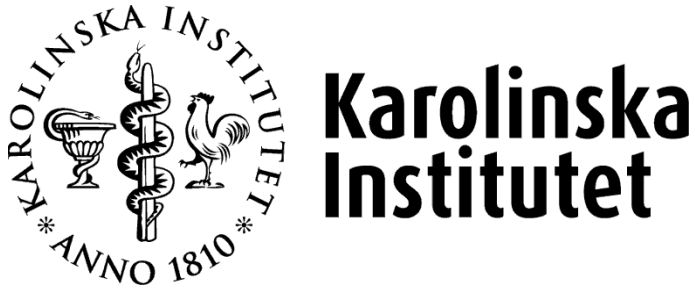
From the Department of Public Health Sciences
Karolinska Institutet, Stockholm, Sweden

Voices of fear and safety:

Women's ambivalence towards breast cancer and breast health practices in Jordan

Hana Taha



Stockholm 2013

Cover photo: Jordan's October 2011 National breast health awareness campaign, *"She'll listen to you…encourage her to get screened"*, Amman, Jordan. This campaign was designed based on the findings of this doctoral research.

Source: Jordan Breast Cancer Program, King Hussein Cancer Foundation, Amman, Jordan.

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Dedication

To our precious daughter Farah:
When I heard your first cry, my heart
beats suddenly became a heavenly poem.
When I first had you in my arms,
my whole existence on this earth
started to make sense.
My soul sprouts with love as I see you blossom
into a shining moon.
Because of you, I am dazzled with
God's glory and my life is wrapped in pink.
Thank you for converting me from a researcher
to a passionate believer in pink; whose mission is
to improve women's health everywhere on this globe.

Karolinska Institutet

Department of Public Health Sciences

Voices of fear and safety:
Women's ambivalence towards breast cancer and breast health practices in Jordan

ACADEMIC DISSERTATION

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ABSTRACT

Background: Although early detection is associated with better prognosis, still, breast malignancies are detected at late stages in Jordan. This thesis aimed to explore women's and men's perceptions about breast cancer and breast health in Jordan and to assess the effectiveness of breast health promotion interventions in improving women's breast health knowledge and practices.

Methods: The data for this thesis was collected from six governorates in Jordan and is organized into four studies (I-IV). In study I, pre- and post-tests data was collected for 2554 women who attended 105 breast health educational lectures. In study IV, 2400 breast health awareness home visits were conducted in a less privileged area in Amman and 2363 women answered a pre-test. After a home-based educational session, 625 women were referred to free mammography screening. Six months later follow-up home visits were conducted to 596 homes and 593 women answered a post-test. In studies I and IV, breast health knowledge and practices were assessed using multivariable analysis. Purposive sampling was used in study II to recruit 64 women for ten focus group discussions and 28 men in study III for semi-structured interviews. The transcribed data in studies II and III was subjected to latent content analysis.

Main Findings: In studies I and IV, low proportion of women reported practicing breast health examinations in the pre-test despite the noticeable level of breast health knowledge at the baseline. In both studies, the mean knowledge scores increased significantly in the post-tests ($p<0.001$). Out of the 625 women who received free mammography vouchers, 73% used them. The post-test showed also a significant improvement ($p<0.001$) in women's reported perceived knowledge and practice of breast-self-examination. In study II, three themes were constructed: a) Ambivalence in prioritizing own health; b) Feeling fear of breast cancer; and c) Feeling safe from breast cancer. The first theme was seen in prioritizing children and family and in experiencing family and social support. The second theme was building on perceiving breast cancer as an incurable disease associated with suffering and death, fear of the risk of diminished femininity, husband's rejection, social stigmatization and apprehensions about breast health examinations. The third theme was seen on their perceiving themselves as not being in the risk zone for breast cancer, accepting breast cancer as a test from God and comfort in acquiring breast health knowledge and skills. In study III, three themes were identified: a) Supporting one's wife; b) Marital needs and obligations c) Constrained by a culture of destiny and shame. The first theme was built on men's responsibility for the family's wellbeing, encouraging the wife to seek health care and providing counselling and instrumental support. The second theme was constructed from men's views about other men's rejection of a wife inflicted by breast cancer, their own perceptions of diminished femininity and their concerns about protecting the family from the hereditary risk of breast cancer. The third theme was seen in perception of breast cancer as an inevitable act of God that is far away from own family, in associating it with improper behaviour and in readiness to face the culture of Eib (shame).

Conclusions: Women's ambivalence towards breast health and their feelings of fear and safety could be addressed by emphasizing the good prognosis of breast cancer when detected early, engaging breast cancer survivors in breast health campaigns, involving husbands to capitalize on family support, conducting culturally appropriate educational lectures and home visits by local community workers and offering free mammography vouchers to women in less privileged areas.

Keywords: Breast cancer, breast health, perceptions, intervention, Jordan

LIST OF PUBLICATIONS

I. Taha H, Halabi Y, Berggren V, Jaouni S, Nyström L, Al-Qutob R, Wahlström R: Educational intervention to improve breast health knowledge among women in Jordan. *Asian Pacific Journal of Cancer Prevention* 2010, **11**(5):1167-1173.

II. Taha H, Al-Qutob R, Nyström L, Wahlström R, Berggren V: "Voices of fear and safety" women's ambivalence towards breast cancer and breast health: a qualitative study from Jordan. *BMC Women's Health* 2012, **12**:21.

III. Taha H, Al-Qutob R, Nyström L, Wahlström R, Berggren V: "Would a man smell a rose then throw it away?" Jordanian men's perspectives on women's breast cancer and breast health (Submitted)

IV. Taha H, Nyström L, Al-Qutob R, Berggren V, Wahlström R: Home visits to improve breast health practices in a less privileged area in Jordan. (Manuscript)

The four studies (I-IV) that were conducted within this doctoral research are reported in four respective articles that will be referred to within this thesis by their roman numerals (I- IV).

CONTENTS

Abstract vi
List of publications vii
List of abbreviations 2
Preface 3
1 Background 4
1.1 Global burden of cancer 4
1.2 Global burden of breast cancer 5
1.3 Cancer in the East Mediterranean region 6
1.4 Breast cancer in Arab countries 7
1.5 Jordan 7
1.6 Jordan's health system 8
1.7 Breast cancer in Jordan 9
1.8 Jordan's breast health guidelines 11
2 Points of departure 12
2.1 Conceptual frameworks 12
3 Aims and objectives 15
3.1 Overall aim 15
3.2 Specific objectives 15
4 Methods 16
4.1 Study setting 16
4.2 Participants, data collection and analysis 19
4.2.1 Article I 19
4.2.2 Article II 19
4.2.3 Article III 20
4.2.4 Article IV 21
4.3 Ethical considerations 24
5 Findings 26
5.1 Breast health knowledge 26
5.2 Breast health practices 27
5.3 Perceptions on breast cancer and breast health 29
5.3.1 Women's perceptions 29
5.3.2 Men's perceptions 35
6 Discussion 42
6.1 Breast health knowledge and practices 42
6.2 Perceptions on breast cancer and breast health 44
6.3 Strengths and limitations 49
7 Conclusions 51
8 Policy and research implications 52
9 Acknowledgements 53
10 References 56
11 Appendices 68

LIST OF ABBREVIATIONS

ANERA	American Near East Refugees Aid
ASIR	Age standardized incidence rate
BHGI	Breast Health Global Initiative
BSE	Breast-self-examination
CBE	Clinical breast examination
EMRO	East Mediterranean Region
FGD	Focus group discussion
HIC	High-income countries
HS	Jordan's health system
HRH	Her Royal Highness
IHCAR	Global health
JBCP	Jordan Breast Cancer Program
JNCR	Jordan National Cancer Registry
JWU	Jordanian Women Union
KI	Karolinska Institutet
KHCC	King Hussein Cancer Center
KHCF	King Hussein Cancer Foundation
LCOW	Local community outreach workers
LMIC	Low- and middle-income countries
MoH	Jordan Ministry of Health
NGOs	Non-governmental organizations
PHC	Primary health care
PHS	Department of Public Health Sciences
RMS	Royal Medical Services
SSII	Semi-structured individual interview
UJ	University of Jordan
UNRWA	United Nations Relief and Works Agency for Palestine Refugees in the Near East
WHO	World Health Organization

PREFACE

I am a certified pharmacist with two master degrees; in global health from Karolinska Institutet (KI) and in health services management from the University of Jordan (UJ). I gained my experience through working in marketing management with multinational pharmaceutical companies and as a public health consultant for the Middle East region. During my tenure as the management task manager in Jordan's health systems strengthening project, I was involved in setting Jordan's ministry of health (MoH) 2008-2012 strategic plan; assessing the local health priorities; developing operational plans with measurable key performance indicators; and establishing supportive supervision systems.

After that I was fortunate to have a career within the King Hussein Cancer Foundation (KHCF), as the head of monitoring and evaluation department in the Jordan Breast Cancer Program (JBCP). KHCF is a non-profit organization that is dedicated to decrease mortality and alleviate suffering from cancer in Jordan and the Middle East region. KHCF is the umbrella responsible for the King Hussein Cancer Center (KHCC), the medical arm of KHCF, and for the JBCP. The JBCP is a national initiative led by the KHCF to improve public awareness about breast cancer and the benefits of early detection and to ensure the provision of quality screening services in Jordan.

Similar to all the KHCF and JBCP team members, I was inspired by Her Royal Highness (HRH) Princess Dina Mired, the Director General of KHCF and the Honorary Chairperson of the National Steering Committee for JBCP. I got absorbed in our mission to reduce morbidity and mortality from breast cancer in Jordan and to shift the current state of diagnosis from its late stages (III – IV) to its earliest stages (0-II). We sought a better understanding of the barriers of breast cancer screening in Jordan to design context sensitive interventions that could down stage the illness at the onset of diagnosis. That was the beginning of this doctoral research which received the support from HRH and from the JBCP's chairman, director and staff. I would like to acknowledge the Swedish Research Council and the Swedish International Development Cooperation Agency for awarding this collaborative research the Middle East and North Africa links grant. I am also grateful for all the organizations that contributed to this research: KHCF, JBCP, JU, American Near East Refugees Aid (ANERA), Jordanian Women Union (JWU), Jordan MoH and the Global health (IHCAR) at the Department of Public Health Sciences (PHS) in KI.

In this doctoral research we used a combination of formative and applied intervention evaluation studies. Both quantitative and qualitative research methods were used to explore the existing barriers to screening and early detection of breast cancer in Jordan. We pursued a better understanding of the problem including gender influences through exploring the perceptions of women as well as men. Based on the research findings that were shared with the JBCP and KHCF, potential solutions were identified, initiated and evaluated. I believe that this research contributed to strengthening the research capacity of the JBCP and provided evidence based data that was used by the JBCP to carefully design breast health interventions that addressed the barriers and encouraged Jordanian women to seek early detection for breast cancer. I hope that the findings of this research will contribute to shifting the late stages of diagnosis of breast cancer in Jordan to early stages, when breast cancer is most curable and survival rates are high.

1 BACKGROUND

1.1 GLOBAL BURDEN OF CANCER

It is estimated that one in every eight deaths worldwide is due to cancer; it causes more deaths than the overall mortality due to AIDS, tuberculosis, and malaria [1]. Cancer is the leading cause of death in high-income countries (HIC) and the second leading cause of death in low-and middle-income countries (LMIC) [1]. In 2008, there were approximately 12.7 million new cancer cases and 7.6 million cancer deaths worldwide [1, 2]. Approximately 56% of the cases and 64% of the deaths occurred in LMIC [1, 3]. Lung, women breast, colorectal and stomach cancers accounted for almost 40% of all the cancer cases (Figure 1) while lung, stomach, liver, colorectal and women breast cancers accounted for almost half of all cancer deaths (Figure 2) [2]. It is anticipated that by 2030, the global burden of cancer is expected to grow to 21.4 million new cancer cases and 13.2 million cancer deaths [1, 2].

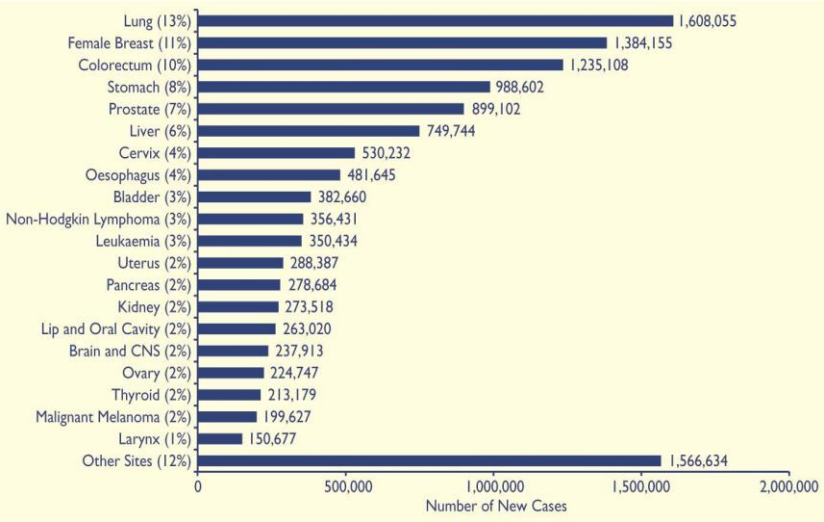


Figure 1: The 20 most commonly diagnosed cancers worldwide
Source: Globocan 2008 estimates [4]

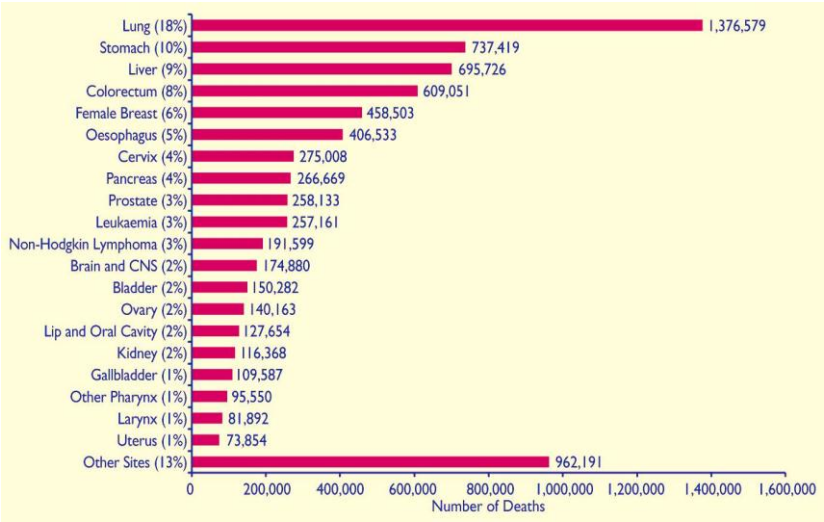


Figure 2: The 20 most common causes of death from cancer worldwide
Source: Globocan 2008 estimates [4]

Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells that could lead to death if the spread is not controlled [1, 5]. The risk factors can be external like tobacco, chemicals, radiation, and infectious organisms and internal like inherited mutations, hormones, immune system disturbances and metabolism generated mutations. Ageing is another substantial risk factor for developing cancer [1, 5]. These factors may act together or in sequence to initiate or promote carcinogenesis. The process of development of most cancers requires various steps that extend over many years. There are certain cancers that can be prevented by eliminating exposure to the modifiable triggering or accelerating risk factors and other malignancies that can be detected early when the disease is most responsive to treatment. Cancer is treated by surgery, radiation, chemotherapy, hormones, and immunotherapy [1].

1.2 GLOBAL BURDEN OF BREAST CANCER

Breast cancer is the most common cancer and the leading cause of cancer mortality among women worldwide. Globally breast cancer constitutes 23% (1.4 million) of all women cancers and 14% (458,400) of the cancer deaths [3, 6]. Nearly 50% of the breast cancer cases and 60% of the deaths occur in LMIC (Figure 3). Despite the lower risk of breast cancer in LMIC there is an increased burden of breast cancer deaths due to: late detection; high case fatality; weak health systems; and inadequate treatment [3, 5, 7].

