	Less than 60%;
	Can/t tell; N/A
Was the duration of the study clearly stated?	Yes; Can't Tell; No;
	N/A
Were there any efforts to address potential sources of	Yes; Can't Tell; No;
bias?	N/A
Was the analysis method clearly described?	Yes; Can't Tell; No;
	N/A
For experimental studies:	

Was there a clear description of the randomisation	Yes; Can't Tell; No;
process?	N/A
Was there allocation concealment and/or blinding?	Yes; Can't Tell; No;
	N/A
Was loss to follow-up acceptable?	Yes; Can't Tell; No;
	N/A
Were there any efforts to address potential sources of	Yes; Can't Tell; No;
bias?	N/A
Was type of analysis clearly stated (intention-to-treat;	
explanatory; cluster)	
Qualitative Component.	
Was there a clear question answerable by qualitative	Yes; Can't tell; No
approaches?	
Was the qualitative approach appropriate?	Yes; Can't Tell; No
Was there a clear description of the sampling method?	Yes; Can't Tell; No
Was there a clear description of the participants?	Yes; Can't Tell; No
Was there a clear description of the data collection?	Yes; Can't Tell; No;
Was there a clear description of analysis?	Yes; Can't Tell; No
i i	

# Appendix 12: Data coding Dictionary (Quantitative Study)

Question Number	Variable Name	Brief Description	Data Type (Number or Text)	Coding Options
Section 1: So	ociodemographics			
1A	nationality	What is your nationality?	N	1-Kuwaiti 2-Syrian 3-Egyptian 4-Lebanese 5-Other Gulf 6-Other Arabic 7-Others -88-missing -77-ambiguous
1B	age	What is your age?	Free text N	-free text -88- missing -77-ambiguous
1C	marital	What is your marital status?	N	1-single 2-married 3-divorced 4-widowed -88-missing- -77-ambiguous
1D	residence	Where do you live?	N	1-capital 2-hawalli 3-jahra 4-ahmadi 5-farwaneya -88-missing -77-ambiguous
1E	education	What is your level of education?	N	1-below secondary 2-secondary (or equivalent) 3-above secondary and below university (college) 4-university and above -88-missing

				-77-ambiguous
1F	employment	What is your current employment status?	N	1-unemployed 2-Housewife 3-working full time 4-working part time 5-retired 6-student -88-missing -77-ambiguous
1G	income	Total household income in Kuwaiti dinar per month	N	1-less than 500 k.d 2-between 500- 1500 k.d 3-between 1500-2500 k.d 4-between 2500-3500 k.d 5-above 3500 k.d -88-missing -77-ambigous
1H	children	Total number of children	N	1-one child 2-two children 3-three children 4-four children 5-more than 4 children 6-no children 7-not married -88-missing -77-ambiguous
11	history	Do you have a family member with history of breast cancer?	N	0-no 1-yes -99-don't know -88-missing -77-ambiguous
1J	friend	Do you have a close friend with a history of breast cancer?	N	0-no 1-yes -99-don't know -88-missing -77-ambiguous

1K	information	Do you have any prior information about breast cancer	Ν	0-no 1-yes -88-missing -77-ambiguous
1L	source	What is / are your source of information?	Ν	1-doctor 2-health educator at clinic 3-tv 4-radio 5-newspaper/ magazine 6-internet 7-friends and family 8-others -88-missing -77-ambiguous

2: signs and	l symptoms			
2A	lump	A lump or thickening in the breast	N	0-no 1-yes -99-don't know -88-missing -77- ambiguous
2B	armlump	A lump or thickening under armpit	N	0-no 1-yes -99-don't know -88-missing -77- ambiguous
2C	disc	Bleeding or discharge from the nipple	N	0-no 1-yes -99-don't know -88-missing -77- ambiguous
2D	pullin	Pulling in of the nipple inside	N	0-no 1-yes -99-don't know -88-missing -77- ambiguous

2E	position	Change in	N	0-no
		position of the		1-yes -99-don't
		nipple		know
				-88-missing
				-77-
2F	rash	Any rash on or	N	ambiguous 0-no
21	10311	around the		1-yes
		nipple		-99-don't
				know
				-88-missing -77-
				ambiguous
2G	redness	Redness of the	N	0-no
		skin of the breast		1-yes -99-don't
		DIEdSL		-99-don t know
				-88-missing
				-77-
2H	size	Change in the	N	ambiguous 0-no
211	5120	Change in the size of breast		1-yes
		or nipple		-99-don't
				know
				-88missing -77-
				ambiguous
21	shape	Change in the	N	0-no
		shape of breast		1-yes
		or nipple		-99-don't know
				-88-missing
				-77-
	a sink as a f	A		ambiguous
2J	painbreast	A pain in one or both breast	N	0-no 1-yes
				-99-don't
				know
				-88-missing
				-77- ambiguous
2K	painarm	A pain in one or	N	0-no
		both armpits		1-yes
				-99-don't
				know -88-missing
				-77-
				ambiguous

2L	dimple	Dimpling on the skin of the breast	N	0-no 1-yes -99-don't know -88-missing
				-77- ambiguous

Section 3: Che	Section 3: Checking				
ЗА	check	How often do you check your breast?	N	1-once a week 2-once a month 3-once every 6 month 4-rarely or never -88-missing -77-ambiguous	
3В	confident	How confident are you of noticing a change in your breast?	N	1-very confident 2-fairly confident 3-not very confident 4-not at all confident -88-missing -77-ambiguous	
3C	notice	What would you do if you noticed a change in your breast?	N	1-seek medical advice 2-search the internet 3-use traditional methods/ healing 4-nothing -99-don't know -88-missing -77-ambiguous	

Section 4:	Screening			
4A	program	To your knowledge, is there a national breast cancer screening program in Kuwait ?	N	0-no 1-yes -88-missing -77-ambiguous

4B	mammography	Are you aware of the Kuwait National Mammography Screening Program ?	N	0-no 1-yes -88-missing -77-ambiguous
4C	screen	Have you ever been for breast cancer screening ?	N	0-no 1-yes -88-missing -77-ambiguous
4C I	location	If yes, which clinic/ hospital?	N	1-public 2-private -88-missing -77-ambigous

Section 5: seeki	ing medical l	nelp		
5	delay	If you found a change in your breast, how soon would you contact your doctor?	text	-free text -99-don't know -88-missing -77-ambigous

Section 6: Reason	s for delaying			
6A	embarras	Too embarrassed to go and see the doctor	N	0-no 1-yes often 2-yes sometime -99-don't know -88-missing -77-ambiguous
6B	scared	Too scared to go and see the doctor	N	0-no 1-yes often 2-yes sometime -99-don't know -88-missing -77-ambiguous
6C	difftalk	My doctor is difficult to talk to	N	0-no 1-yes often 2-yes sometime -99-don't know -88-missing