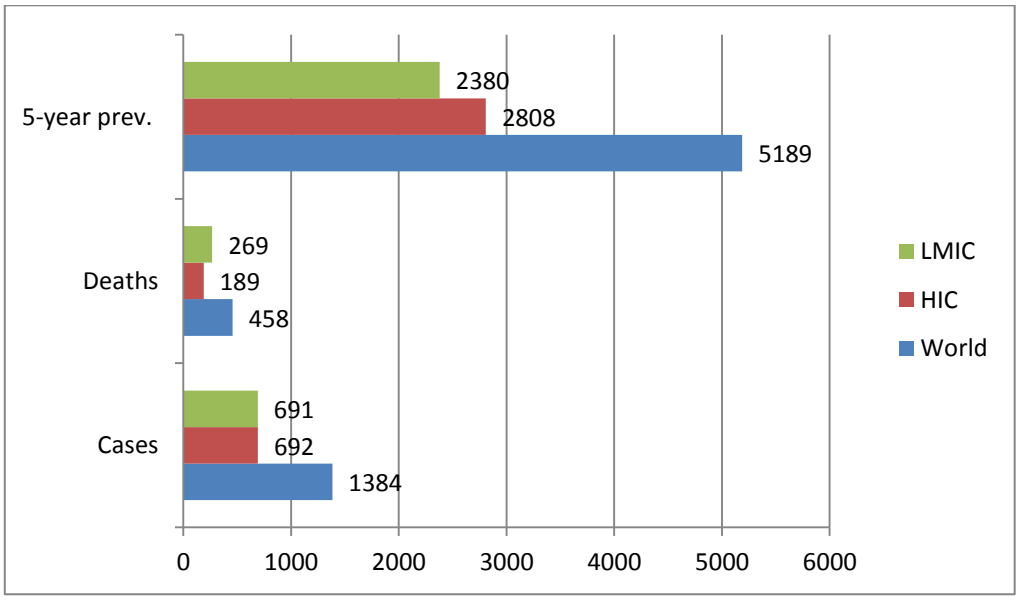


Figure 3: Estimated numbers (thousands) of breast cancer incidence, mortality and prevalence worldwide in 2008.
Source: Globocan 2008 estimates [1, 4]

It is estimated that 1.7 million women will be diagnosed with breast cancer in year 2020 with a 26% increase from current statistics, and the majority of these cases will be in LMIC [8]. Early detection of breast cancer is essential for LMIC, because breast cancer at early stages has a better prognosis with more cost-effective treatment [9]. The 5-year survival rate reaches 93% and 88 % when breast cancer is detected in its earliest stages 0 and I respectively, compared to 15% in stage IV [10].

1.3 CANCER IN THE EAST MEDITERRANEAN REGION

In 2008, it was estimated that there were 429,000 new cancer cases (Figure 4) and 314, 000 cancer deaths (Figure 5) in the East Mediterranean region (EMRO). The EMRO includes: Afghanistan, Bahrain, Djibouti, Egypt, Iran, Iraq, Jordan, Kuwait, Lebanon, Libya, Morocco, Oman, Pakistan, Qatar, Saudi Arabia, Somalia, Sudan, South Sudan, Syria, Tunisia, United Arab Emirates, Yemen, Palestinian authority and Gaza strip [2, 11]. The most frequent cancers in the EMRO region are breast cancer in females, and lung and bladder cancers in males [2]. It is expected that the EMRO region will have the largest increase (100% to 180%) in cancer incidence among the World Health Organization (WHO) regions in the next 15 years [11-13].

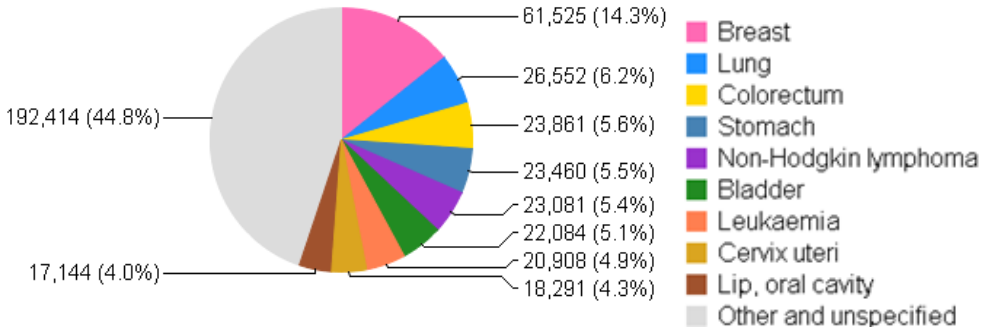


Figure 4: Incidence of cancer in EMRO region

Source: GLOBOCAN 2008 [4, 5]

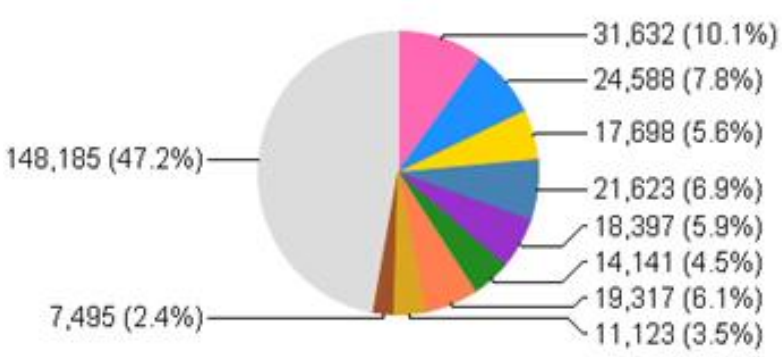


Figure 5: Mortality of cancer in EMRO region

Source: GLOBOCAN 2008 [4, 5]

The resources for cancer control in the EMRO region are inadequate and in most of the countries, cancer is presented at relatively late stages, which render the treatment to be ineffective and lead to poor prognosis [11]. The WHO EMRO regional strategy for cancer prevention and control aims to establish and strengthen comprehensive national cancer control plans, policies, legislations and regulations to prevent the cancers that could be prevented by eliminating or reducing modifiable risk factors, curing the cancers that have good prognosis through early detection and effective diagnosis and treatment, relieving the pain and improving the quality of life for cancer patients through effective palliative care strategies, strengthening the health care systems and the monitoring and evaluation of interventions [11].

1.4 BREAST CANCER IN ARAB COUNTRIES

Breast cancer is the leading cause of cancer deaths in Arab countries [14-16]. Advanced stages of breast cancer is very common and mastectomy is performed in more than 80% of the cases [16]. In Jordan, Egypt, Lebanon, Oman and Tunisia, the median age of women presented with breast cancer is less than 50 years, while in USA it is most commonly diagnosed in women aged 50 years and older [14]. There is still a gap of knowledge about the possible reasons for the delayed presentation of breast cancer in the Middle East. A systematic review by Alhurishi et al (2011) found six studies on the explanatory factors for the delayed presentation of breast cancer in the ME and all of them employed quantitative methods. Older age and lower educational level were found to have strong effects in explaining late presentation, while having no family history of breast cancer was found to have moderate effect [17].

There is a need for better understanding of the motivators and the barriers of women's breast health seeking behaviour to optimize breast cancer screening [18, 19]. Breast health awareness campaigns in the Arab world should address possible barriers like poor access to breast health care, fear, shyness, lack of breast health knowledge [16]. Arabic countries should aim at down staging breast malignancies at presentation and adapting international guidelines to local circumstances [16, 20]. Studies from Egypt showed that failure to practice breast-self-examination (BSE) was associated with diagnostic delay of breast cancer [21], while screening using clinical breast examination (CBE) was associated with earlier diagnosis of breast cancer and breast conserving surgery [16]. Mammography screening in Arabic countries which have the necessary resources should promote mammography screening starting from the age of 40 years because of the younger age of presentation of breast cancer in these countries [16].

1.5 JORDAN

The Hashemite Kingdom of Jordan is located in the EMRO region; sandwiched between Saudi Arabia in the south and east, Syria and Iraq in the north (Figure 6).

Figure 6: Jordan map.
Source: http://schema root.org

Table1: 2011 Selected indicators [22]	
Total fertility rate per woman	3.8
Crude birth rate Per 1000	28
Crude death rate Per 1000	7.0
Natural growth %	2.1
Dependency %	68
Life Expectancy (years)	
Male	72
Female	74
Age at marriage	
Male	30
Female	26
Age (years)	
Less than 15	37%
15- 64	60%
More or equal 65	3.2%

The country has a constitutional monarchy governance system and occupies an area of 89,213 square kilometres [22]. It is an upper-middle-income country with a population of 6.25 million (49% females) [22, 23]. In 2011, the annual per capita share from the gross domestic product was 4627 USD [22]. The kingdom has a free of charge mandatory educational system for the first 10 years [22, 24]. Jordan is classified among the better Arab states in the basic indicators including life expectancy, adult literacy, school enrolment and female literacy [25]. Table1 lists 2011 selected demographic indicators [22]. The girls' primary school enrolment ratio is approximately 96% of that of boys [22]. The illiteracy rate among women aged 15 years and above is 10% in comparison to 3.6% among men. It is a paradox that despite the high literacy rate of Jordanian women, there is a clear difference in the percentage of working women compared to men; in 2011 women constituted 18% of the work force [22, 24]. The main strength of Jordan's economy is in the educational system and the main challenges are unemployment, persistent poverty pockets and scarcity of natural resources specially water [25]. Jordan is one of the world's ten most water scarce countries with an average of 156 litres/citizen/day [25].

1.6 JORDAN'S HEALTH SYSTEM

Jordan's health system (HS) is governed by the MoH and its 12 directorates in each governorate. MoH is responsible for protecting health, delivering, organizing and supervising health services, providing public sector health insurance, certification, education and training of health professionals and health institutions [25]. In 2011, the total annual expenditure on health per capita was 505 USD [26]. Primary health care (PHC) services in Jordan are well accessible and highly subsidized by the MoH. There is a wide coverage nationwide with a density of 2.3 PHC centres per 10,000 capita and accessibility level of approximately 97% [25].

Health care services in Jordan are provided by the public and private sectors [25]. The private sector provides services to out of pocket patients, to employees who have private health insurance, and to the MOH insurers through contracting agreements [25].The public sector includes: MoH, Royal Medical Services (RMS), University hospitals and the United Nations Relief Works Agency (UNRWA). The UNRWA runs 24 primary health care centres, serving nearly two million registered Palestinian refugees in Jordan [27]. Although most of the Palestinian refugees in Jordan have been granted citizenship and have similar access to healthcare as other Jordanian citizens, still, an estimated 140,000 from the refugees who emigrated to Jordan in 1967 have restrictions on their access to healthcare because they don't have Jordanian citizenship which make them most vulnerable [27]. The UNRWA health centres deal with over 2.3 million visits each year and face difficulties addressing unmet needs including early detection of cancers [27].

Jordan had great achievements in health status including: universal child immunization since1988, polio free since 1995 [25]. In 2009 the infant mortality rate was 23/1000 and the under-five mortality rate 28/1000 [22]. The HS faces several challenges including demographic transition, increased life expectancy and life style changes that have led to an increase in non-communicable and chronic diseases. Cardiovascular diseases are the most common cause of death followed by cancer. There is also inequitable accessibility to health services due to poverty, increased need for health services and more burdens on MoH due to refugees and asylum seekers in Jordan from Iraq, Syria and other countries in the region due to the Arabic

spring. The country's population has doubled over the last 20 years, and estimated to double again by 2035 [25]. Consequently, the anticipated demographic transition and the increase of non-communicable diseases will lead to further challenges to the HS.

1.7 BREAST CANCER IN JORDAN

Breast cancer is the most frequently diagnosed cancer (Figure 7) in Jordan [28]. In 2009, it accounted for 37% of female cancer cases (Figure 8) and 23% of the deaths [28]. Breast cancer is the most common cancer afflicting women in Jordan, comprising nearly 20% of all new cancer cases and approximately 37% of all female cancers. The age standardized incidence rate (ASIR) of female breast cancer increased from 29 per 100,000 female in 1996 to 54 per 100,000 in 2009 [28].

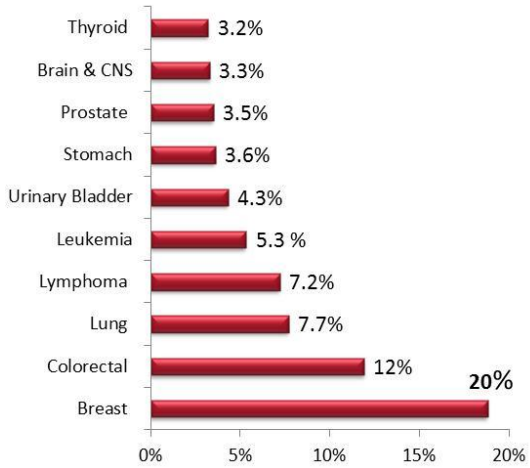


Figure 7: Ten most common cancers among Jordanians both genders, 2009

Source: Jordan national cancer registry (JNCR) 2009

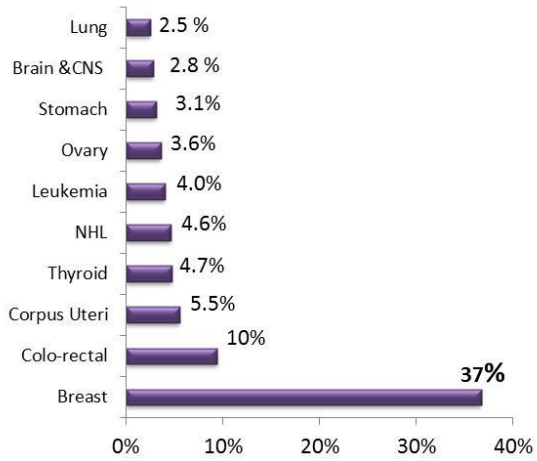


Figure 8: Ten most common cancers among Jordanian females, 2009

Source: JNCR 2009

Almost 70% of the breast cancer cases in Jordan are diagnosed in women aged less than 60 years (Figure 9). The 2005 and 2006 statistics from the KHCC (Figure 10), which administers more than two-thirds of the Kingdom's cancer cases indicated that approximately 70% of the breast cancer cases were diagnosed at stages III and IV of the disease [29, 30]. During the period from 1997 to 2002 the five-year survival rate of breast cancer in Jordan was 83% for stage I, 72% for stage II, 59% for stage III, and 35% for stage IV cancers [31].

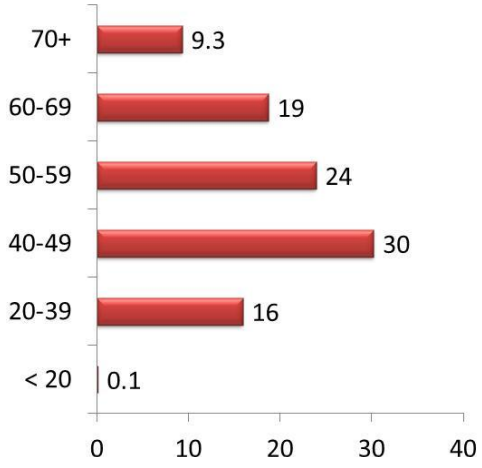


Figure 9: % of female breast cancer cases by age group during 1996-2009

Source: JNCR 2009

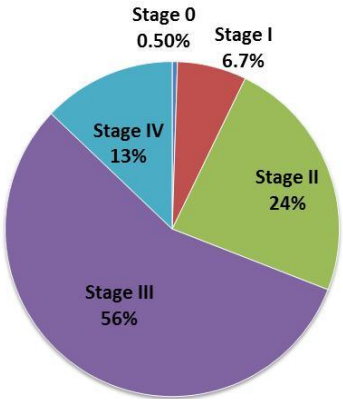


Figure 10: Stages of breast cancer cases based on KHCC's experience 2005-2006

Source: JBCP newsletter issue 1, October 2008 [http://www.jbcp.jo/files/newsletter.pdf]

Based on these statistics it was suggested that creating breast health awareness to women aged 20 years and above in addition to conducting targeted mammography screening for women aged 40 years or more might lead to earlier detection of breast cancer and thus to higher survival rates [31]. The Jordan Breast Cancer Program (JBCP) was established as a national initiative led by the King Hussein Cancer Foundation (KHCF) to drive the transformation of Jordanian women's breast health practices through increasing public awareness about the importance of breast cancer early detection in saving women's lives (Figure 11) [29, 30].

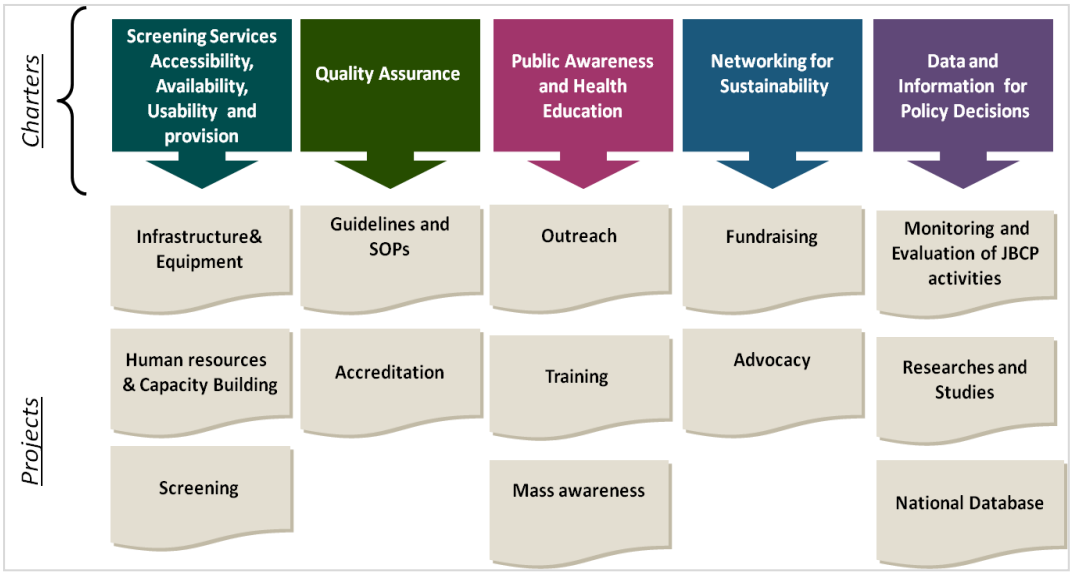


Figure 11: JBCP charters and projects
Source: JBCP 2013 action plan *(unpublished)*

The JBCP embarked on synthesizing its own model which addressed the issue of breast cancer from the bottom-up; starting at the grassroots level and working its way through awareness and advocacy, riding the existing non-governmental organizations (NGOs) outreach networks, capacity building of health professionals, setting up infrastructure and upgrading of mammography screening facilities, development of national early detection guidelines, and quality assurance of breast health services. At the same time, JBCP mobilized the national synergy through partnering with the MoH and with all the major stakeholders in the health sector including engaging international donors to build screening services and raise awareness while institutionalizing policy [32]. This has helped to bring about a significant reduction in late-stage diagnosis of breast cancer in Jordan. In 2009, 3 % of the cases diagnosed were in stage 0 (in situ), 26% in stage I, 30% in stage II, 23% in stage III and 10% in stage IV [28].

JBCP mobile mammography unit
Source: JBCP

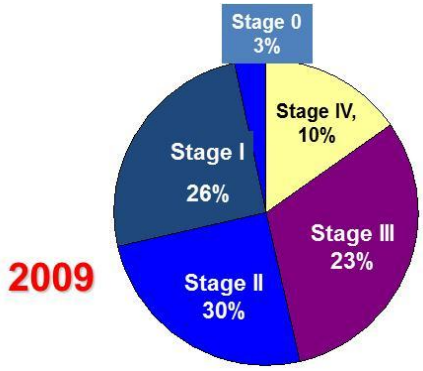


Figure 12: Staging of breast cancer in Jordan
Source: JNCR 2009

1.8 JORDAN'S BREAST HEALTH GUIDELINES

Although the benefits of BSE had not been confirmed indisputably in the literature [33, 34] several studies have indicated that women who regularly practice BSE initially present with smaller tumours that less frequently involve the axillary lymph nodes [35-37]. Hence, the Jordan National breast health guidelines promote breast health awareness to all Jordanian women including a recommendation that women should start practicing monthly BSE from the age of 20 years [38]. This is consistent with the recommendations of the Breast Health Global Initiative (BHGI) for countries with limited resources [39, 40].

A literature review by Miller and Baines [41] suggested that in countries where breast cancer is presented at advanced stages, screening by CBE combined with teaching of BSE will probably be effective in reducing breast cancer mortality. The first randomized controlled trial of combined mammography screening and CBE showed 25% lower breast cancer mortality [42]. In Jordan, CBE is recommended once every 1-3 years in the age group 20-39 years and annually in women aged 40 years or more [38]. CBE services are available at the public comprehensive PHC centres (PCPHCC) and at maternal and child health centres.

Invitations to mammography screening were found to be associated with 20-30% reduction in breast cancer mortality [43]. A review of the evidence of the impact of long-standing breast cancer mammography screening programmes in ten countries showed 16% to 36% breast cancer mortality reduction in women invited to screening and 24% to 48% mortality decrease in women who attended at least one screening [44]. Several trials and meta-analyses showed statistically significant mortality reductions for women aged 40 to 69 associated with an invitation to mammography screening [45-51]. Jordan's national breast health guidelines recommend mammography screening once every 1-2 years starting from age 40 years and above [38].

Based on the records of the JBCP operations department, there are 67 functional mammography screening units in Jordan that are inequitably distributed with higher coverage in urban areas; 28 of them are within the MoH, 31 are in the private sector, two in the RMS, two in KHCC and four in UH. Breast cancer early detection services are provided for free within the MoH civil health insurance system. Recently the JBCP in collaboration with KHCC placed and operated new mobile mammography unit in an underserved area in the North of Jordan.

Table 2: Jordan national breast health guidelines [38]

Screening/ Age	20-29	30-39	40-52	52+
BSE	Monthly	Monthly	Monthly	Monthly
CBE	Once every 1-3 years	Once every 1-3 years	Annually	Annually
Mammography screening	----------	----------	Once every 1-2 years	Once every 2 years

2 POINTS OF DEPARTURE

Common predictors of breast cancer screening behaviours include perceived risk, knowledge, and general health motivation [52]. Educational interventions can be designed to enhance breast cancer early detection behaviours [52] by simple and cost-effective ways [53]. However, health beliefs are culture sensitive and context related [54]. A thorough understanding of Arabic women's health beliefs is necessary for designing interventions to change their breast health seeking behaviour [55, 56].

Given the level of knowledge about the benefits of early detection and timely treatment of breast cancer, it was not clear, at the onset of this research, to what extent or why women do not access breast health services in Jordan. Breast cancer is a gender sensitive illness with emotional gravity since it affects a body organ that is symbolic of femininity and motherhood. We did not find any studies about the influence of gender power relations on women's breast health seeking behaviour in Jordan or in the ME. Petro-Nustas and Al-Qutob (2002) studied birth spacing in Jordan and found that despite discussing the subject with the wife, the final decision regarding using contraceptives was taken by the husband [57]. Since Middle Eastern societies are traditionally conservative, we assumed that Jordanian women health practices might be controlled by male family members [58] who might be unaware of or disfavour breast cancer screening. Thus, in this doctoral research we employed qualitative methods to explore the perceptions of women as well as men on breast cancer and breast health including gender influences. We also designed two community outreach interventions and used quantitative methods to evaluate their effectiveness in bringing about improvement in women's breast health knowledge and practices.

2.1 CONCEPTUAL FRAMEWORKS

The quantitative deductive approach is ideal for measuring the prevalence of known phenomena and patterns of association, while qualitative inductive approach allows for explanation of previously unknown processes including the why, the how and the range of their effects [59, 60]. Because of the fragmented former knowledge about breast cancer in Jordan, we used in this thesis a quantitative deductive approach in articles I and IV and a qualitative inductive approach in articles II and III. The multiple data sources and the mixed-methods enabled us to have a better understanding of the sociocultural context and enhanced the quality of our interpretation of the overall research findings [59]. Various methods were applied to answer similar research questions that enhanced, explained and guided each other [59]. This made it possible for us to detect consistencies and contradictions during the research process and to adjust and expand the breadth of our inquiry [59]. The findings of this doctoral thesis will be related in the discussion section to the following conceptual frameworks:

Social Cognitive Theory: Explains how people initiate and maintain certain behaviours through a triadic and dynamic model in which behaviour, personal factors, and environmental influences all interact. Social norms influence both cognition and behaviour [61]. An individual's behaviour is uniquely determined by these interactions. Based on this women with high levels of self-efficacy who strongly believe that positive outcomes will result from their breast health care seeking behaviour will most likely comply with periodic breast health care examinations [62].

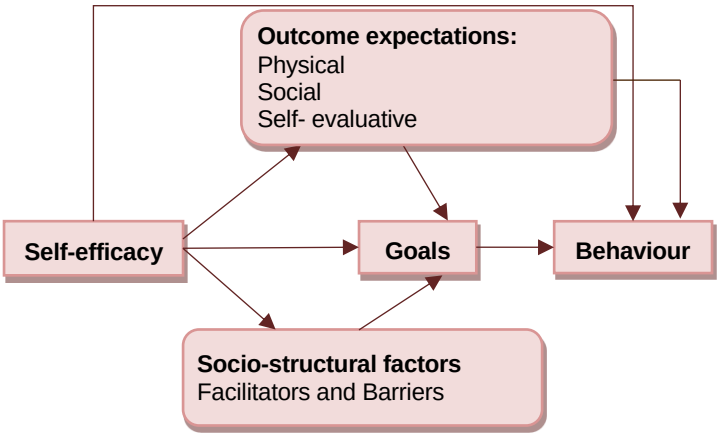


Figure 13: Social Cognitive Theory
Adapted from Bandura (2004), *Health Education & Behaviour, 31,* 143-164.

Revised Health Belief Model: Perceived seriousness of and susceptibility to breast cancer influence perceived threat [63]. Similarly, perceived benefits from early detection of breast cancer and perceived barriers to screening influence breast health-seeking behaviour. Demographic and socio-psychological variables influence perceived susceptibility, perceived seriousness, perceived benefits and perceived barriers to action. In addition, general health motivation, self-efficacy and confidence in the ability to successfully perform the behaviour enhance breast health practices.

Table 3: Revised Health Belief Model

Concept	Definition
1. Perceived susceptibility	One's belief of the chances of getting a condition
2. Perceived severity	One's belief of how serious a condition and its consequences are
3. Perceived benefits	One's belief in the efficacy of the advised action to reduce risk or seriousness of impact
4. Perceived barriers	One's belief in the tangible and psychological costs of the advised behaviour
5. Cues to action	Strategies to activate "readiness"
6. Self-efficacy	Confidence in one's ability to take action

Adapted from: Glanz, K., Marcus Lewis, F. & Rimer, B.K. (1997). *Theory at a Glance: A Guide for Health Promotion Practice.* National Institute of Health.

Theory of Social Support: Perceived support from the women's social network, such as health providers, family, friends and co-workers influence her health practices including that of BSE [64]. Social support can be classified into formal or informal support [65]. Formal support is offered by health providers through giving information, guidance and advice. Informal support can be affective, appraisal, and instrumental and is considered the more effective type of support. Affective support involves mutual trust and genuine concern. Appraisal support confirms the self-value and is often provided by co-workers or through social influence. Instrumental support includes symbolic or material and tangible aid usually provided by family [65].

Social Identity Theory: In 1979 Henri Tajfel and John Turner [66] suggested that there are three cognitive processes related to the individual's perceiving to be part of an in-group, or of an out-group: Social categorisation, the process of deciding which group the person belongs to; Social identification, the processes by which the person identify to be with an in-group more openly; Social comparison, the own self-concept or the social concept of the person becomes closely enmeshed in with perceptions of group membership. Such group membership can be associated with the prejudice and discrimination related to the perceived affiliation with the group [67].

3 AIMS AND OBJECTIVES

3.1 OVERALL AIM

To explore women's and men's perceptions about breast cancer and breast health in Jordan and to assess the effectiveness of breast health promotion interventions in improving women's breast health knowledge and practices.

3.2 SPECIFIC OBJECTIVES

1. To assess the effectiveness of a public educational campaign conducted to improve breast health knowledge among women in Jordan and to relate their knowledge to their breast health practices (Article I);

2. To explore Jordanian women's views and perceptions about breast cancer and breast health (Article II);

3. To explore Jordanian men's individual and contextual perspectives on women's breast cancer and their own role in the breast health of the females within their families (Article III);

4. To assess the effect of a home visits community outreach educational intervention that included offering free mammography screening vouchers on changing women's breast health knowledge and practices in a less privileged area in Jordan and to explore the barriers that hinder these women from practicing breast cancer early detection examinations (Article IV).

4 METHODS

This thesis comprises four separate studies that resulted in four respective articles. Each study was designed to answer a set of research questions. Figure 14 shows an overview of the study design.

Article I: A quantitative study that used pre and post self-administered structured questionnaires to evaluate the effect of 105 public breast health educational lectures conducted in five governorates in Jordan on changing women's breast health knowledge and relate their knowledge to their baseline breast health practices.

Article II: A qualitative study that purposively recruited 64 Jordanian women aged 20 to 65 years with no previous history and no symptoms of breast cancer from four governorates in Jordan to participate in ten focus group discussions (FGDs). We used this method to explore women's views and perceptions about breast cancer and breast health.

Article III: A qualitative study that purposively recruited 28 Jordanian men aged between 20-65 years who did not have any females within their direct family who had a previous diagnosis of breast cancer. We used semi-structured individual interviews (SSIIs) to explore the men's individual and contextual perspectives on women's breast cancer and their own role in the breast health practices of the females within their families.

Article IV: A quantitative study in which we used a before and after study design to evaluate the effect of an educational home visits intervention in a less privileged area in Jordan that included offering free mammography vouchers. The evaluation included: assessment of women's breast health knowledge and breast cancer screening practices at baseline before a home-based educational session and a post-test of women's retained knowledge and their screening practices during the six months after the first visit.

4.1 STUDY SETTING

Jordan has three administrative regions representing the north, middle and south, with a total of 12 governorates [22]. Eight out of ten inhabitants (83%) live in cities and the rest in rural areas and desert [22, 23]. The population is unequally distributed; the north region hosts 28% of the population, the middle 63% and the south 9%. We collected the data of this research from six governorates: Amman, Irbid, Zarqa , Balqa, Jarash and Karak. These governorates constitute 85% of the population [68] and express the socio-cultural texture of the Jordanian society.

Amman is located in the middle region and has a total population of 2.4 million [68]. There are clear socio-economic disparities between Amman's western and eastern parts. West Amman is the affluent side of the city, while east Amman is

the less privileged side. People in the respective parts of the city have different lifestyles, experiences, beliefs, and perceptions [69, 70]. Zarqa is in the middle region, located 25 km south west of Amman, has a population of 931,000 and hosts over 50% of Jordan's factories [71]. Balqa has a population of 419 000 and is also situated in the middle region close to Amman. Irbid and Jarash are located in the north region with a population of 1.1 million and 183,000 respectively. Karak is located in the south region with a population of 243 000 [68].