				-77-ambiguous
6D	diffappt	Difficult to make an appointment with the doctor	Ν	0-no 1-yes often 2-yes sometime -99-don't know -88-missing -77-ambiguous
6E	busy	Too busy to make time to go to the doctor	N	0-no 1-yes often 2-yes sometime -99-don't know -88-missing -77-ambiguous
6F	worry	Too many other things to worry about	Ν	0-no 1-yes often 2-yes sometime -99-don't know -88-missing -77-ambiguous
6G	transp	Difficult to find transportation to the doctor's clinic	Ν	0-no 1-yes often 2-yes sometime -99-don't know -88-missing -77-ambiguous

6H	worrfind	Worrying about	N	0-no
		what the		1-yes often
		doctor might		2-yes
		find, will stop		sometime
		me from going		-99-don't know
		to the clinic in		-88-missing
		the future.		-77-ambiguous
				_

61	notconf	Not confident talking to the doctor about my symptoms	Ν	0-no 1-yes often 2-yes sometime -99-don't know -88-missing -77-ambiguous
	further	Further reason for not going to the doctor	text	-free text -88-missing -77-ambiguous

Question number	Variable name	Brief description	Data type (number of text)	Coding option
Section 7: Age Risk	agerisk	Whose most likely to get breast cancer?	Ν	<ul> <li>4- above 50</li> <li>3- between 41-50</li> <li>2- between 30-40</li> <li>1- less than 30</li> <li>-99- don't know</li> <li>-88- missing</li> <li>-77-ambiguous</li> </ul>

Question number	Variable name	Brief description	Data type (number of text)	Coding option	
Section 8: fact	Section 8: factors increasing the chance of breast cancer				
8A	pasthist	A woman who was cured from breast cancer, can she get it again?	N	4-strongly agree 3-agree 2-disagree 1-strongly disagree -99-don't know -88-missing -77-ambiguous	

8B	contraceptive	Using contraceptive bills might increase the chance of breast cancer	Ν	4-strongly agree 3-agree 2-disagree 1-strongly disagree -99-don't know -88-missing -77-ambiguous
8C	weight	A 30 kg increase in body weight might increase the chance of breast cancer	Ν	4-strongly agree 3-agree 2-disagree 1-strongly disagree -99-don't know -88-missing -77-ambiguous
8D	relative	Having a relative with breast cancer might increase the chance of having breast cancer	Ν	4-strongly agree 3-agree 2-disagree 1-strongly disagree -99-don't know -88-missing -77-ambiguous
8E	kidslate	Having kids at an older age might increase the chance of breast cancer	Ν	4-strongly agree 3-agree 2-disagree 1-strongly disagree -99-don't know -88-missing -77-ambiguous
8F	nokids	A woman with no kids will have a higher chance of getting breast cancer	Ν	4-strongly agree 3-agree 2-disagree 1-strongly disagree -99-don't know -88-missing -77-ambiguous
8G	period	Having the period at an early age might increase the chance of breast cancer	Ν	4-strongly agree 3-agree 2-disagree 1-strongly disagree -99-don't know -88-missing -77-ambiguous

8H	latemeno	Late menopause might increase the chance of breast cancer	Ν	4-strongly agree 3-agree 2-disagree 1-strongly disagree -99-don't know -88-missing -77-ambiguous
81	exercise	Regular physical exercise might decrease the chance of getting breast cancer	Ν	4-strongly agree 3-agree 2-disagree 1-strongly disagree -99-don't know -88-missing -77-ambiguous
8J	stress	Stress might increase the chance of getting breast cancer	Ν	4-strongly agree 3-agree 2-disagree 1-strongly disagree -99-don't know -88-missing -77-ambiguous
8К	fattyfood	Fatty food might increase the chance of breast cancer	Ν	4-strongly agree 3-agree 2-disagree 1-strongly disagree -99-don't know -88-missing -77-ambiguous
8K	envy	Evil eye or envy might increase the chance of breast cancer	Ν	4-strongly agree 3-agree 2-disagree 1-strongly disagree -99-don't know -88-missing -77-ambiguous

## Appendix 13: Validated Modified BCAM (Quantitative Study)

Clinic ID

Participant's ID

**Title Page** 

Please answer the questions carefully, following the instructions provided. If you have any questions, please ask the researcher.

1	Please circle or write down the ap Only one answer is required for e		
Α	What is your nationality?		
В	What is your age?		
С	What is your marital Status?	1- Single 2- Married	3- Divorced 4- Widowed
D	Area of Residence		
E	Education level	1-Below Secondary (Primary or Intermediate) 2-Secondary (High School)	3-Above Secondary & below University (College) 4-University & above
F	What is your current employment status?	1-Unemployed 2-Housewife 3-Working full-time	4-Working part-time 5-Retired 6-Student
G	Total household income in Kuwaiti Dinars (K.D) per month	1-Less than 500 K.D 2- Between 500-1500 K.D	3- Between 1500-2500 K.D 4-Between 2500-3500 K.D 5-Above 3500 K.D
Η	Total Number of Children		- Not married
I	Do you have a family member with history of breast cancer?	1- Yes 2- No	3- I don't know
J	Do you have a close friend with history of breast cancer?	1- Yes 2- No	3- I don't know
K	Do you have any prior information about breast cancer?	1- Yes	2- No
L	If yes, what is/ are your source(s) of information? (Please select all that apply)	1- Doctor 2- Health educator at the clinic 3- TV 4- Radio	5- Newspaper/Magazine 6- Internet 7- Friends and family 8- Others

2	Please choose the answer you consider as a sign and/ or a symptom of breast cancer or not. Only one answer is required for each question.						
		- Yes	- No	- I don't know			
Α	A lump or thickening in the breast.						
В	A lump or thickening under the armpit.						
C	Bleeding or discharge from the nipple.						
D	Pulling in of the nipple inside.						
E	Change in position of the nipple.						
F	Any rash on or around the nipple.						
G	Redness of the skin of the breast.						
Н	Change in the size of the breast or nipple.						
I	A change in the shape of the breast or nipple.						
J	A pain in the breast or underarm.						
К	Dimpling on the skin of the breast.						