Jordan hosts approximately two million registered Palestinian refugees, 346,000 of them live in ten official camps [27, 72, 73]. In article IV the intervention was implemented in the second largest Palestinian refugees' camp in Jordan [74]. The camp was set up in 1955 on an area of 488,000 square meters south east of Amman. The refugees were initially accommodated in 1,400 shelters, but over the years the camp has grown into an urban neighbourhood surrounded by areas of high population density. Currently, there are more than 51,500 registered refugees living in the camp. The UNRWA operates 13 schools, one community-based rehabilitation centre, one women's program centre and one health centre in the camp. The health centre delivers PHC services including CBE. However, UNRWA does not offer or provide mammography screening services to beneficiaries. The circumstances in which UNRWA operates are becoming more challenging with the increased burden of non-communicable diseases among the Palestinian refugees due to aging. Other socio-demographic determinants that could negatively influence the health status of these refugees include crowdedness, early marriage and divorce, poverty, unemployment, lack of social security and lack of secondary and tertiary health care insurance [74].

The specific sites of articles I- IV are described below:

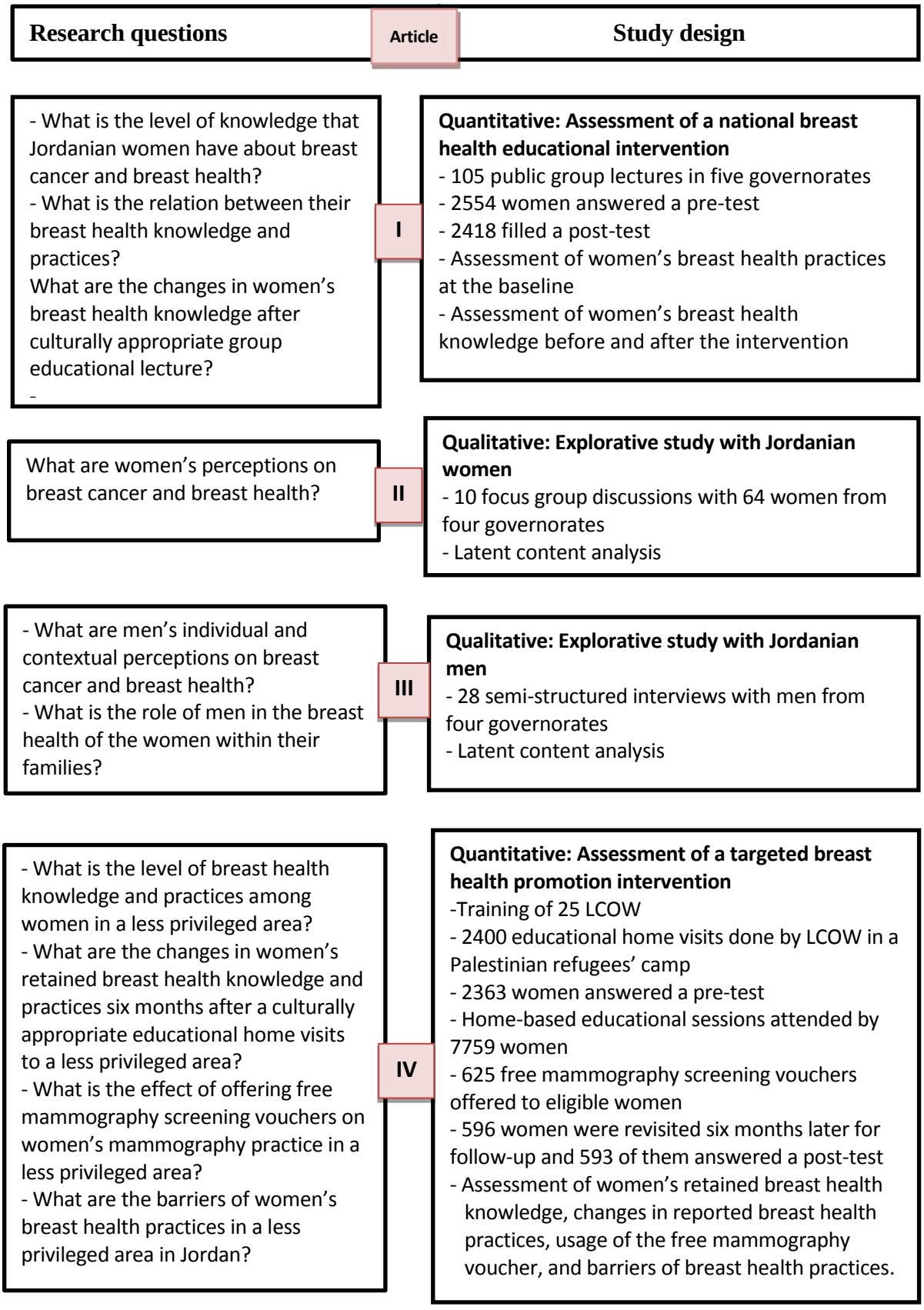
Article I: The women responded voluntarily to the advertisement about the public breast health awareness lectures that was issued by local community PHC centres, women NGOs and municipalities. The lectures were conducted in the facilities of these organizations in Amman, Irbid, Zarqa , Balqa and Jarash.

Articles II: Women participated in FGDs in four governorates: Amman, Balqa, Irbid and Karak. They were recruited through women's NGOs and from the clients of PHC centres. The FGDs were conducted in a quiet room with a round table setup in these venues.

Article III: Men who participated in the study were recruited from the clients of three urban and two public comprehensive PHC centres in four governorates: Amman, Balqa, Irbid and Karak. These centres provide CBE screening services, general health care services, family health, maternal and child health care, gynaecology, paediatric, internal medicine, dermatology, ophthalmology, general surgery and dentistry.

Article IV: Trained local community outreach workers (LCOW) conducted home visits in a Palestinian refugees' camp in east Amman. The visit included a home-based educational session, offering of free mammography voucher, and data collection of the pre- and the post-tests. All was performed in the women's homes.

Figure 14: Overview of study design



4.2 PARTICIPANTS, DATA COLLECTION AND ANALYSIS

4.2.1 Article I

4.2.1.1 Educational intervention

Between the 1st and 31st of October 2008 the JBCP conducted 105 educational lectures with a median of 24 (Range: 9-38) female participants per lecture: 46 lectures in Amman, 28 in Irbid, 20 in Balqa, 8 in Zarqa and 3 in Jarash. Directly after answering a pre-test, 2554 participants attended an educational lecture on breast cancer and breast health. All the lecturers were women nurses, midwives or PHC physicians trained and certified by the JBCP as community breast health trainers. The lectures comprised two 45 minutes sessions and were presented in an informal way following adult learning methodologies. Directly after the lecture 2418 (95%) of the participants filled a post-test that included the same breast health knowledge questions as in the pre-test.

4.2.1.2 Measuring instrument

The pre- and post-test questionnaire was developed by the JBCP communication team and was reviewed by the oncologists at KHCC. The questionnaires were validated and adjusted by JBCP based on two pilot lectures in Amman and Balqa with 20 participants each. The pre-test questionnaire included three sections: socio-demographic characteristics; breast health practices and participation in any previous lecture about breast cancer; and 15 knowledge statements to be answered true or false. The pre and post questionnaires are shown in Appendix 1.

4.2.1.3 Data analysis

SPSS software was used for data analysis. The 15 breast health knowledge questions were coded as correct or incorrect and each correct answer was given the weight of one point. Number of correct answers were summarised and categorized into three levels: less or equal 8, 9-13, and 14-15. The associations between the participants' characteristics, their knowledge scores and their breast health practices were analysed using chi-square test. The difference between the proportion of correct answers in the pre- and post-test was analysed using Student's t-test. Multiple logistic regression analysis was performed to estimate the impact of covariates on the dependent variables ever practiced BSE, ever done a CBE and ever done a mammogram.

4.2.2 Article II

4.2.2.1 Study population

We purposively [75-77] recruited 64 women aged 20 to 65 years (median=38) with no previous history and no symptoms of breast cancer. We set that inclusion criterion based on the national guidelines of breast cancer early detection in Jordan. As well, we aimed to provide the JBCP with evidenced based data for their campaigns and interventions that promote breast health practices to healthy women to downstage breast cancer at the onset of detection in Jordan. The women participated in ten FGDs, with 5-8 participants in each FGD and displayed different

attributes with regard to site of residence, social group, age and educational level. Thirty-five of the women were from urban areas and 29 from rural areas; 39 of the women were married, 19 were single, three were divorced and three were widows; 36 women were 20 to 39 years old and 28 women were aged 40 to 65 years; 35 women were housewives, 23 were salaried employees, five were retired and one was a student; 40 women had a monthly income of less than 700 USD, 13 women had an income between 700 and 1400 USD, one woman had an income above 1400 USD, and ten women did not disclose their income; 12 women had primary education, 18 had finished high school, eight women had a precollege diploma, 23 had a bachelor's degree and three had completed postgraduate studies.

4.2.2.2 Data collection

We developed the FGD guide based on a review of the literature and used it to moderate two pilot FGDs with 20-65 years old Jordanian women. Based on these we revised the FGD guide to facilitate discussion and decided to split the participants by age (20-39 years and 40-65 years) to overcome the shyness of the younger participants. The FGD guide is shown in Appendix 2. I moderated all the FGDs in Arabic and each lasted about 50-60 minutes. The FGDs were audio-taped and a female Arabic speaking research assistant attended in order to observe and take notes. The tape recorded data from all the FGDs, including the pilot ones, were transcribed in Arabic and thereafter half of them were translated to English for analysis by the English speaking co-researchers. Based on the flow of the information while the research was on-going we stopped at ten FGDs when saturation and information redundancy occurred [78].

4.2.3 Article III

4.2.3.1 Study population

We recruited 28 Jordanian men aged 22 to 65 years (median= 40) purposively [79] from public comprehensive PHC centres. The primary inclusion criteria were: Jordanian man aged between 20-65 years, married and with no females within their direct family who had a previous diagnosis of breast cancer (wife, sister, mother, or daughter). I started by interviewing 24 married men who mostly responded about the wife's breast health. Therefore, I interviewed four more single men in the age group 22-29 years. I approached males in the waiting area of these centres who were either patients waiting to see the doctor or were escorting another family member. There is no appointment system for doctors' consultations at these centres; clients usually turn up and wait for their turn based on first come first served basis. Four of the men that met the inclusion criteria declined to be interviewed: one in Irbid, one in Karak and two in west Amman.

4.2.3.2 Data collection

I used SSIIs for the data collection to ensure privacy and to allow the opinions of the respondents to be freely spoken [75], as breast cancer is considered a sensitive subject in Jordan. The SSII guide was prepared with open-ended questions to encourage the interviewees to talk spontaneously about their individual and contextual perspectives on women's breast cancer and their role in

the breast health of the females within their families. The SSIIs were carried out during the period from January to March 2011. Two pilot SSIIs were conducted in January 2011: the interviewer in the first one was a Jordanian male researcher and I conducted the second one. The interviewees were from west Amman and Balqa respectively. Before these two SSIIs, both men indicated clearly that they preferred to be interviewed individually and declined to participate in any group discussion. They perceived that it would be inappropriate to share their perceptions about the breast health of the females within their families with other men. The second interviewee felt more comfortable and talked to me freely without any of the restrictions that the first interviewee displayed while talking to the male researcher. After these pilot SSIIs the guide was revised according to the findings and the research team decided that I should conduct all the SSIIs. The revised SSII guide is shown in Appendix 3.

Each SSII was carried out in a quiet room in the health centre and lasted from 20-40 minutes. I probed to get spontaneous responses from the interviewees and avoided influencing or judging their views [77]. All the SSIIs were conducted in Arabic and were face to face with each individual interviewee without being escorted by any of their family members. The SSIIs were audio-taped and an Arabic speaking female research assistant attended to observe and take notes. The tape-recorded data from all the SSIIs including the pilot ones were transcribed in Arabic and thereafter six of them were translated into English for analysis by the English-speaking co-researchers. Based on the accumulating information, I stopped when information redundancy occurred in each governorate [80, 81].

4.2.3.3 Data analysis of articles II and III

We used latent content analysis [82] to analyse the transcriptions of the FGDs in article II and the SSII in article III. In the initial step, I read through the transcripts several times while making notes in the transcripts. After that I condensed the Arabic text into meaning units followed by English coding and categorization. The coding and categorization of the data was validated by all the co-researchers. Thereafter we clustered the categories into themes. Triangulation of researchers was used to enhance the trustworthiness of the findings [83, 84].

4.2.4 Article IV

This home visits intervention incorporated: a culturally appropriate home-based breast health educational session; and referral of women aged 40 years or more who met the inclusion criteria to a free-of-charge mammography screening at a nearby mammography unit. The effect of the intervention was evaluated by collecting pre-test data to assess women's breast health knowledge and breast cancer screening practices at the baseline and a post-test of women's retained knowledge and screening practices at a follow up visit six months after the first visit.

4.2.4.1 Training of the outreach workers

In December 2010 the JWU trained 22 local community outreach workers (LCOWs) to conduct home visits to create awareness of breast cancer and breast health. The JWU had previous experience in conducting health awareness home visits in the targeted camp and had a network of trained LCOWs. The LCOWs were 25-35 years old, had at least high school education**,** and had previous experience of community outreach work in the camp. A JBCP certified trainer conducted a three-days training workshop for the LCOWs. The first day of the training included: information about breast cancer statistics; risk factors; signs and symptoms; and national guidelines for breast cancer early detection examinations, including practical training on BSE. In the second day, the LCOWs were trained on communication and community health promotion skills. They were also taught how to address myths and socio-cultural barriers to women's breast health practices. In the third day, the participants had practical sessions on how to use a specially designed culturally appropriate educational kit, and how to collect data using the study questionnaires.

Based on the trainer's evaluation of their practical skills, six LCOWs were selected to conduct the home visits and another six were selected for assistance in the field. The remaining trained LCOWs were standby for any needs during the implementation of the intervention. This training was also attended by two data entry specialists from JWU and three field supervisors from JBCP, ANERA and JWU. All the trained LCOWs were prepared to serve as grassroots leaders to enhance the sustainability of breast health awareness in the camp.

4.2.4.2 Conducting home visits

Between 1 January and 30 April 2011, 2400 breast health awareness home visits were conducted by the trained LCOW in the camp. The home visit eligibility criterion was: a home within the camp that had at least one female aged 20 years or more. The camp was divided into six areas based on a map of the streets, neighbourhoods, landmarks, mosques and schools. The home visits were conducted non-randomly in each of these six areas. The weekly home visits schedule of each of the six LCOW was set based on JWU previous outreach experience and was discussed and approved by the JBCP and ANERA field supervisors. To reach the targeted 2400 home visits, an additional 123 homes (5%) had to be visited, but could not be included for the following reasons: did not allow the LCOW to enter (n=76, 3%); the female head of the household was busy (n=33, 1.3%); or the house was closed (n=14, 0.6%).

At the beginning of each home visit the LCOW approached the female head of the household and collected baseline data about her socio-demographic characteristics and her breast health knowledge and practices through interview-administrated questionnaires. The pre-test data was collected for one woman per home visit. In total, 2363 women aged 20-79 years (median= 41) answered the pre-test (response rate =98%). In some visits the daughter or the daughter in law attended the session and was interviewed instead of the head of the household if she refused to participate. After that the LCOW used the educational kit to educate the women on

breast cancer and breast health. In total 7759 women attended these home-based educational sessions; the median number of attendees per home was 3 women.

4.2.4.3 Educational intervention

A specially designed culturally appropriate educational kit was developed by the JBCP health communication department to be used by the trained LCOW during their home visits. Each kit consisted of a flip cards presentation, visual aids, pre- and post-tests, referral vouchers to a free of charge mammography and a breast model for demonstration on how to perform BSE and how different sized lumps may feel like. Each home visit lasted 70-90 minutes; 25-30 minutes for the interview and 45-60 minutes for the educational session. The educational session covered the following topics: what is breast cancer, breast cancer statistics in Jordan, breast cancer risk factors, signs and symptoms, benefits of early detection, how breast cancer is diagnosed, BSE training, CBE and mammography, breast health national guidelines, breast cancer treatment options and patient support groups in Jordan.