3	Please select the response that applies most to you. Only one answer is required for each question							
A	How often do you check your breast?	Rarely or never	At least once every 6 months	At least once a month	At least once a week			
В	How confident are you of noticing a change in your breasts?	Not at all confident	Not very confident	Fairly confident	Very confident			
C	What would you do if you noticed a change in your breast?	Nothing	Use traditional methods/ healing	Search the Internet	Seek medical help/get a doctor's appointment			

4	Please select the response that applic Only one answer is required for each		
A	To your knowledge, is there a national breast cancer screening program in Kuwait?	Yes	No
В	Are you aware of the Kuwait National Mammography Screening Program and its activities?	Yes Yes	No
C i	Have you ever been for breast cancer screening to any facility in Kuwait?	Yes	No
ii	If yes, where did you go for screening?		
5	If you found a change in your		

	If you found a change in your breast, how soon would you contact your doctor?		I don't know
--	---	--	--------------

6-Sometimes people put off going to see the doctor, even when they have a symptom that the
think might be serious. Could you say if any of these might put you off going to the doctor?
Only one answer is required for each question

	ly one answer is required for	Yes often	Yes sometimes	No	Don't know
A	Too embarrassed to go and see the doctor				
В	Too scared to go and see the doctor				
с	Worried about wasting the doctor's time				
D	l find my doctor difficult to talk to				
E	Difficult to make an appointment with the doctor				
F	Too busy to make time to go to the doctor				
G	Too many other things to warry about				
н	Difficult to arrange transport to doctor's surgery				
Ι	Worrying about what the doctor might find may stop me from going to the doctor				
	Not feeling confident talking about my symptom with the doctor				

Please write here anything else that can you think of that might put you off going to the doctor

7	Please select the appropriate response according to you: Who is most likely to develop breast cancer among women in Kuwait?	A woman younger than 30 years old	A woman 30 to 40 years old	A woman 40 to 50 years old	A woman more than 50 years old	l don't know
---	---	--	----------------------------------	----------------------------------	---	-----------------

8	Please select to what degree you agree that the following are risk factors for breast cancer. Only one answer is required for each question.								
		Strongly agree	Agree	Not sure	Disagree	Strongly disagree			
A	Having a personal past history of breast cancer.								
В	Using oral contraceptives.								
с	Being overweight (more than 30 kg above normal weight).								
D	Having family members with history of breast cancer.								
E	Having children later in life.								
F	Not having children.								
G	Having period at an early age.								
н	Having delayed menopause.								
I	Participating in regular physical activity or exercise/ sports.								
J	Stress and psychological tension.								
К	Consuming a lot of fatty food.								
L	Evil eye/ envy								

Thank you for taking the time to complete this questionnaire.

# Appendix 14: Interview Topic Guide Questions (Qualitative Study)

#### Interview topic guide

Name of participants: Place of work: Qualifications:

The aim of the study is to inform the development of a tailored intervention in Kuwait aimed at improving breast cancer awareness and knowledge, screening uptake, and early presentation.

This study is solely aimed to gather information and insights on best approaches to develop a breast cancer intervention from stakeholders involved in breast cancer management.

- What do you think about breast cancer in Kuwait?
- Do you know any of the campaign done in Kuwait?
- What was the outcome of the campaign? Was it successful or not? Why?

In my survey study I tried to measure breast cancer awareness in 5 districts of Kuwait

(The Capital, Hawalli, Farwaneya, Ahmadi & Jahra). I collected my data from few polyclinics within each district. I found that:

- Participants living in the Capital district are more aware than participants living in other districts.
- Most common barrier perceived by the participant is being too scared to go and see the doctor (71%)

• How to reach those people in order to increase their awareness? In my survey result, I also found that nearly half of participants thought that 'evil eye' is one of the risk factors for having breast cancer

- What do you think about this?
- What about the 'evil eye' do you think this saying would stop or be a reason of decreasing awareness and screening uptake?
- How to overcome this belief or idea?

After watching the breast cancer ads video:

- What do you think about these ads?
- Are they applicable in the Kuwaiti context? Yes, or no? Why?

In general, what is the best way to improve breast cancer awareness in Kuwait

### Appendix 15: URLs

PROSPERO <u>http://www.crd.york.ac.uk/PROSPEROCRD42017058343</u> (Systematic Review)

Video adverts <a href="https://youtu.be/1M3tyrRYafU">https://youtu.be/1M3tyrRYafU</a>) (Qualitative Study)

### **Bibliography**

- A. ELBASMI, A. A.-A., Y. AL-NESF AND A. AL-AWADI 2010. Cancer in Kuwaitmagnitude of the problem. G. J. O.
- ABDEL-AZIZ, S. B., AMIN, T. T., AL-GADEEB, M. B., ALHASSAR, A. I., AL-RAMADAN, A., AL-HELAL, M., BU-MEJDAD, M., AL-HAMAD, L. A. & ALKHALAF, E. H. 2017. Perceived Barriers to Breast Cancer Screening among Saudi Women at Primary Care Setting. *Asian Pac J Cancer Prev*, 18, 2409-2417.
- ABU ABED, M., HIMMEL, W., VORMFELDE, S. & KOSCHACK, J. 2014. Video-assisted patient education to modify behavior: a systematic review. *Patient Educ Couns*, 97, 16-22.
- ADELAIDE, T. U. O. 2020. *Critical appraisal tools* [Online]. Available: <a href="https://jbi.global/critical-appraisal-tools">https://jbi.global/critical-appraisal-tools</a> [Accessed].
- AGARWAL, G., RAMAKANT, P., SÁNCHEZ FORGACH, E. R., RENDÓN, J. C., CHAPARRO, J. M., BASURTO, C. S. & MARGARITONI, M. 2009. Breast Cancer Care in Developing Countries. *World Journal of Surgery*, 33, 2069-2076.
- AL KHASAWNEH, E. M., LEOCADIO, M., SESHAN, V., SIDDIQUI, S. T., KHAN, A. N.
   & AL MANASEER, M. M. 2016. Transcultural adaptation of the Breast
   Cancer Awareness Measure. International Nursing Review, 63, 445-454.
- AL OTAIBI, S., AL HARBI, M., AL KAHMOAS, A., AL QHATANI, F., AL MUTAIRI, F., AL MUTAIRI, T., AL AJMI, R. & AL MOUSAWI, F. 2017. General Breast Cancer Awareness among Women in Riyadh City. *Asian Pac J Cancer Prev*, 18, 159-163.
- AL RAMADHAN, M. A. 2017. Eradicating Breast Cancer: Longevity Impact on Kuwaiti Women. Asian Pac J Cancer Prev, 18, 803-809.
- AL-AWADI, L. & KHAN, A. R. 2019. Indoor radon levels in schools and residential dwellings in Kuwait. INTERNATIONAL JOURNAL OF ENVIRONMENTAL SCIENCE AND TECHNOLOGY, 16, 2627-2636.
- AL-AZRI, M., AL-AWISI, H., AL-RASBI, S., EL-SHAFIE, K., AL-HINAI, M., AL-HABSI,
  H. & AL-MOUNDHRI, M. 2014. Psychosocial impact of breast cancer diagnosis among omani women. *Oman Med J*, 29, 437-44.
- AL-MADOUJ, A. N., ELDALI, A. & AL-ZAHRANI, A. S. 2011. Ten years cancer incidence among nationals of the GCC states 1998-2007.