4.2.4.4 Referral to free mammography screening

The LCOWs had 625 free mammography vouchers for an assigned mammography unit to offer to women who met the eligibility criteria: 40 years or older; never had a mammography before or not during the last year; had at least one breast cancer risk factor; had no health insurance; or had an annual family income of less than 5475 USD annually which was Jordan's National Average Absolute Family Poverty Line for food and non-food in year 2008 for the average family size of 5.7 members. The list of the risk factors that made the woman illegible for the free mammography voucher was adapted from the Susan G. Komen's breast cancer risk factors list and included: family history of breast, ovarian or prostate cancer (first degree relative); giving birth to the first child after the age of 35 years (or childless); having a personal history of breast cancer or undergoing breast biopsies in the past; late onset of menopause after the age of 55 years; starting menstruation before the age of 12 years; previous radiation therapy; having taken hormonal replacement therapy after menopause; having used contraceptives within the last ten years; did not breastfeed her children; obesity based on having a body mass index of 30 or higher; lack of exercise or physical activity; eating fatty food and smoking.

Eighteen of the eligible women (3%), who were offered the free voucher refused to take it. When that happened the voucher was offered at another home visit to another eligible woman. Each referred woman was given an appointment to go for mammography screening within one month of the date of the home visit. All the referred women had the flexibility to re-schedule their appointments within the one month time frame. The selected mammography unit was located nearby which made it accessible to the women. The unit meets local and international standards with regard to comfort, privacy and encouraging atmosphere. It was staffed with an experienced radiologist and technician who were both trained by JBCP. In addition, JBCP hired a consultant radiologist to implement double reading of the mammograms to ensure the quality of the screening.

4.2.4.5 Follow up visit

The LCOWs scheduled follow-up visits for the 600 women in the homes that were first visited in January 2011 to be conducted in July 2011 to assess women's retained knowledge and changes in breast health practices during the past six months. The LCOWs conducted 596 follow up visits and collected post-test data from 593 women aged 20-76 years (median= 42) (response rate=99%).

4.2.4.6 Measuring instruments

Pre- and post-test questionnaires were developed by the research team. The pre-test questionnaire included four sections: socio-demographic characteristics; breast cancer risk factors; ever had previous BSE, CBE and mammography screening; breast health knowledge based on 16 true or false statements; and participation in any previous lecture about breast cancer. The post-test questionnaire included three sections: breast health knowledge; BSE, CBE and mammography screening during the previous six months; and barriers to BSE, CBE and mammography screening.

The knowledge section was the same in the pre-test and in the post-test and included 16 knowledge statements to be answered by true or false. In the practices section, the woman was asked about mammography screening, if she had had a CBE and if she had practised BSE during the past six months after the first visit.
The questionnaires were validated and adjusted based on the educational intervention in Article I and a previous home visits project conducted in a similar underprivileged area in Amman. The pre- and post-tests questionnaires are shown in Appendix 4.

4.2.4.7 Data analysis

The answers to the 16 breast health knowledge questions were coded as correct or incorrect. Each correct answer was given the weight of one point and the maximum score was 16 points. Paired t-test was used to assess whether there was any improvement in women's breast health knowledge at six months' follow-up. The effects of the educational intervention on women's screening practices including BSE, CBE and mammography were determined using the chi-square test. The effect of receiving a free mammography voucher on the actual mammography practice was also assessed using chi-square and Fisher's exact test. The data analysis was carried out using SPSS 19. The level of statistical significance was set at $p \leq 0.05$.

4.3 ETHICAL CONSIDERATIONS

This research was conducted according to the ethical principles of the World Medical Association Declaration of Helsinki [85]. It was approved in February 2009 by the Jordan MoH Research Ethics Committee. The participants were informed of the purpose the study, the voluntary nature of their participation and their right to access findings. They had the full autonomy to change their minds and withdraw at any time, without giving a reason. All the participants were informed

about their right not to reveal any personal information. The data collected was kept confidential and anonymous.

Article I: Women responded voluntarily to the advertisement about the lectures within their local community. Those who agreed to participate in the study gave a verbal consent.

Articles II and III: After the participant had read all the relevant information about the study, he or she signed a written consent form. From the ethical point of view these two studies do not carry any serious harm for the study subjects who were all healthy women and men who do not have anyone in their direct family diagnosed with breast cancer. We recruited the participants with this specific inclusion criterion because the JBCP aims to downstage breast cancer at diagnosis through interventions and mass media campaigns that promote the national breast health practices guidelines to all women aged 20 years and more. The participants in articles II and III were comfortable and talked freely; however, there was a possibility that the explorative open-ended questions that invited the participant to talk about breast cancer may have caused anxiety feelings or worries. On the other hand, to sooth any possible fears, directly after each SSII and FGD, I conducted a brief educational session about breast cancer and early detection examinations and distributed educational brochures.

Article IV: Women received full information and had full autonomy to refuse the home visit and to refuse to participate in the study. Those who agreed to be interviewed in the pre- and post-tests and those who agreed to receive a free mammography voucher gave a verbal consent to the outreach worker in the presence of a field research assistant. Based on the literature, mammography screening reduces the risk of mortality from breast cancer by 25% [86]. Detecting breast cancer early reduces the suffering and pain associated with the disease and its treatment [51, 87]. However, there are risks associated with involving the women in mammography screening that are often overlooked, including exposure to x-ray, stress associated with getting a false-positive result, fear from having breast cancer and worry from going through invasive diagnostic procedures [51, 87].

The 2009 recommendations of the U.S. Preventive Services Task Force increased the age for mammography screening and made it biannual with the start at the age of 50 years instead of 40 [88]. This triggered controversy as the American Cancer Society, Susan G. Komen, Breast Cancer Foundation and National Comprehensive Cancer Network did not change their recommendations on mammography [89]. In Jordan the national guidelines recommend mammography starting from the age of 40 years as the benefits overweight the risks. Worries from mammography become minor when compared to the woman discovering that she had breast cancer that reached advanced stages without her finding out [90]. In Article IV, women who decided to voluntarily take the free mammography vouchers had the opportunity of detecting breast cancer at an early stage which could lead to better health outcomes and higher survival rate.

5 FINDINGS

5.1 BREAST HEALTH KNOWLEDGE

The educational interventions in articles I and IV were associated with a significant improvement in breast health knowledge.

Article I: The mean knowledge score increased significantly from 10.9 in the pre-test to 13.5 in the post-test ($p<0.001$). The pre-test showed a significant association between knowledge score level and governorate, age group, marital status, work status, attending previous lectures about breast cancer, BSE practice, and having had a previous CBE and mammogram ($p<0.001$) . The percentage with minimum 14 correct answers to the 15 questions increased from 18% in the pre-test to 63% in the post-test ($p<0.001$). The median percentage of correct answers for the 15 knowledge statements were 76% (Range: 49%-87%) and 88% (Range: 80%-98%) at pre- and post-test respectively. Table 4 shows that the proportion of correct answers increased significantly between the pre- and post-test for all the 15 knowledge statements ($p<0.001$).

Table 4: Article I, percentage of correct answers on the 11 true and 4 false knowledge statements before and after participating in the group lecture

Statement /Question	% correct answers	
	Pre-test (n=2554)	Post-test (n=2418)
True:		
Breast cancer can be cured	84	98
Breast cancer risk increases with older age	52	85
Breast cancer cure rate depends on its stage at detection	86	97
Breast feeding protects from breast cancer	72	88
There is an association between obesity and breast cancer	54	86
When a women feels any abnormal changes in her breasts she should go to see her doctor	83	97
Practicing a monthly breast self-examination help in early detection of breast cancer	87	97
During breast self-examination you need to examine the underarm	82	96
All women are advised to seek clinical breast examination starting from age 20	76	81
At ages 40-50, mammogram should be done once every two years even if the previous mammogram results were normal	83	93
After the age of 50 mammogram should be done once every year even if the previous mammogram results were normal	83	95
False:		
All breast lumps are cancer	49	88
All nipples secretions are normal regardless of the colour	75	85
Breast cancer is always associated with severe pain	58	80
Having breast cancer means mastectomy	62	81

% correct answers increased significantly between pre- and post-test for all 15 statements (p<0.01)

Article IV:
In this intervention, 55% of the women who received the first visit were aged 40 years or more; 81% had low family income; 74% had no health insurance; 96% were housewives; 80% were married; 8.7% were illiterate and 44% had primary or secondary education, 10% of the women's husbands were unemployed and 54% worked as handyman or driver. Women who received the first visit had similar characteristics as those who received the follow-up visit except for trivial differences with regard to age groups, woman's occupation and attending a previous lecture about breast cancer. In addition, the proportion of women with a low knowledge score in the pre-test was higher among the women who were revisited (45% versus 37%).

The mean knowledge score increased significantly ($p<0.001$) from 11.4 in the pre-test to 15.7 in the post test. The median percentage of correct answers on the 16 knowledge questions at the pre-test was 77% (Range: 37%- 95%) for the 1770 women who did not receive a follow up visit and 75% (Range: 30%- 97%) for the 593 women who later received a follow up visit. In the post-test the median percentage of correct answers was 99% (Range: 93%-100%). The percentage of correct answers increased significantly between the pre- and the post-test for 14 knowledge statements ($p<0.001$).

5.2 BREAST HEALTH PRACTICES

In both articles I and IV, women had relatively low breast health practices at the baseline. **In article I**, previous attendance to a lecture on breast cancer more than doubled the likelihood for ever practised BSE, ever having had a CBE or a mammogram. The likelihood for ever practised BSE and ever had a CBE also increased for married and widowed/divorced as compared with single, and for government officers, privately employed and housewives as compared with other employees. However, the likelihood for ever had a mammogram was elevated only for divorced/widowed (OR=1.9; 95%CI: 1.1-3.4) and housewives (OR=2.2; 95% CI: 1.2-3.9). As expected the likelihood for breast health practices also increased by increasing age.

In article IV, Women had relatively inadequate breast health practices at the baseline, however, their perceived BSE knowledge, ever did BSE, ever had CBE and previous mammography screening were significantly associated with higher breast health knowledge score in the pre-test (Table 5). Previous mammography screening was also significantly associated with being aged 40 years or older, having an annual family income above 5 475 USD and having health insurance ($p<0.001$). The post-test showed a significant improvement ($p<0.001$) in the reported BSE perceived knowledge, BSE practice and mammography screening. Table 6 shows the reported perceived knowledge and practices of BSE, and CBE in the pre-test versus the post-test.

Table 5: Article IV, pre-test breast health knowledge scores in relation to woman's perceived BSE knowledge and breast health practices at the baseline. P-value for test of difference between lower and higher breast health knowledge score levels.

	Knowledge score						
	0-11 n=930		12-16 n=1433		Total		*P-value*
	n	%	n	%	n	%	
Attended a previous lecture	164	18	396	28	560	24	<0.001
Ever had mammography screening *(Aged 40 years or more)*	30	5.4	72	9.8	102	7.9	0.004
Perceived to have BSE knowledge	326	35	795	55	1121	47	<0.001
Ever did BSE	141	16	433	31	574	25	<0.001
Ever had CBE	147	16	392	27	539	23	<0.001

Table 6: Article IV, reported perceived BSE knowledge and practices of BSE and CBE (%) in the pre and post- tests. P-value for test of difference between the pre-test and the post test for women revisited.

Reported knowledge and practices at the baseline	**Pre-test**			**Reported knowledge and practices in the last six months**	**Post-test**	
	Had a first visit (n=2363) %	Not revisited (n=1770) %	Revisited (n=593) %		Revisited (n=593) %	*P-value*
Perceived BSE knowledge	47	46	51	Perceived BSE knowledge	99	**<0.001**
Ever did BSE	25	24	27	Had monthly BSE	96	**<0.001**
Ever had CBE	23	22	26	Had CBE	29	0.22

Receiving a free mammography voucher increased the likelihood of women's mammography screening. Out of the 625 referred women 73% (n= 457) used their free vouchers and had their mammography done in the assigned unit. The number of free mammography screening vouchers to be distributed was limited to 625. However, there were 563 more women who were aged 40 years or more and never had a previous mammography screening, but could not be offered a free voucher, due to the limited number available. Only two of these women had mammography screening in the assigned unit and paid for it and 13 reported in the post-test that they had mammography in other mammography units.

Higher usage of the free mammography voucher was seen in women who received a follow-up visit (n= 203, 83%) compared to those who were not revisited (n= 254,

67%) ($p<0.001$). There was also more usage of the free vouchers among women who reported in the pre-test that they attended a previous lecture about breast cancer, had a perceived BSE knowledge and practice and ever had a CBE. Women who practiced CBE during the six months that followed the first visit were also more likely to use their free mammography screening vouchers. However, there were no significant associations between the women's mammography screening by using the free voucher and their age, marital status, family income, education level, occupation, husband's education, husband's occupation. Table 7 shows the usage of the free vouchers in relation to women's pre-test and post-test reported knowledge and practices. Being busy and having other priorities was the most reported barrier in the post-test for women's BSE, CBE and mammography screening practices.

Table 7: Article IV, use of the free vouchers in relation to women's knowledge and reported practices (%). P-value for the test of difference between women who used and those who did not use the free voucher.

	Used the free mammography voucher		
	Yes	No	p-value
At pre-test (n=625):	***n=457***	***n=168***	
	%	%	
Ever attended a lecture	28	14	**0.001**
BSE perceived knowledge	49	32	**0.001**
Ever did BSE	26	17	**0.014**
Ever had CBE	27	13	**0.001**
At post-test (n=246):			
Had CBE	35	12	**0.002**

5.3 PERCEPTIONS ON BREAST CANCER AND BREAST HEALTH

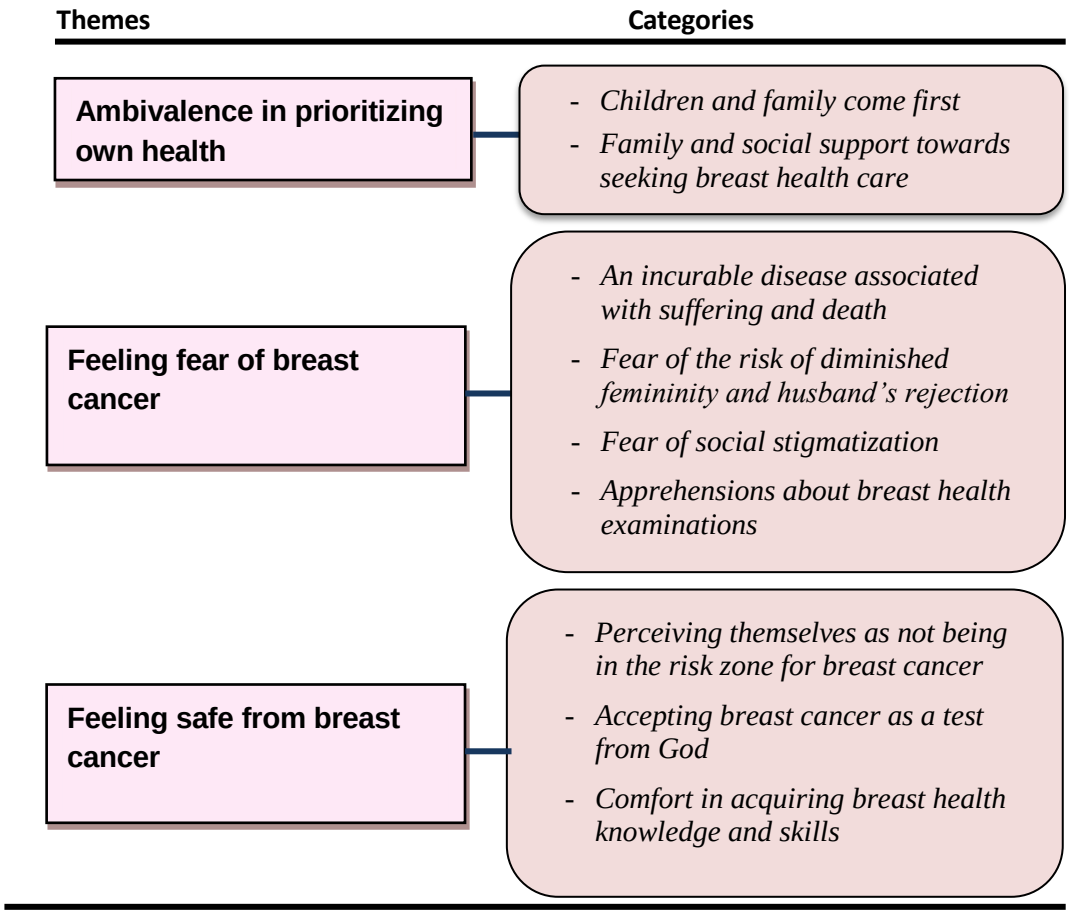
5.3.1 Women's perceptions

The following themes were developed based on the analysis of the transcripts of the women's FGDs in article II: a) Ambivalence in prioritizing one's own health; b) Feeling fear of breast cancer, and c) Feeling safe from breast cancer. All the themes and related categories are listed in Figure 15. The themes are written below in bold and the categories in bold-italic. The quotations were labelled using the FGD number followed by the woman number.