- AL-ZAHRAN, K. R. A. A. S. 2009. Association of reproductive factors with the incidence of breast cancer in GCC countries. *Eastern Mediterranean Health Journal*, 15.
- AL-ZALABANI, A. H., ALHARBI, K. D., FALLATAH, N. I., ALQABSHAWI, R. I., AL-ZALABANI, A. A. & ALGHAMDI, S. M. 2018. Breast Cancer Knowledge and Screening Practice and Barriers Among Women in Madinah, Saudi Arabia. *Journal of Cancer Education*, 33, 201-207.
- ALAM, A. A. 2006. Knowledge of breast cancer and its risk and protective factors among women in Riyadh. *Saudi Med J*, 26, 272-277.
- ALAWADI, S. A. & OHAERI, J. U. 2009. Health related quality of life of Kuwaiti women with breast cancer: a comparative study using the EORTC Quality of Life Questionnaire. *BMC Cancer*, 9, 222.
- ALBESHAN, S. M., MACKEY, M. G., HOSSAIN, S. Z., ALFURAIH, A. A. & BRENNAN,
  P. C. 2018. Breast Cancer Epidemiology in Gulf Cooperation Council
  Countries: A Regional and International Comparison. *Clin Breast Cancer*, 18, e381-e392.
- ALDOSARI, H. 2017, May. The effect of gender norm's on women's health in Saudi Arabia.
- ALHARBI, N. A., ALSHAMMARI, M. S., ALMUTAIRI, B. M., MAKBOUL, G. & EL-SHAZLY, M. K. 2019. Knowledge, awareness, and practices concerning breast cancer among Kuwaiti female school teachers. *Alexandria Journal* of Medicine, 48, 75-82.
- ALHAWAMDEH, A. K., ALGHIZZAW, M., HABES, M., S., M. A. & ALSHIBLY 2020. The Relationship Between Media Marketing Advertising and Encouraging Jordanian Women to Conduct Early Detection of Breast Cancer. *European Journal of Business and Management*, 12, 118-129.
- ALHURISHI, S., LIM, J. N., POTRATA, B. A. & WEST, R. 2011. Factors Influencing Late Presentation for Breast Cancer in the Middle East. *Asian Pacific Journal of Cancer Prevention*, 12.
- ALKHASAWNEH, E., AL-FARSI, Y., AL-SIMADI, F. & LEOCADIO, M. 2017. Development and Validation of a Culturally-Tailored Breast Cancer Health Education Programme for Arab Women. *Sultan Qaboos University medical journal*, 17, e181-e190.

- ALKHAWARI, H. A., ASBEUTAH, A. M., ALMAJRAN, A. A. & ALKANDARI, L. A. 2021. Kuwait National Mammography Screening Program: outcomes of 5 years of screening in Kuwaiti women. *Annals of Saudi Medicine*, 41, 257-267.
- ALMEGEWLY, W., GOULD, D. & ANSTEY, S. 2019. Hidden voices: an interpretative phenomenological analysis of the experience of surviving breast cancer in Saudi Arabia. *J Res Nurs*, 24, 122-132.
- ALWAHAIBI, N. Y., ALRAMADHANI, N. M., ALZAABI, A. M. & ALSALAMI, W. A. 2017. Knowledge, attitude and practice of Pap smear among Omani women. ANNALS OF TROPICAL MEDICINE AND PUBLIC HEALTH, 10, 396-403.
- ANGUERA, M. T., BLANCO-VILLASEN OR, A., LOSADA, J. L., SA NCHEZ-ALGARRA,
   P. A. & ONWUEGBUZIE, A. J. 2018. Revisiting the difference between mixed methods and multimethods: Is it all in the name? *Quality & Quantity*, 52, 2757-2770.
- ARRIVAL, E. 2022. Heathcare in Kuwait [Online]. Available: <u>https://www.expatarrivals.com/middle-east/kuwait/healthcare-kuwait</u> [Accessed].
- ASC, A. C. S. 2019. Breast cancer: facts and figures [Online]. Available: <u>https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/breast-cancer-facts-and-figures/breast-cancer-facts-and-figures-2019-2020.pdf</u> [Accessed].
- AZAMI-AGHDASH, S., GHOJAZADEH, M., SHEYKLO, S. G., DAEMI, A.,
  KOLAHDOUZAN, K., MOHSENI, M. & MOOSAVI, A. 2015. Breast Cancer
  Screening Barriers from the Womans Perspective: a Meta-synthesis. Asian
  Pac J Cancer Prev, 16, 3463-71.
- BENDARDAF, R., SAHEB SHARIF-ASKARI, F., SAHEB SHARIF-ASKARI, N., YOUSUF
   GURAYA, S., S, A. A. & ABUSNANA, S. 2020. Incidence and
   Clinicopathological Features of Breast Cancer in the Northern Emirates:
   Experience from Sharjah Breast Care Center. Int J Womens Health, 12, 893-899.
- BOLLINGER, S. & KREUTER, M. W. 2012. Real-time moment-to-moment emotional responses to narrative and informational breast cancer videos in African American women. *Health Educ Res*, 27, 537-43.
- BOULOS, D. N. & GHALI, R. R. 2013. Awareness of breast cancer among female students at Ain Shams University, Egypt. *Glob J Health Sci*, 6, 154-61.

BREAST CANCER RESEARCH UK. 2019. Breast cancer Statistics [Online]. Available: <u>https://www.cancerresearchuk.org/health-</u> professional/cancer-statistics/statistics-by-cancer-type/breast-cancer [Accessed].

- BREAST CANCER RESEARCH UK. 2022. Reduction in women screened for breast cancer between 2020 and 2021, NHS report finds [Online]. Available: <u>https://news.cancerresearchuk.org/2022/02/25/reduction-in-women-</u> <u>screened-for-breast-cancer-between-2020-and-2021-nhs-report-finds/</u> [Accessed].
- BRM, B. R. M. 2011. Positivism research philosophy [Online]. Available: <u>https://research-methodology.net/research-philosophy/positivism/</u> [Accessed 2022].
- CAL, A., KABATAS YILDIZ, M. & AYDIN AVCI, I. 2018. Examination of Knowledge and Fear Levels of Breast Cancer With the Spiritual Characteristics of Nurses. *Front Public Health*, 6, 331.
- CANCER RESEARCH UK. 2020. Breast cancer risk factors [Online]. Available: <u>https://www.cancerresearchuk.org/about-cancer/breast-cancer/risks-</u> <u>causes/risk-factors</u> [Accessed].
- CANCER RESEARCH UK. 2021. Breast cancer statistics [Online]. Available: <u>https://www.cancerresearchuk.org/health-professional/cancer-</u> <u>statistics/statistics-by-cancer-type/breast-cancer#heading-Two</u> [Accessed 2021, December].
- CFR, C. F. R. 2021. In-depth interviews: data collection advantages and disadvantages [Online]. Available: <u>https://www.cfrinc.net/cfrblog/in-depth-interviewing</u> [Accessed].
- DARENG, E. O., JEDY-AGBA, E., BAMISAYE, P., ISA MODIBBO, F., OYENEYIN, L.
  O., ADEWOLE, A. S., OLANIYAN, O. B., DAKUM, P. S., PHAROAH, P. D. &
  ADEBAMOWO, C. A. 2015. Influence of Spirituality and Modesty on
  Acceptance of Self-Sampling for Cervical Cancer Screening. *PLoS One*, 10, e0141679.
- DONNELLY, T. T., AL KHATER, A. H., AL KUWARI, M. G., AL-BADER, S. B., AL-MEER, N., ABDULMALIK, M., SINGH, R., CHAUDHRY, S. & FUNG, T. 2015. Do socioeconomic factors influence breast cancer screening practices among Arab women in Qatar? *BMJ Open*, 5, e005596.

DONNELLY, T. T. & HWANG, J. 2015. Breast cancer screening interventions for Arabic women: a literature review. J Immigr Minor Health, 17, 925-39.

Middle East study. PLoS ONE [Electronic Resource], 12, e0180696.

- DR MAY SEIKALY, R. R., AND & DRS CORINE VAN EGTEN 2014. The situation of women in the Gulf states.
- DUCHON, B. K. A. D. 1988. Combining qualitative and quantitative methods in information system-a case study. *MIS Quarterly*, 12, 571-586.
- EL SAGHIR, N. S., KHALIL, M. K., EID, T., EL KINGE, A. R., CHARAFEDDINE, M., GEARA, F., SEOUD, M. & SHAMSEDDINE, A. I. 2007a. Trends in epidemiology and management of breast cancer in developing Arab countries: a literature and registry analysis. *Int J Surg*, **5**, 225-33.
- EL SAGHIR, N. S., KHALIL, M. K., EID, T., EL KINGE, A. R., CHARAFEDDINE, M., GEARA, F., SEOUD, M. & SHAMSEDDINE, A. I. 2007b. Trends in epidemiology and management of breast cancer in developing Arab countries: A literature and registry analysis. *International Journal of Surgery*, 5(4), 225-233.
- ELIAS, F., RABAH, H., SALIH, M., BOUSHNAK, M. & SAID, C. 2021. Effectiveness of breast cancer screening campaigns from 2012 to 2017 by analysis of stage at diagnosis, Lebanon. *Eastern Mediterranean Health Journal*, 27, 580-586.
- ELOBAID, Y., AW, T. C., LIM, J. N. W., HAMID, S. & GRIVNA, M. 2016. Breast cancer presentation delays among Arab and national women in the UAE: a qualitative study. SSM Popul Health, 2, 155-163.
- ELOBAID, Y. E., AW, T. C., GRIVNA, M. & NAGELKERKE, N. 2014. Breast cancer screening awareness, knowledge, and practice among arab women in the United Arab Emirates: a cross-sectional survey. *PLoS One*, 9, e105783.
- EMAMI, L., GHAHRAMANIAN, A., RAHMANI, A., MIRZA AGHAZADEH, A., ONYEKA,
   T. C. & NABIGHADIM, A. 2021. Beliefs, fear and awareness of women about breast cancer: Effects on mammography screening practices. *Nurs Open*, 8, 890-899.

- ERIKSSON, E., WEJAKER, M., DANHARD, A., NILSSON, A. & KRISTOFFERZON, M. L. 2019. Living with a spouse with chronic illness the challenge of balancing demands and resources. *BMC Public Health*, 19, 422.
- EYAD FAWZI ALSAEED, M. A. T., YASSER BAYOUMI, OMAR ALOBEED, AHMAD ZUBAIDI AND FARJAH ALQAHTANI 2015. Knowledge, attitude and practices among urban women of Riyadh, Saudi Arabia, regarding breast cancer. *Kuwait Medical Journal*, 47, 215-220.
- FACIONE, N. C. & GIANCARLO, C. A. 1998. Narratives of breast symptom discovery and cancer diagnosis: Psychologic risk for advanced cancer at diagnosis. *Cancer Nursing*, 21, 430-440.
- FANG, S. Y., SHU, B. C. & CHANG, Y. J. 2013. The effect of breast reconstruction surgery on body image among women after mastectomy: a meta-analysis. *Breast Cancer Res Treat*, 137, 13-21.
- FEARON, D., HUGHES, S. A. & BREARLEY, S. G. 2020. Experiences of breast cancer in Arab countries. A thematic synthesis. *Qual Life Res*, 29, 313-324.
- FILIPPI, M. K., NDIKUM-MOFFOR, F., BRAIUCA, S. L., GOODMAN, T., HAMMER, T. L., JAMES, A. S., CHOI, W. S., GREINER, K. A. & DALEY, C. M. 2013. Breast cancer screening perceptions among American Indian women under age 40. J Cancer Educ, 28, 535-40.
- FORBES, L. J., ATKINS, L., THURNHAM, A., LAYBURN, J., HASTE, F. & RAMIREZ,
  A. J. 2011. Breast cancer awareness and barriers to symptomatic
  presentation among women from different ethnic groups in East London.
  Br J Cancer, 105, 1474-9.
- FORBES, L. J., WARBURTON, F., RICHARDS, M. A. & RAMIREZ, A. J. 2014. Risk factors for delay in symptomatic presentation: a survey of cancer patients. *Br J Cancer*, 111, 581-8.
- GALE, N. K., HEATH, G., CAMERON, E., RASHID, S. A. & REDWOOD, S. 2013. Using the framework method for the analysis of qualitative data in multidisciplinary health research. *Medical Research Methodology* 13.
- GHONCHEH, M., POURNAMDAR, Z. & SALEHINIYA, H. 2016. Incidence and Mortality and Epidemiology of Breast Cancer in the World. *Asian Pac J Cancer Prev*, 17, 43-6.
- GIL-GARCIA, J. R. A. & PARDO, T. A. 2006. Multi-Method Approaches to Digital Government Research: Value Lessons and Implementation Challenges.

Proceedings of the 39th Annual Hawaii International Conference on System Sciences (HICSS'06).

- GRUNFELD, E., RAMIREZ, A., HUNTER, M. A. & RICHARDS, M. A. 2002. Women's knowledge and beliefs regarding breast cancer. *British Journal of Cancer*, 86, 1373 1378.
- GULSHAN KARBANI, J. N. L., JENNY HEWISON, KARL ATKIN, KIERAN HORGAN, MARK LANSDOWN AND CAROL E CHU 2011. Culture, Attitude and Knowledge about Breast Cancer and Preventive Measure: a Qualitative Study of South Asian Breast Cancer
- Patients in the UK,
- . Asian Pacific journal of cancer prevention: APJCP 12, 1619-1626.
- GUPTA, A., SHRIDHAR, K. & DHILLON, P. K. 2015. A review of breast cancer awareness among women in India: Cancer literate or awareness deficit? *Eur J Cancer*, 51, 2058-66.
- HASHIM, M. J., AL-SHAMSI, F., AL-MARZOOQI, N. A., AL-QASEMI, S. S., MOKDAD,
  A. H. & KHAN, G. 2018a. Burden of breast cancer in the Arab world-Findings from global burden of disease. *Journal of Epidemiology and Global Health*, 8, 54-58.
- HASHIM, R., ABO-FANAS, A., AL-TAK, A., AL-KADRI, A. & ABU EBAID, Y. 2018b. Early Detection of Oral Cancer- Dentists' Knowledge and Practices in the United Arab Emirates. Asian Pacific journal of cancer prevention : APJCP, 19(8), 2351-2355.
- HOOVER, L. 2021. What is qualitative vs.quantitative study? [Online]. Available: <u>https://www.gcu.edu/blog/doctoral-journey/what-qualitative-vs-</u> <u>quantitative-study</u> [Accessed].
- HUSSEIN, D. M., ALORF, S. H., AL-SOGAIH, Y. S., ALORF, S. H., ALASKAR, R. S.,
  AL-MAHANA, A. M., ALSALHOWB, W. F., ALIBRAHIM, A. K., SAKA, M. Y.,
  ALHAZIMI, A. M., BAGHIROVA, A. A. & HINDAWI, S. I. 2013. Breast cancer awareness and breast self examination in Northern Saudi Arabia. Saudi Med J, 34.
- HWANG, J. J., DONNELLY, T. T., EWASHEN, C., MCKIEL, E., RAFFIN, S. & KINCH,J. 2017. Sociocultural Influences on Arab Women's Participation in BreastCancer Screening in Qatar. *Qualitative Health Research*, 27, 714-726.