Theme1: Ambivalence in prioritizing one's own health

On the one hand, women shared the experience that they prioritize children and family needs, at the cost of their own health, while, on the other hand, they talked about receiving family and social support to safe-guard their own health and seek breast health care.

Figure 15: Article II, themes and categories



Children and family come first

Giving priority to children and family above their own health was discussed. Women mentioned that if there were enough resources they would take care of their own health, however, when money was limited, they prioritized their children's needs.

"If I have money allocated for my health, then my son needs money or my daughter wanted a dress, I would put their requests first and leave my own needs last" (4, 1)

This did not appear as prevalent in the FGDs with women from more affluent areas. They prioritized their children and family without neglecting their own health. Those women told about their own healthy practices that included diet, sports and seeking periodic screening for breast cancer.

"I do my chores but I try to take care of myself too, I don't forget myself, because we usually pamper our children and forget ourselves" (6, 7)

In all the FGDs, women perceived their own health value from the perspective of being in charge of taking care of the family, and they mentioned that this was also the perception of their husbands.

"My health is important, because if something bad happens to me, my whole family will be lost, because the mother is the nerve of life" (4, 4)

Family and social support towards seeking breast health care

In all the FGDs, family and social support appeared to be a motivator that enabled women to overcome their ambivalence towards seeking breast health care. The women experienced and appreciated receiving encouragement from their husbands or their mothers to practice breast health care. They told about older daughters and sons booking the appointment and escorting them to the mammography unit. They also mentioned being reminded by a sister to practice BSE or being accompanied by a neighbour or a friend to go for CBE.

"My family considers my health first, but for me; my health is one of my priorities but not the first" (4, 7)

In all the FGDs except two, women commented that they did not feel they needed to ask for permission before seeking breast health care but they informed or consulted or were accompanied by the husband if married or the mother if single.

"I just tell him I am going to the doctor, he is my husband he has to know, but I don't ask for his permission" (4, 8)

The FGDs in which women felt that they needed the husband's permission prior to seeking breast health care were from less privileged areas.

Theme 2: Feeling fear of breast cancer

The second theme is built on four categories: 1) perception of breast cancer as an incurable disease associated with suffering and death; 2) fear of the risk of diminished femininity and husband's rejection; 3) fear of social stigmatization; and 4) apprehensions about breast health examinations.

An incurable disease associated with suffering and death

In all the FGDs women perceived breast cancer as a source of suffering for the woman and her loved ones followed by death. Women questioned if there really is a possibility to be cured, telling about witnessing relatives or friends who had suffered this vicious disease (in Arabic: khabeeth). There were women who explained that even if a woman gets cured for a few years, breast cancer will come back and kill her.

"Breast cancer means body disfigurement, suffering, family life disruption and death" (3, 1)

However, in all the FGDs there were also stories about possible good prognosis of breast cancer when detected early.

"My colleague, they discovered her breast cancer in early stages, she was healed after receiving chemotherapy; without a mastectomy" (9, 7)

Fear of the risk of diminished femininity and husband's rejection

In all the FGDs, women associated breast cancer with fear of a distorted body image and loss of femininity.

"A woman who gets breast cancer will be devastated; since losing her breasts means that she is finished as a woman and as a mother" (2,2)

"We, women, care about beauty, and the breast is part of a woman's beauty that she needs to show her husband....her feeling of inferiority remains regardless of how well her husband deals with her...this remains inside us" (9, 2)

It was a common perception that young women hit by breast cancer suffer more than older ones. The women reasoned that older women have grown-up children who would take care of them, while the younger women's children are still too young and thus the younger woman will be more vulnerable if the husband rejects her.

"I know a young woman who had breast cancer; her husband married her best friend, Poor woman, her children are still young and can't take care of her" (6, 2)

Women had the opinion that there are few men who would stand by the wife if she had breast cancer. In all the FGDs, women had observed that men whose wives had been stricken by breast cancer had started looking for other women.

"I know a woman who had breast cancer her husband rejected her and married another woman because she lost her femininity" (3, 8)

"In our society a woman is manipulated as a toy, a man whose wife gets inflicted with breast cancer, this hits his masculinity and usually immediately his eyes starts wandering after other women looking for a replacement" (6,4)

"A man hates having a sick wife, he prefers that his wife stays healthy and strong, my neighbour had cancer, her husband and daughters felt sorry for her, however after a while her husband started looking for a new bride" (8, 3)

On the other hand, in some FGDs, women talked about husbands that supported the wife when she was inflicted with breast cancer.

"She had chemotherapy and as a result she became bold, her four sons along with their father cut their hair and became bold in solidarity with their mother" (6, 6)

In one FGD women talked about breast cancer being contagious and narrated about husbands rejecting their wives after they had been diagnosed with cancer because they were afraid they might catch the illness.

"These are viruses or bacteria that start eating the breast and continue to eat the whole body leading to death at the end" (4, 2)

"The husband said that this is a virus, a small organism inside the body which eats from the body, it would be possible that it can be transferred to him and live upon him too" (4, 7)

Fear of social stigmatization

Women in all FGDs told that breast cancer is a taboo subject in Jordan. The women explained that the word cancer by itself is a source of fear that is overstated by the society, which leads to it being referred to in people's conversations as "that disease". Women experienced that some women try to hide their illness because of fear of being socially stigmatized.

"A woman inflicted with breast cancer in our society hides having that illness, because breast is a sensitive issue for a woman and because that illness is considered to be vicious" (9, 4)

In all the FGDs women told that having a mother who had breast cancer might hinder the marriage of her daughters.

"When some people hear about a mother affected by breast cancer, they think that her daughter is going to be affected by the same disease due to heredity" (6, 2)

Apprehensions about breast health examinations

Women in all the FGDs discussed fear as a barrier that stopped them from practicing breast health examinations. Women told about avoiding touching their breasts or going for CBE or mammography because they feared finding a lump. Some women expressed that even if they had cancer, they did not want to know.

"I wish if that happened to me, God forbid, I wouldn't know and die without knowing about it" (5, 1)

On the other hand, in all the FGDs there were women who perceived that they are at higher risk of breast cancer due to having a personal or a family history of breast lumps or being childless or never having breastfed their children. These women had fear from breast cancer that outweighed their concerns towards screening.

"I am scared, because I had a benign lump before and I did the surgery, now I do self-exam every month to be on the safe side." (3, 2)

In some FGDs the women perceived mammography examination as painful and harmful. The women explained that such worries about possible harmful effects of x-rays were confirmed by their physicians.

"I asked the doctor whether I should do a mammogram test… she told me not to, and that I should first do physical manual examination….she did not advise me to do mammogram because the x-rays themselves affect the body negatively"(4, 2).

In all the FGDs some women expressed feeling uncomfortable and shy about having their CBE done by a male doctor.

"I have wanted to do it a long time ago but I have not found a female doctor, because it is impossible for me to visit a male doctor" (7, 2)

Shyness was also discussed as a barrier that stopped unmarried women from seeking breast health care. They commented that they felt embarrassed to talk about breast cancer or to seek breast health examinations because they were still unmarried.

Theme 3: Feeling safe from breast cancer

The third theme emerged from the women's perceiving themselves as not being in the risk zone for breast cancer and in their accepting breast cancer as a test from God. In contrast, women also experienced comfort in acquiring breast health knowledge that soothed their fears and motivated them to seek early detection examinations.

Perceiving themselves as not being in the risk zone for breast cancer

In all the focus groups women explained that they felt safe from breast cancer and did not seek CBE or mammography screening because they did not feel any symptoms or due to their doing BSE at home and not noticing any abnormal changes in the breasts.

"If, by the self-exam, something is found, I would go, but if nothing is wrong, why should I go to get a clinical examination" (9, 5)

In all the FGDs there were women who felt safe because they had breastfed their children.

"I don't feel fear, I guess all is the result of God's will and moreover I breastfed so I hope all will be fine" (3, 8)

Women also expressed that they felt safe when the results of their first CBE or mammography screening were negative and because of that they did not feel a need to go for periodic examinations.

"I only did clinical examination and mammography once in my whole life, I had pain in my chest, and my examination results came normal, after that I didn't feel that I need to go for periodic tests"(4,2)

Accepting breast cancer as a test from God

The name of God was present in all the FGDs. In some FGDs women expressed that breast cancer is a test of human patience by God. They explained that they feel that breast examinations are not necessary since the issues of illness, life and death should rather be left to Allah Almighty. Whenever anyone mentioned this it was left without being questioned and it put a lid on the discussion.

"Last year my doctor referred me to mammography but I agreed with my husband not to do it, if God wanted to test me with such illness, then I accept God's will, but I will not continue checking myself (1, 1)

For the women who took this perspective, breast cancer was perceived as a plight from Allah and if a woman is destined to have cancer, no matter all her precautions, she will be inflicted.

"Glory be to God, it is a test from Allah, he wants to see if one can be patient or not" (4, 8)

At the same time as there were FGDs in which women expressed being tested by God, women in all the FGDs told that God created a cure for every illness.

"God created a cure for every illness and breast cancer does not mean the end of life" (2, 2)

Comfort in acquiring breast health knowledge and skills

In all the FGDs, women talked about seeing or hearing about breast cancer and breast health examinations on TV, radio, billboards, doctor's clinics, newspapers, lectures, home visits. They expressed that their fears were soothed following to acquiring breast health knowledge and skills and this encouraged them to practice breast health examinations.

"I attended a lecture two years ago performed by a female doctor and I was encouraged to have my breasts examined" (6, 3)

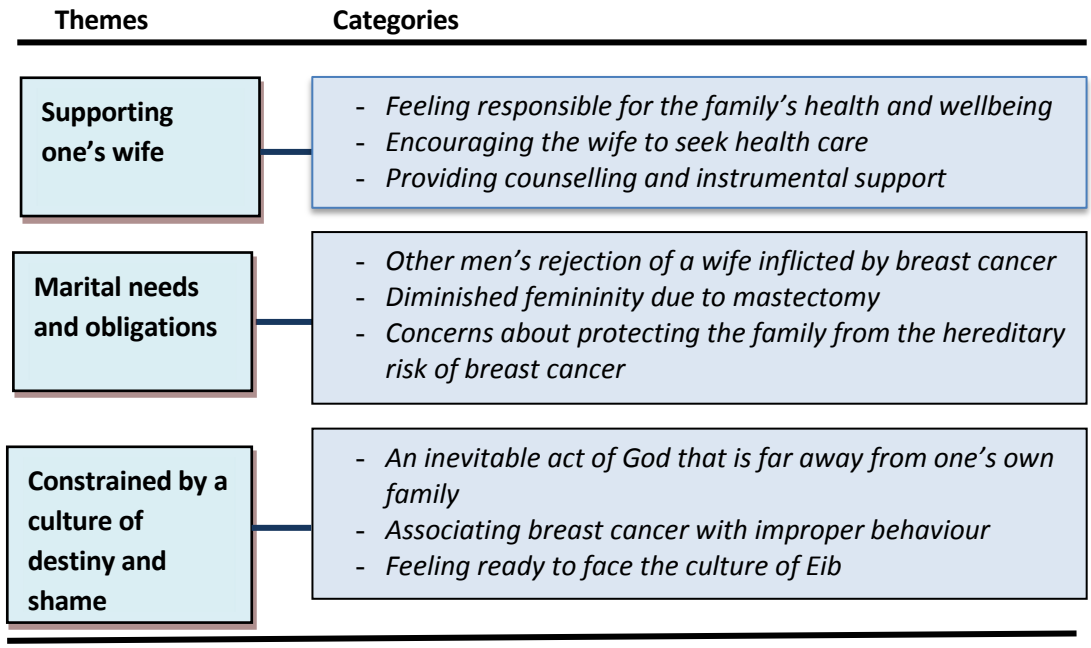
In all the FGDs women experienced forgetfulness due to having many chores that keep them busy and distract them from practising BSE, seeking CBE or mammography. The women appreciated being reminded by the media and through other breast health promotion activities. It was commented that it would be valuable if women who actually had survived breast cancer participated in the breast health promotion activities.

"She should be a woman who has been cured after detecting her breast cancer early and receiving treatment for it, this would provide me with hope, as I would prefer to die and be buried in one piece than being cut and sold by kilo" (4, 7)

5.3.2 Men's perceptions

Three themes were constructed from the men's SSII transcripts: *First theme:* Supporting one's wife; *Second theme:* Marital needs and obligations; and *Third theme:* Constrained by a culture of destiny and shame. The themes and related categories are listed in Figure 16.

Figure 16: Themes and categories of men's perceptions about breast cancer and their role in women's screening decisions



The themes are written below in bold and the categories in bold-italic. The quotations of the interviewees were labelled using the interviewee number followed by the letters A, B, C, D or E for the governorates; different letter codes were used for Amman's east and west sides.

Theme1: Supporting one's wife

The first theme was built on the interviewees' feelings of responsibility for the family's health and well-being, their experiences of encouraging the wife to seek health care and their providing counselling and instrumental support.

Feeling responsible for the family's health and well-being

The interviewees talked about breast cancer as a concern not only for women but also for men, since this disease might afflict their wives, daughters, sisters or mothers. Overall, men used religion as a reference point for their compassion towards their families.

"We are in this world to worship Allah and raise happy and healthy families that avoid diseases ... until now, thank God, I have preserved my family, if they complain of anything I would take them to the health centre immediately" (7C)

"If a needle pricks my wife or any of my children I would not wait, I would take them to the doctor immediately" (15B)

The respondents expressed their belief that a man and his wife are one entity and talked about the precious value of the wife. They pointed out that the husband is responsible for counselling and guiding the wife to protect herself from breast cancer and for supporting and treating her if she gets inflicted with breast cancer. They spoke about the wife as being an embodiment of the home; meaning if a mother gets afflicted with breast cancer, the tranquillity of family life would be disrupted and her children and husband will suffer as well.

"The wife has her status and respect even more than the man as she is the one who nurtures the young generation while the man is busy outside the home…she is the core of the family, her health is a higher priority than my health" (23E)

Encouraging the wife to seek health care

Most of the interviewees viewed breast cancer as a treatable disease that can be cured if detected at early stages. They talked about hearing from the media that early detection is the best way to combat breast cancer.

"As we hear in the media, early detection is the best way to control breast cancer…it leads to a complete cure" (7C)

The respondents spoke about their experience of encouraging their wives to get more information about breast cancer and to seek early detection examinations.

"My wife went to the doctor recently and had a breast examination, she was afraid but I encouraged her, I told her it is better to go and face your doubts and fears, even if God has decided to test you with breast cancer, you will be able to discover the disease early when it is easily treatable" (2A)

The interviewees had had experience of trying to convince their wives to seek breast examination and they said that the reasons for women reluctance could be shyness, fear, and lack of knowledge or negligence.

"I wish she would *ask me to take her to the doctor, but she doesn't like to go, I encourage her but she refuses as she is afraid that he might discover she has the disease"(23E)*

"Some women don't go for a check-up at the clinic ... they are afraid of finding cancer, like my mother…in my opinion, she should be examined for the sole purpose of confirmation… whether she had it or not" (1A)

The interviewees pointed out that BSE is important as it enables the woman to seek advice from a doctor as soon as she discovers any changes in her breasts.