- JASSIM, G. A. & WHITFORD, D. L. 2014a. Understanding the experiences and quality of life issues of Bahraini women with breast cancer. *Social Science and Medicine*, 107, 189-195.
- JASSIM, G. A. A. & WHITFORD, D. L. 2014b. Understanding the experiences and quality of life issues of Bahraini women with breast cancer. *Soc Sci Med*, 107, 189-95.

JENNIE POPAY, H. R., AMANDA SOWDEN, MARK PETTICREW, LISA ARAI, MARK RODGERS, NICKY BRITTEN, KATRINA ROEN AND STEVEN DUFFY. 2006. *Guidance on the conduct of narrative synthesis in systematic reviews*. [Online]. Available: <u>https://www.lancaster.ac.uk/media/lancaster-university/content-assets/documents/fhm/dhr/chir/NSsynthesisguidanceVersion1-April2006.pdf</u> [Accessed].

- JONES, C. E., MABEN, J., JACK, R. H., DAVIES, E. A., FORBES, L. J., LUCAS, G. & REAM, E. 2014. A systematic review of barriers to early presentation and diagnosis with breast cancer among black women. *BMJ Open*, *4*, e004076.
- KARAYURT, O., OZMEN, D. & CETINKAYA, A. C. 2008. Awareness of breast cancer risk factors and practice of breast self examination among high school students in Turkey. *BMC Public Health*, 8, 359.
- KHAN, K. S., KUNZ, R., KLEIJNEN, J. A. & ANTES, G. 2003. Five steps to conducting a systematic review. JOURNAL OF THE ROYAL SOCIETY OF MEDICINE, 96.
- KISSAL, A., VURAL, B., ERSIN, F. & SOLMAZ, T. 2018. The effect of women's breast cancer fear and social support perceptions on the process of participating in screening. *Glob Health Promot*, 25, 52-59.
- KNOWLEDGE, H. & EDUCATION, C. A. R. F. P. 2017. Measure of disease burden "(event-based and time-based)

and population attributable risks including identification

of comparison groups appropriate to Public Health [Online]. Available: <u>https://www.healthknowledge.org.uk/public-health-textbook/research-</u> <u>methods/1a-epidemiology/measures-disease-burden</u> [Accessed].

- KREUTER, M. W., HOLMES, K., ALCARAZ, K., KALESAN, B., RATH, S., RICHERT,
  M., MCQUEEN, A., CAITO, N., ROBINSON, L. & CLARK, E. M. 2010.
  Comparing narrative and informational videos to increase mammography in low-income African American women. *Patient Educ Couns*, 81 Suppl, S6-14.
- LEON-RODRIGUEZ, M. M. R.-F. A. E. 2017. Delays in breast cancer detection and treatment in developing countries. *Breast Cancer: Basic and Clinical Research*, 12, 1-5.
- LINSELL, L., BURGESS, C. C. & RAMIREZ, A. J. 2008. Breast cancer awareness among older women. *Br J Cancer*, 99, 1221-5.
- LINSELL, L., FORBES, L. J., BURGESS, C., KAPARI, M., THURNHAM, A. & RAMIREZ,
   A. J. 2010. Validation of a measurement tool to assess awareness of
   breast cancer. *Eur J Cancer*, 46, 1374-81.
- MACLEOD, U., MITCHELL, E. D., BURGESS, C., MACDONALD, S. & RAMIREZ, A. J. 2009. Risk factors for delayed presentation and referral of symptomatic cancer: evidence for common cancers. *Br J Cancer*, 101 Suppl 2, S92-S101.
- MARMOT, M. G., ALTMAN, D. G., CAMERON, D. A., DEWAR, J. A., THOMPSON, S.G. & WILCOX, M. 2013. The benefits and harms of breast cancer screening: an independent review. *Br J Cancer*, 108, 2205-40.
- MARYAM KHAZAEE-POOL, A. M., FERESHTEH MAJLESSI, ABBAS RAHIMI FOROUSHANI, SAHARNAZ NEDJAT & SHOJAEIZADEH, A. D. 2014. Breast cancer-preventive behaviors-exploring Iranian women's experiences. *BMC Women's Health*, 14.
- MCQUEEN, A., KREUTER, M. W., KALESAN, B. & ALCARAZ, K. I. 2011. Understanding narrative effects: the impact of breast cancer survivor stories on message processing, attitudes, and beliefs among African American women. *Health Psychol*, 30, 674-82.
- MHASKAR, R., EMMANUEL, P., MISHRA, S., PATEL, S., NAIK, E. & KUMAR, A. 2009. Critical appraisal skills are essential to informed decision-making. *Indian J Sex Transm Dis AIDS*, 30, 112-9.

- MOHAMMED, R., MANSOUR, M. A. M. A. & DORGHAM, L. S. 2014. Breast cancer awareness among saudi females in Taif Saudi Arabia. *International Journal of Science and Research (IJSR)*, 3.
- MORGAN, M. A., SMALL, B. J., DONOVAN, K. A., OVERCASH, J. & MCMILLAN, S. 2011. Cancer patients with pain: the spouse/partner relationship and quality of life. *Cancer Nurs*, 34, 13-23.
- NAGEETI, T. H., ABDELHAMEED, A. A. N., JASTANIA, R. A. & FELEMBAN, R. M. 2017. Perspective of Saudi women in the Makkah region on breast cancer awareness. *J Family Community Med*, 24, 97-101.
- NAJJAR, H. & EASSON, A. 2010. Age at diagnosis of breast cancer in Arab nations. *Int J Surg*, 8, 448-52.
- NHS. 2019. Breast cancer in women [Online]. Available: <u>https://www.nhs.uk/conditions/breast-cancer/</u> [Accessed].
- NICOLA BROWN, J. S., AMANDA BRASHER, DEBBIE RISIUS, ANNA MARCZYK AND JOANNA 2018. Breast education for schoolgirls; why, what, when and how? *Breast Journal*, 24, 377-382.
- NISHA, B. & MURALI, R. 2020. Impact of Health Education Intervention on Breast Cancer Awareness among Rural Women of Tamil Nadu. *Indian J Community Med*, 45, 149-153.
- O.J., M., P. O., A., B.L., A. A. & O.Y, M. 2013. Breast cancerknowledge and practice of breast self examination among women in rural community of Ondo state, Nigeria. *Journal of Pharmacy and Biological Sciences*, 8, 32-37.
- OBEIDAT, R. F. 2012. Controlling fear, Jordanian women's perceptions of diagnosis and surgical treatment of early stage bbreast cancer. *Cancer Nursing* 36.
- OBEIDAT, R. F. A. & LALLY, R. M. 2014. Health-related information exchange experiences of Jordanian women at breast cancer diagnosis. *J Cancer Educ*, 29, 548-54.
- OMRANI, A., WAKEFIELD-SCURR, J., SMITH, J., WADEY, R. & BROWN, N. 2020. Breast Education Improves Adolescent Girls' Breast Knowledge, Attitudes to Breasts and Engagement With Positive Breast Habits. *Front Public Health*, 8, 591927.