"If she is doing self-examination, she can recognize if she has a lump as soon as it occurs and seek a doctor's advice, this will save her life" (17B)

All the interviewees preferred that the females within their families get their CBE done by a female doctor; however, the majority accepted a male doctor conducting CBE in the husband's presence, if a female doctor was not available.

"As long as there are female doctors why should it be performed by a male doctor? I would not accept it for a regular examination, let alone breast examination" (19D)

Providing counselling and instrumental support

The respondents felt that they have an instrumental role in their wives' health. They explained that their wives consult them prior to seeking breast health examinations and that they give advice and guidance. They also said that they drive or accompany their wives or give them money to go to the health centre. Few men mentioned that their wives are not used to leave home unless being escorted by the husband or older sons.

"She asks my opinion before going to the doctor, so I give her money and tell her to go to the doctor" (15B)

"I bring her to the health centre as we live away from the health centre, how else can she come here? ... Her sons also bring her to the centre when she wants" (13B)

Some men said that their wives are doing BSE and as long as everything is normal, the wife does not talk to the husband. However, as soon as she notices any abnormality in her breasts she consults the husband about going to seek a doctor's opinion.

"My wife doesn't tell me if she does not suspect anything abnormal, as she practices self-examination…however, when she feels anything strange, she consults me and ask me to take her to the doctor"(20D)

Few men commented on their experiences as sons or brothers and their being consulted by the mother about breast health or driving their mothers or sisters to the health centre.

"If my mother had mammography I would've known.., since it is me who drives her to the hospital" (21D)

"Sisters do not give any details… they only say we need to go to the health centre and one of their brothers or the father can accompany them. However, my mother consults me if she has any pain in the breast" (12B)

Theme 2: Marital needs and obligations

The second theme emerged from the interviewees' views about other men's rejection of a wife inflicted by breast cancer, their own perceptions of diminished

femininity due to mastectomy and their own concerns about protecting the family from the hereditary risk of breast cancer.

Other men's rejection of a wife inflicted by breast cancer

The interviewees said that fear of breast cancer as a threat that might lead to family destruction and the loss of a loved one might make the man feel helpless and he may not cope with the financial and psychological burdens if the wife was afflicted with breast cancer. They explained that if the man cannot afford the treatment of his wife's breast cancer, he might have a negative reaction towards her. Since these feelings of helplessness could undermine his role as the head of the family who is responsible for taking care of his wife.

"*It depends on the social and financial status of the man, if he couldn't cope with it, this could be because he feels that the wife became a burden….. He might feel helpless if he cannot afford to treat her" (6A)*

"Some will neglect the breast cancer inflicted wife and try to get rid of her…… the man would say it is better to get a new wife instead of treating a sick wife" (4A)

"In our society, if a woman gets breast cancer, her children stick by her, as for the husband, his eyes will start wandering around, looking for a new wife" (12B)

The respondents felt that the good man who is a believer in God's fate supports his wife if she gets breast cancer and such a test from God might strengthen their marital relation and maximize his compassion towards her. They talked about some husbands within their social context who coped with the burden of the wife's breast cancer and supported her all through the treatment process until recovery.

"The good man would support his wife and stand by her; he doesn't let her suffer alone, would a man smell a rose then throw it away? A wife should not be thrown away, she must be protected and have a holy status. I know a man who supported his wife when she had breast cancer because he felt that she belongs to him and considered her the jewel of his life" (7C)

"The man must guide and treat his wife and stand by her until she gets well, not react negatively and not reject her because he can't handle the burden of her illness" (23E)

Diminished femininity due to mastectomy

Most of the interviewees perceived breast cancer as a dangerous disease that can be fatal if detected late. They talked about mastectomy as a consequence of the illness. However, few young men associated that with female body deformation. The same young men expressed that a woman afflicted with breast cancer will become less of a woman and deficient.

"It means that there is a defect in her body, if she has had a mastectomy, she will be done with as a female, almost half of her femininity would be gone"(8C)

They commented that it is difficult for a husband to accept this diminished femininity; and instead of coping with this and standing by his wife, the husband

will marry another woman because the wife who is inflicted with breast cancer cannot fulfil her marital duties towards her husband.

"It is tough on the man ..... how can he cope with this woman who now has a defect in her body, usually, instead of standing by the wife who needs his support to be able psychologically to fight her illness, frequently the man rejects this wife and marries another one who can satisfy his needs" (9C)

"If the woman's breast is removed, this will cause a defect that is difficult for the man to accept as it is not something normal" (21D)

It also emerged in a few interviews that mastectomy is tougher on younger women inflicted with breast cancer as it will affect their relationship with the husband and their breast feeding ability.

"If the woman is over 40 and had a mastectomy, it might be acceptable. However, if she is young it is difficult to accept….this will influence her marriage chances, and if she is already married, her husband will be young and this will influence their relation and also it will be more difficult as the woman needs to breastfeed her kids" (26E)

Furthermore, a few men mentioned that the psychological burden of mastectomy on the woman augments her feeling of difference from other women who pity her situation.

"It is very tough on a woman, as she is a female; she needs to feel complete and a whole person, without anything missing. If her breast is removed …she will be different from other women, her husband might reject her and she will be isolated in the society, women will start talking about her breast being removed. She will feel less of a woman in comparison to other women" (9C)

Concerns about protecting the family from the hereditary risk of breast cancer

Most of the respondents believed that breast cancer is hereditary and said that a man should better avoid marrying a girl who has a family history of breast cancer. Some explained that, since the man has the choice to select a wife, who will be the mother of his future children, he better seek perfection. On the other hand, a few men commented that breast cancer is not hereditary and a family history of breast cancer should not affect a woman's chances of marriage.

"If her mother was inflicted with breast cancer then we would not take the daughter for marriage" (13B)

"Frankly, I wouldn't marry a girl if her mother had breast cancer, I would be afraid that the disease can be inherited, if it is in their genes. I think that everybody asks about such matters and then drops the idea of seeking marriage from a family with hereditary susceptibility, why not?" (19D)

Theme 3: Constrained by a culture of destiny and shame

The third theme was seen in the interviewees' perception of breast cancer as an inevitable act of God that is far away from one's own family, and in associating

breast cancer with improper behaviour and in their readiness to face the culture of Eib (shame).

An inevitable act of God that is far away from one's own family

Most of the interviewees felt that the women in their families were at risk of breast cancer since illness is an act of God and no one can stop destiny. However, they mentioned that it is a remote risk since they do not have a family history of breast cancer or because their wives were practicing BSE and never had pain or noticed any abnormal changes in the breast. They explained that having no symptoms and no pain means that the woman is safe and there is no need for worry.

"Breast cancer is a disease like other diseases, all women are vulnerable, it is God's will, it is a test from God and therefore a person should accept it" (18D)

"My wife doesn't have any symptoms, if she examined herself and found any symptoms, I would take her to the doctor immediately, but no symptoms means that there is nothing to worry about" (14B)

"I feel that breast cancer is far away from my family, since we do not have a family history of this illness" (6A)

Breastfeeding emerged in the married men's interviews either as a protector or as a predisposing factor for breast cancer.

"The woman who has babies and breastfeeds, God protects her from breast cancer at least until she ends that phase" (21D)

"When the woman is breastfeeding and her clothes are not clean, bacteria may pass through the milk and this may lead to breast cancer" (5A)

Associating breast cancer with improper behaviour

A few men said that within their context, breast cancer is perceived to be contagious and could be transmitted to the husband. It was pointed out that this perception depends on the husband's educational level. In four interviews men associated breast cancer with promiscuous behaviour. They said that a husband will feel ashamed and reject his wife to avoid catching the illness himself. One man with primary level education perceived that breast cancer is caused by doing things prohibited by Allah (God), such as taking drugs and alcohol.

"Breast cancer comes from promiscuous behaviour; if my sister or aunt gets breast cancer I will disown her as she has brought shame to the family" (28C)

"Some think it is contagious and if a man's wife is inflicted with breast cancer, this would bring shame to him and his family" (7C)

Feeling ready to face the culture of Eib

The interviewees spoke about the society's pitiful view towards women inflicted with breast cancer. They explained that Jordan is a tribal society and cancer by itself is a taboo word that is avoided because it is seen as a fatal disease. The tribal nature of the society was also brought up within the context that although nowadays

women might go to the examination alone, there are still women who cannot go on their own and if the woman tried to tell her husband that she has breast cancer symptoms, he might avoid taking any action to avoid being stigmatized.

"For me it is a disease like any other disease and one should cope with God's act, however most of the people look with pity towards a woman inflicted with breast cancer" (2A)

"We live in a tribal society. Nobody talks about this subject. If anybody is inflicted with cancer, they would just say, he is ill, because the word cancer is horrific, a reason for late detection might be the husband's denial, he prefers to keep the problem hidden because he belongs to a tribal society" (8C)

Some men talked about the culture of Eib (shame) and that breast cancer is perceived as a sensitive subject that is not openly discussed in the society because of embarrassment. In Jordan, the culture of Eib can be described as violation of the societal values or norms that could bring disgrace and shame to the individual society member, to his direct family and possibly to his tribe depending on the type and the magnitude of the individual's inappropriate conduct.

"We have the culture of Eib in our society, you feel shy when there is both fear and shame……but a person should have some courage and decide to go because there is nothing to be afraid or ashamed of" (7C)

Men also mentioned that shyness inhibits the woman from talking about breast cancer and from seeking breast examinations; only two men mentioned that their daughters might talk to them directly if they had any symptoms in the breast.

If there is a sensitive women issue like this, my daughters tell their mother, they feel shy to talk to me, but the mother tells me (22D)

The interviewees said that the awareness campaigns about breast cancer helped both women and men to acquire knowledge about the disease and that this contributed to breaking the silence about breast cancer and to challenging the culture of Eib.

"As an eastern society, the majority of us feel sensitive to this matter; some people are embarrassed to talk about this subject. However, I noticed billboards saying "We have had an examination, have you?" … wherever you go, you would hear them talking about the same thing….now everyone has the courage to talk about it, no more embarrassment" (1A)

6 DISCUSSION

6.1 BREAST HEALTH KNOWLEDGE AND PRACTICES

In both articles I and IV, the educational interventions resulted in a significant improvement in women's breast health knowledge. Low proportion of women reported practicing breast health examinations in the pre-tests. Additionally, there were significant associations between previous BSE, CBE and mammography screening and women's breast health knowledge score and attending a previous lecture about breast cancer. Previous mammography screening was also significantly associated with being aged 40 years or older. In article IV, the post-test showed a significant improvement in women's perceived BSE knowledge, BSE practice and mammography screening. Women who received a free voucher and had a pre-set follow up visit were more likely to have mammography screening. Being busy and having other priorities was the most reported barrier for women's breast health practices in the post-test.

In articles I and IV, women's reported breast health practices in the pre-test were low and previous mammography screening was significantly associated with being aged 40 years or older. This is consistent with what Petro-Nustas and Mikhail (2002) found [91]when they adapted Champions Revised Health Belief Model Scale [92-94] to test a random sample of 519 females aged 18-59 in Jordan. Although 67% of the participants heard about BSE, only 26% of them reported practicing BSE in the previous 12 months, 7% stated that they performed BSE on a regular monthly basis, 9% reported performing BSE every 2–3 months, 5% once every 6 months and 6% once a year. A total of 73% of the participants indicated that they had never performed a BSE. The same scale was used to assess the beliefs of 72 Jordanian women aged 15 to 69 years about mammography screening and the results showed that older age, hearing or reading about or receiving information about mammography from friends were predictors for current mammography practice. While past mammography practice was related to the women's family or personal history of breast tumours and receiving information from the media about mammograms or from family members [95].

In articles I and IV, there was a significant association between previous BSE, CBE and mammography screening in the pre-tests and women's breast health knowledge score and attending a previous lecture about breast cancer. This is consistent with the Revised Health Belief Model and the Social Cognitive Theory, as higher breast health knowledge may increase the woman's perceived risk and susceptibility to breast cancer, while enhancing her perceived self-efficacy and benefits of screening. Public awareness can contribute to earlier detection of breast cancer if it was culturally appropriate and tailored to the specific population[53]. Educational programs that enhance women's perceived self-efficacy and perceived benefits can lead to significant improvement in breast health practices [96]. Therefore, breast health educational interventions that provide balanced health information might empower women to take an informed and an more active decision-making role than they initially intended [97].

The educational interventions in both articles I and IV were associated with significant improvements in breast health knowledge scores. In a study by Valdez et al [98], a total of 1197 Latina women were randomly assigned to a control or an educational intervention group about breast cancer. Women in the intervention group exhibited significantly higher knowledge scores in the post-test than the pre-test with the highest increase among never-screened women. The intervention also increased the likelihood of women seeking information about a mammogram. A study by Hall et al [94], found that multifaceted culturally sensitive and linguistically appropriate breast cancer educational interventions can improve women breast health knowledge and reduce their perceived barriers to early detection and screening.

In article IV we found a significant association between receiving a free voucher and mammography screening. Out-of-pocket payments have been reported in the literature as a barrier to screening [99]. In a study by Earp et al [100], they described an intervention that included one-to-one conversations between lay community health advisors and women, use of culturally sensitive materials to promote breast cancer screening, increasing access to mammography by providing transportation and promoting lower charges. The intervention was significantly more effective in increasing mammography screening among lower income women than in the higher income group. There are several other studies which reported that vouchers for free mammography could improve mammography screening in low-income women and those with no health insurance [101-105]. A systematic review to synthesize evidence from all prospective controlled studies in USA found that lay community health workers programs were effective in improving mammography screening rates in medical settings, urban settings, and in participants who were racially or ethnically concordant with these community workers [106]. Another study found that recruiting women by lay health workers who offered them screening appointments was associated with a significant increase in breast and cervical cancer screening [107].

Article IV demonstrated more usage of the free mammography screening vouchers among the women who received the pre-set follow-up visit from the LCOW. This is consistent with the social support theory [64, 65] as perceived support from the women's social network, such as the LCOW, is assumed to influence her health practices. Social support can be classified into formal or informal support [65]. Formal support is offered by health providers through giving information, guidance and advice. Informal support can be affective, appraisal, and instrumental and is considered the more effective type of support. Affective support involves mutual trust and genuine concern. Appraisal support confirms the self-value and is often provided by co-workers or through social influence. Instrumental support includes symbolic or material and tangible aid usually provided by family [65]. Mauad et al [108] found that home visits by outreach workers, who were well known in the community, were effective in improving the number of women screened for breast and cervical cancer in a low income setting. Since these outreach workers might share with the women similar culture and socio-economical class which enhances the effectiveness of communication [108, 109]. Several other outreach interventions used local lay community workers to conduct educational sessions about breast cancer [100, 110] and cervical cancer [111, 112] have shown statistically significant increases in screening participation rates.

Article IV showed a significant improvement in the after six months post-test with regard to women's perceived BSE knowledge, reported BSE practice and mammography screening. Based on the literature, perceived self-efficacy to perform breast health practices is strongly related to perceived knowledge and not actual knowledge [113]. This means that breast health knowledge is necessary but not sufficient for changing breast health seeking behaviour, and that educational interventions must be effective in improving the actual knowledge level and in convincing women that they know what to do, how to do it and why to do it [113]. Due to the increase in availability of and quantity of health promotion messages, women might be selective with regard to the messages they receive and retain in their minds. Thus, health communication interventions should use the preferred formats, desired times and be more tailored and responsive to the targeted audience [114]. Communication models have demonstrated that women's cancer screening behavioural change in underprivileged areas requires an approach that is specifically tailored to the targeted women [115, 116].

Article IV also indicated that being busy and having other priorities was the most reported barrier by women for their BSE, CBE and mammography screening practices. Lack of time was reported in the literature as one of the most common barriers for breast cancer screening among women in Asia [117].This is consistent with the findings of Article II which indicated that Jordanian women were ambivalent to prioritize their own health. Thus, home visits by local outreach workers could be more effective within this specific context in changing beliefs and practices than other breast health promotion strategies [116], as these women may have barriers to screening that could limit their financial, geographical and transportation accessibility [116]. It is also possible that they prioritize their family needs or have to attend to their children and household duties.