- PADELA, A. I., GUNTER, K., KILLAWI, A. & HEISLER, M. 2012. Religious values and healthcare accommodations: voices from the American Muslim community. *J Gen Intern Med*, 27, 708-15.
- PAGE, M. J., SHAMSEER, L. & TRICCO, A. C. 2018. Registration of systematic reviews in PROSPERO: 30,000 records and counting. *Syst Rev*, 7, 32.
- PASI, T. P. A. F. C. I. 2022. *Statistics Services System* [Online]. Available: <a href="https://www.paci.gov.kw/stat/">https://www.paci.gov.kw/stat/</a> [Accessed].
- PASTOR, J. E. A. J. 2004. Using a multimethod approach to research enterprise systems implementations. *Electronic Journal of Business Research Methods*, 2, 69-82.
- PETERS, M. D., GODFREY, C. M., KHALIL, H., MCINERNEY, P., PARKER, D. & SOARES, C. B. 2015. Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc*, 13, 141-6.
- PRUITT, L. C. C., STELLA ODEDINA, I. A., TOLULOPE MUMUNI, HELEN ODUNTAN, ADEYINKA ADEMOLA, IMRAN O. MORHASON-BELLO, TEMIDAYO O.
  OGUNDIRAN, MILLICENT OBAJIMI, OLADOSU A. OJENGBEDE, AND
  OLUFUNMILAYO I. OLOPADE & PRUITT, S. O., IMARIA ANETOR, TOLULOPE
  MUMUNI, HELEN ODUNTAN, ADEYINKA ADEMOLA, IMRAN O. MORHASON-BELLO, TEMIDAYO O. OGUNDIRAN, MILLICENT OBAJIMI, OLADOSU
  A.OJENGBEDE, AND OLUFUNMILAYO I.OLOPADE 2020. Breast cancer
  knowledge assessment of health workers in Ibadan, Southwest Nigeria.
  American Society of Clinical Oncology, 6, 387-394.
- PRUSTY, R. K., BEGUM, S., PATIL, A., NAIK, D. D., PIMPLE, S. & MISHRA, G. 2020. Knowledge of symptoms and risk factors of breast cancer among women: a community based study in a low socio-economic area of Mumbai, India. BMC Womens Health, 20, 106.
- RAHMAN, S. A., AL-MARZOUKI, A., OTIM, M., KHALIL KHAYAT, N. E. H., YOUSUF,
  R. & RAHMAN, P. 2019a. Awareness about Breast Cancer and Breast Self-Examination among Female Students at the University of Sharjah: A Cross-Sectional Study. *Asian Pacific journal of cancer prevention : APJCP*, 20, 1901-1908.

- RAHMAN, S. A., AL-MARZOUKI, A., OTIM, M., KHALIL KHAYAT, N. E. H., YOUSUF,
  R. & RAHMAN, P. 2019b. Awareness about Breast Cancer and Breast Self-Examination among Female Students at the University of Sharjah: A Cross-Sectional Study. Asian Pac J Cancer Prev, 20, 1901-1908.
- RAMIREZ, A. J., WESTCOMBE, A. M., BURGESS, C. C., SUTTON, S., LITTLEJOHNS,
  P. & RICHARDS, M. A. 1999. Factors predicting delayed presentation of symptomatic breast cancer: a systematic review. *The Lancet*, 353, 1127-1131.
- RAMYA AHMAD, S., ASMAA AHMAD, A., NESREEN ABDULLAH, A., RANA AHMAD BIN, S., SHAIMAA AMER, A., AISHA, T. & MOHAMMAD SHAHID, I. 2019. Awareness Level, Knowledge and Attitude towards Breast Cancer between Medical and Non-Medical University Students in Makkah Region: A Cross Sectional Study. International Journal of Cancer and Clinical Research, 6.
- RICHARDS, M. A., WESTCOMBE, A. M., LOVE, S. B., LITTLEJOHNS, P. & RAMIREZ,
  A. J. 1999. Influence of delay on survival in patients with breast cancer: a systematic review. *The Lancet*, 353, 1119-1126.
- RYAN, C., HESSELGREAVES, H., WU, O., PAUL, J., DIXON-HUGHES, J. & MOSS, J.
   G. 2018. Protocol for a systematic review and thematic synthesis of patient experiences of central venous access devices in anti-cancer treatment. Syst Rev, 7, 61.
- SAEED, R. S., BAKIR, Y. Y. & ALI, L. M. 2014a. Are women in Kuwait aware of breast cancer and its diagnostic procedures? *Asian Pac J Cancer Prev*, 15, 6307-13.
- SAEED, R. S., BAKIR, Y. Y. & ALI, L. M. 2014b. Are women in Kuwait aware of breast cancer and its diagnostic procedures? Asian Pacific Journal of Cancer Prevention: Apjcp, 15, 6307-13.
- SALE, J. E. M., LOHFELD, L. H. A. & BRAZIL, K. 2002. Revisiting The Quantitative-Qualitative Debate:Implication for Mixed-Methods Research. Quality & Quantity, 36, 43-53.
- SALEM, H. & DAHER-NASHIF, S. 2020. Psychosocial Aspects of Female Breast Cancer in the Middle East and North Africa. *Int J Environ Res Public Health*, 17.
- SERGIO RODRI GUEZ-CUEVAS, C. G. M., DIDO FRANCESCHI AND SONIA LABASTIDA 2001. Breast carcinoma presents a decade earlier in Mexican women than in women in the United. *Cancer*, 91.

- SETIA, M. S. 2016. Methodology Series Module 3: Cross-sectional Studies. Indian J Dermatol, 61, 261-4.
- SHULMAN, L. N., WILLETT, W., SIEVERS, A. & KNAUL, F. M. 2010. Breast cancer in developing countries: opportunities for improved survival. J Oncol, 2010, 595167.
- SOLIKHAH, S., PROMTHET, S. & HURST, C. 2019. Awareness Level about Breast Cancer Risk Factors, Barriers, Attitude and Breast Cancer Screening among Indonesian Women. *Asian Pac J Cancer Prev*, 20, 877-884.
- STANGE, K. C., CRABTREE, B. F. & MILLER, W. L. 2006. Publishing multimethod research. *Ann Fam Med*, 4, 292-4.
- SUNG, H., FERLAY, J., SIEGEL, R. L., LAVERSANNE, M., SOERJOMATARAM, I., JEMAL, A. & BRAY, F. 2021. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. CA Cancer J Clin, 71, 209-249.
- TAHA, H., NYSTROM, L., AL-QUTOB, R., BERGGREN, V., ESMAILY, H. & WAHLSTROM, R. 2014. Home visits to improve breast health knowledge and screening practices in a less privileged area in Jordan. BMC Public Health, 14, 428.
- TANNER, L. T. A. & CHEUNG, K. L. 2020. Correlation between breast cancer and lifestyle within the Gulf Cooperation Council countries: A systematic review. *World J Clin Oncol*, 11, 217-242.
- TAWFIK, G. M., DILA, K. A. S., MOHAMED, M. Y. F., TAM, D. N. H., KIEN, N. D., AHMED, A. M. & HUY, N. T. 2019. A step by step guide for conducting a systematic review and meta-analysis with simulation data. *Trop Med Health*, 47, 46.
- TAZHIBI, M. & FEIZI, A. 2014. Awareness levels about breast cancer risk factors, early warning signs, and screening and therapeutic approaches among Iranian adult women: a large population based study using latent class analysis. *Biomed Res Int*, 2014, 306352.
- THE WORLD BANK GROUP. 2022. Adjusted net national income per capita (current US \$)- Kuwait [Online]. Available: <a href="https://data.worldbank.org/indicator/NY.ADJ.NNTY.PC.CD?locations=KW">https://data.worldbank.org/indicator/NY.ADJ.NNTY.PC.CD?locations=KW</a> [Accessed].
- TZ-LI WANG, A. Y.-H. B. L. 2012. The power of using video data. *Quality & Quantity*, 47, 2933-2941.

UK, B. C. R. 2020. *Breast screening* [Online]. Available: https://www.cancerresearchuk.org/about-cancer/breast-cancer/getting-

diagnosed/screening/breast-screening [Accessed].

- UK, C. R. 2009. Breast cancer awareness measure BCAM
- UK, C. R. 2018. Breast cancer statistics [Online]. Available: <u>https://www.cancerresearchuk.org/health-professional/cancer-</u> <u>statistics/statistics-by-cancer-type/breast-cancer#heading-Three</u> [Accessed].
- UNIVERSITY OF NEWCASTLE LIBRARY GUIDES UON. 2020. *Research Guides* [Online]. Available: <u>https://libguides.newcastle.edu.au/researchmethods</u> [Accessed December 6 2021].
- UNIVERSITY OF YORK. 2016 Guidance notes for registering a systematic review protocol with PROSPERO [Online]. Available: <u>https://www.crd.york.ac.uk/prospero/documents/Registering%20a%20rev</u> <u>iew%20on%20PROSPERO.pdf</u> [Accessed].
- UOL, U. O. L. 2022. Doing postgraduate research [Online]. Available: <u>https://libguides.city.ac.uk/postgraduate\_research/scoping#s-lg-box-15363249</u> [Accessed].
- VANGEEST, J. B., JOHNSON, T. P. & WELCH, V. L. 2007. Methodologies for improving response rates in surveys of physicians: a systematic review. *Eval Health Prof*, 30, 303-21.

VIEIRA, R. A., BILLER, G., UEMURA, G., RUIZ, C. A. & CURADO, M. P. 2017. Breast cancer screening in developing countries. *Clinics*, 72, 244-253.

- VRINTEN, C., MCGREGOR, L. M., HEINRICH, M., VON WAGNER, C., WALLER, J., WARDLE, J. & BLACK, G. B. 2017. What do people fear about cancer? A systematic review and meta-synthesis of cancer fears in the general population. *Psychooncology*, 26, 1070-1079.
- WALTERS, S., MARINGE, C., BUTLER, J., RACHET, B., BARRETT-LEE, P., BERGH, J., BOYAGES, J., CHRISTIANSEN, P., LEE, M., WARNBERG, F., ALLEMANI, C., ENGHOLM, G., FORNANDER, T., GJERSTORFF, M. L., JOHANNESEN, T. B., LAWRENCE, G., MCGAHAN, C. E., MIDDLETON, R., STEWARD, J., TRACEY, E., TURNER, D., RICHARDS, M. A., COLEMAN, M. P. & GROUP, I. M. W. 2013. Breast cancer survival and stage at diagnosis in Australia, Canada, Denmark, Norway, Sweden and the UK, 2000-2007: a population-based study. *Br J Cancer*, 108, 1195-208.

- WANG, X. & CHENG, Z. 2020. Cross-Sectional Studies: Strengths, Weaknesses, and Recommendations. *Chest*, 158, S65-S71.
- WANG, Y. J., WANG, F., YU, L. X., XIANG, Y. J., ZHOU, F., HUANG, S. Y.,
  ZHENG, C., FU, Q. Y., LI, L., GAO, D. Z., ZHANG, Q., MA, Z. B., YU, Z. G.
  & LIU, L. Y. 2021. Worldwide review with meta-analysis of women's awareness about breast cancer. *Patient Educ Couns*.
- WEINER, S. 2020. Saudi Arabia guardianship women religious freedom.
- WHO, W. H. O. 2021. Breast cancer in Kuwait [Online]. Available: <u>https://gco.iarc.fr/today/data/factsheets/populations/414-kuwait-fact-sheets.pdf</u> [Accessed Jan 5 2022].
- WORLD CANCER RESEARCH FUND. 2021, Dec 21. World cancer data [Online]. Available: <u>https://www.wcrf.org/dietandcancer/worldwide-cancer-data/</u> [Accessed 2022].
- WORLD HEALTH ORGANIZATION WHO 2015. Kuwait health systems profile.
- YOULDEN, D. R., CRAMB, S. M., DUNN, N. A., MULLER, J. M., PYKE, C. M. & BAADE, P. D. 2012. The descriptive epidemiology of female breast cancer: an international comparison of screening, incidence, survival and mortality. *Cancer Epidemiol*, 36, 237-48.
- ZAHEDI, R., MOLAVI VARDANJANI, H., BANESHI, M. R., HAGHDOOST, A. A.,
  MALEKPOUR AFSHAR, R., ERSHAD SARABI, R., TAVAKOLI, F. & ZOLALA, F.
  2020. Incidence trend of breast Cancer in women of eastern
  Mediterranean region countries from 1998 to 2019: A systematic review
  and meta-analysis. BMC Womens Health, 20, 53.
- ZAILINAWATI ABU HASSAN, P. S., DANIELLE MAZZA 2006. Doing a pilot study- why is it essential?. *Malaysian Family Physician* 1, 70-73.