6.2 PERCEPTIONS ON BREAST CANCER AND BREAST HEALTH

Articles II and III showed a close interaction between individual, family and community influences on Jordanian women's screening behaviour. Women had fears about breast cancer, but they also felt safe and not at risk of the disease. They prioritized the needs of children and family above their own health. However, acquiring breast health knowledge and skills soothed their fears and receiving encouragement from the husband and other family members motivated them to seek early detection of breast cancer. Jordanian men perceived themselves to have a vital role in supporting their wives to follow breast cancer early detection recommendations. They viewed other men's rejection of a wife inflicted by breast cancer as a failure of the husband to meet the burden of his obligations towards the sick wife and incapacity of the sick wife to meet the marital needs. They voiced their concerns about breast cancer being a taboo subject in Jordan's tribal society and appreciated the contribution of breast health awareness campaigns to their talking openly about the disease and to their readiness to face the culture of Eib (shame).

Article II revealed the hindering effect of women's prioritizing children and family needs and the facilitating effect of their experiences of family and social support to overcome their ambivalence towards prioritizing their own health. Women perceived that their main role is to take care of the family. This is consistent with

the findings by Trigoni et al [118], who conducted in-depth interviews with 30 women aged 45-65 years in Crete and found that family obligations were one of the reasons for their deferred mammography screening behaviour. Furthermore, Lamyian et al [119] interviewed 31 Iranian women and found that the women's caring for their own health was motivated by their role as caregivers for their households. However, the same study found that competing priorities such as taking time to care for the family was a barrier to Iranian women's attendance for breast cancer screening.

Women in article II experienced receiving encouragement to prioritize their own health from husband, family, friends and neighbours. Similarly men in article III talked about encouraging their wives to follow breast cancer early detection recommendations. They said that they give advice, guidance or accompany the wife to the health centre or give her money to go on her own. This confirms the findings of article II and indicates that receiving encouragement from the husband enhances the woman's breast cancer screening practices. This is consistent with the findings of Waggle and co-workers' [65] about the influence of the social support network in soothing the stress related to cancer and enhancing women's practice of BSE. Moreover, they suggested that breast health awareness campaigns that address women's formal and informal social support networks can positively influence screening behaviour. Based on the literature, receiving social support especially from spouses can positively influence women's breast cancer screening decisions [117, 120, 121].

Few men in article III mentioned that their wives were not used to leaving home without being escorted by the husband or older sons. Other studies have indicated that women's cancer screening decisions can be inhibited by unsupportive spouses and suggested that breast health awareness interventions should include the targeting of the partners of women to enhance their supportive leverage towards breast cancer screening [122-125]. Gotay & Wilson [126] described within the frame of the Theory of Social Support four dimensions of social support that can enhance women's screening behaviour: emotional, instrumental, appraisal and informational support. They suggested that family members can offer emotional support by being compassionate, showing concern, listening and establishing ties of trust. Instrumental support can be through offering tangible assistance by giving time, money and effort. Informational support can take the form of counselling, guidance and advice. As for appraisal support, it affirms the woman's status and feeling of self-value.

Women in article II perceived cancer as an incurable disease associated with suffering and death, risk of diminished femininity and husband's rejection. Fear of diminished femininity and treatment suffering was also described by Remennick [127]. The perceived link between cancer and death was reported by Bener et al [128] based on a survey with 1750 Arabic women in the United Arab Emirates. Men in Article III talked about mastectomy as a consequence of breast cancer, but few of them associated that with female body deformation and diminished femininity. Fear of death or becoming less of a woman and failing to meet the husband's marital needs as a consequence of mastectomy had a profound voice in women's FGDs narratives in article II. Women's fear of the consequences of

screening and breast cancer diagnosis with regard to the potential risk of death or mastectomy, distorted body and partner's abandonment was reported by Peek et al [129] in a study based on focus group discussion with African-American women about their perceptions on breast cancer screening. Breast cancer affects the woman's perceived body image and sexuality and that is strongly influenced by the perceptions of others [130-132]. Women may *wrongly* perceive that their partner will be repulsed by the women's changed body image as a result of mastectomy [133].

Men in article III expressed more support and compassion than the women's perceptions as shown in article II. However, they confirmed the women's views that, if the wife gets breast cancer, her children usually stick by her while the husband might have a negative attitude and some might reject the sick wife or start looking for a new one. The interviewees in article III perceived other men's rejection of the wife if she gets breast cancer as a withdrawal strategy to avoid feeling helpless which could undermine the man's role as the head of the family who is responsible for taking care of the sick wife. This is consistent with the findings of Vlassoff [134] literature review about gender and health, which indicated that women with a chronic disease were less likely to receive support from their husbands. The marital obligations and needs as explained by the men in article III could to some extent be an expression of the socio-cultural constructs of gendered roles and obligations that they felt that men in Jordan are bound to live up to. According to the literature, men experience relatively greater social pressure than women to comply with gendered societal beliefs about masculinity including being independent, strong and in control [135-139].

Both articles II and III uncovered some misconceptions about breast cancer being a transmissible illness. Such false beliefs are often based on lack of knowledge. Articles I and IV showed that women with higher levels of breast health knowledge had significantly more breast health practices compared to those with less knowledge. In article III men associated getting breast cancer with the woman's improper behaviour. Men's knowledge about breast cancer and their attitudes towards their partner's breast cancer screening is context sensitive and largely unexplored in literature. In their qualitative study Flores and Mata [122] found that Latino males lacked specific knowledge about their spouse's breast and cervical cancer screening, procedures, or recommended frequency of such examinations. They suggested that preventive health measures could be improved by a better understanding of the husbands knowledge base and attitudes towards the wife‘s health and health seeking efforts. Conversely, in a postal survey conducted by Chamot and Perneger [140] in Switzerland, men were found as knowledgeable about breast cancer and mammography screening as women but had more favourable attitudes toward breast cancer screening than women.

In articles II and III women and men voiced their concerns about breast cancer being a stigmatizing illness and a taboo subject that is not openly discussed in the society. Jordan's tribal context highly values the collective good above the individual's best interests. Thus, one might feel obliged to hide a stigmatizing illness to accommodate the expectations of others; to avoid embarrassment and to

save the family's reputation; especially if the disease is socially perceived to be inheritable [141]. In the Mediterranean cultures, honour is centred on avoiding shameful behaviours and conserving the individual's and the family's good reputation from stigmatizing labels based on the masculine and feminine honour prescriptions of a socially interdependent culture [142]. The social stigma associated with breast cancer was described Baron-Epel et al [143] to be attached to those inflicted by the illness and those who go for screening. The social stigma of cancer was also reported in other studies [91, 144]. Kawar [144] reported embarrassment in talking about breast cancer in immigrant Jordanian and Palestinian women in USA. The respondents in that study viewed cancer as a shame label that could stigmatize the woman and her family.

Women's fear from breast cancer in article II can be interpreted as a potential barrier to screening behaviour. Women feared that if they seek screening they might get a breast cancer diagnosis and felt it is better not to know. This was also reported by Bener et al [18] in his qualitative study with Arabic women in the United Arab Emirates. This is also consistent with the findings of Petro-Nustas [145], who assessed the beliefs of a convenience sample of 59 young Jordanian women aged 18 to 45 years towards mammography screening. The study showed that even though 76% of the participants agreed about the benefits of mammography, half of them identified fear of discovering breast cancer as the main barrier to mammography.

Articles II and III showed that both women and men preferred the CBE to be conducted by a female health provider. However, if there were no female providers of CBE, men and women indicated that a male provider can do CBE in the husband's presence and found that to be consistent with their Islamic beliefs. Women might perceive breast exposure with discomfort and embarrassment [145]. This is also consistent with previous literature, which indicated that women prefer female health providers, especially for sex-sensitive examinations [146-150]. Studies have shown that women are more likely to undergo screening with Pap smears, CBE and mammograms if they see female rather than male physicians, particularly if the physician is an internist or family practitioner [150, 151]. Ahmad et al [150] found that physicians' gender plays a role in sex-sensitive examinations and recommended enhancing physician-patient interactions for sex-sensitive cancer screening examinations by health education initiatives targeting male physicians and women themselves. Studies revealed that Islamic beliefs can influence Muslim women's screening behaviour and recommended breast health programs to be carefully tailored to the needs and the religious beliefs of these women [56, 152, 153]. Montazeri et al [154] studied the beliefs of 410 Muslim women in Tehran regarding screening modalities of breast cancer and found that 90% did not perceive that BSE practice was against their Islamic beliefs, 58% preferred to be examined by a female physician and 47% said that CBE by a male physician was not against their Islamic beliefs.

In article II, women mentioned that their fears towards mammography screening were confirmed by their health care providers. Physician's recommendation and beliefs are essential factors for developing effective mammography screening interventions [155]. Studies indicated that physicians and nurses have a major role in motivating women to have mammograms and CBE and to practice BSE [52,

156, 157]. A study by Leslie et al [158] showed that even highly educated women lack knowledge about breast cancer and age specific recommendations for screening. The authors suggested that practitioners must continue to council and update women about breast cancer to reinforce their breast cancer-screening practices. In addition, they recommended that providers should improve their rates of performing CBE with physical examinations [158].

Article II showed that women felt safe and out of the risk zone for breast cancer while article III showed that men perceived breast cancer to be a faraway risk from their own families. Based on the Revised Health Belief Model, perceived seriousness of and susceptibility to breast cancer influence perceived threat and this could enhance breast health practices [63]. Hence, these findings could be interpreted as a barrier to Jordanian women's breast health-seeking behaviour; as woman's perception of risk [52, 159] or susceptibility to developing an illness is an important determinant of her health seeking behaviour [159]. Religion was reported in the literature as a facilitator in terms of motivating women to take charge of their own health [160] and as a barrier when breast cancer is passively accepted as a test from God [18, 160, 161].

Article II also indicated that acquiring knowledge and skills made the women feel safe and encouraged them to practice breast health examinations. Juon et al [162] found that the strongest correlate with regular mammograms was the knowledge of screening guidelines. Secginli and Nahcivan [163] examined the variables related to the breast cancer screening behaviours of 656 Turkish women and found that knowledge of breast cancer screening guidelines was a major predictor of regular screening. Women in article II mentioned that they received their knowledge about breast cancer and breast health from TV, maternity and child health care female doctors, family members, neighbours, newspapers, radio, internet, magazines, home visits by an outreach social worker and lectures. Previous studies in Jordan suggested that creating awareness through the media and culturally appropriate educational interventions could improve women's knowledge about breast cancer and early detection examinations [91, 95, 145].

In article III, men talked about the contribution of the awareness campaigns to their willingness to talk openly about breast cancer and to their readiness to face the culture of Eib (shame). Based on the Social Identity Theory of Tajfel & Turner [66], individuals' define themselves as members of a social group and strive to preserve a positive image within the group because the respect within the group enhances the individual member's self-value. Social stigma as explained by Erving Goffman [164] is an attribute or a behaviour which leads to a reaction by other members within the social group that affects the normal identity of the stigmatized member. Pasick & Burke [165] conducted a critical review of theory about breast cancer screening that highlighted the importance of the social context as a dynamic shaper of individual's beliefs and experiences and recommended using multilevel interventions that integrate social and individual approaches in promoting breast cancer screening. Based on a literature review of published articles, Randolph & Viswanath [166] concluded that effective health promotion campaigns should ensure sufficient exposure of the audience to carefully tailored appropriate messages and be able to create a supportive social environment that allows the

target audience to make the recommended behavioural change. In addition, they suggested that the campaigns must be based on careful understanding of the determinants of health behaviour that could potentially lead to the desired health outcome.

6.3 STRENGTHS AND LIMITATIONS

A strength of this doctoral research is that the findings are consistent with previous studies in the Middle East. Several potential barriers were reported in the literature to negatively influence Middle Eastern women's breast health seeking behaviour, including lack of breast health knowledge, lack of physician's recommendation, fear of cancer, worry about finding a breast tumour, fear of stigma, embarrassment, preference of female health providers, opposition of the husband or other male family members, lack of perceived benefits, perceptions that breast cancer is fatal and not curable, lack of time and lack of accessibility to breast health services and fatalistic religious beliefs [18, 55, 56, 91, 95, 128, 143, 145, 160, 161, 167-169]. However, the findings of this thesis should be interpreted within the context of several strengths and limitations.

Article I was limited by the lack of control group and the non-random sampling. Women who responded to the advertisement about the lectures could be those who perceived that they were at higher risk. Additionally, it was not possible to link the pre-test questionnaire to the post-test questionnaire due to the fact that the questionnaires were filled in anonymously. Therefore, we could not estimate the individual performance. Finally, the post-test did not give any information on how much of the acquired knowledge would be retained in the long term nor about the relation between the improved knowledge and the breast health behaviour. However, conducting the post-test directly after the lecture minimized the influence of confounders.

The strengths of articles II and III are in their design including the purposive recruitment of women and men from different age groups and from four governorates in Jordan which contributed to the richness of data, the triangulation of the researchers who thoroughly reviewed the transcripts and the codes and contributed to the thematic interpretation [83]. The researchers brought rigour into the analysis because of their different qualifications, experiences and familiarity with the Jordanian context. Previous engagement of the authors in public health research in Jordan and the Middle East might have also enhanced the trustworthiness of the findings [170]. As far as we know, article III is the first study to explore Jordanian men's individual and contextual perspectives on women's breast cancer and their role in the breast health of the females within their families. The interviewees were engaged and after the interview they sought to get answers to their inquiries.

Article II and III could be transferable to other similar contexts; however, they cannot be generalized to all Jordanian women or men. In article II, the FGDs data collection methodology raises the question of whether the women responses were spontaneous or were they a reaction to the group setting. However, as the moderator, I tried not to influence the opinions of the participant and the

atmosphere was relaxed and normal which enhanced the natural dynamics of the FGDs [171].

In article III, although the pilot interviews showed that men felt more comfortable talking to me as a female interviewer about the breast health issues of the females within their family, still, there may still be a potential that the findings of this study might have been affected by social desirability bias. One could argue that the participants might have provided answers that they believed that I wanted to hear. To avoid this potential problem, I attempted to remain open-minded and unbiased and avoided leading questions.

The findings of article III were focused on the husband's role in the wife's breast health. I recruited 24 married men and 4 single men, on the assumption that married men could provide a wider span of experiences related to their contribution to the breast health of the females within their families. However, the majority of the married interviewees responded primarily about the wife and when I probed about their role in the breast health of other female family members, the narratives exposed the culture of Eib, which was also strongly present in the narratives of the single men.

In article III, there was an apparent contradiction in the data with regard to the respondents' own supportive perceptions and attitudes versus other men's rejection of a wife inflicted by breast cancer. However, this cannot be interpreted as a sign of on-going ambivalence or a shift in social norms because the interviewees were purposely selected based on not having any females within their direct family with a previous diagnosis of breast cancer. Thus, their contextual views about husband's rejection of a breast cancer inflicted wife don't reflect their own reaction if they themselves experienced having a wife with breast cancer.

Article IV had several strengths including: recruiting a relatively large sample for the first home visits; the design that used multifaceted breast health promotion strategies; the assessment of improvement in retained breast health knowledge and practices in a sub sample six months after the first home visit; and the opportunity to track the actual utilization of the free mammography vouchers at the assigned mammography unit. Following to mammography screening, women had all the necessary further investigations including: extra views, ultrasound, and ultrasound guided biopsy and stereotactic biopsy. Two women who never had previous mammography screening before this intervention used their free mammography screening vouchers and were diagnosed with stage II breast cancer. They were referred for treatment in the public sector.

Still, article IV had some limitations due to the lack of control group and the non-random sampling; thus, the results cannot be directly generalized to other women in less privileged settings in Jordan. Although this study assessed the retained knowledge and changes in breast health practices six months after the home visits educational intervention. There is still a need to assess the long-term sustainability and the cost-effectiveness of such an intervention. Another limitation was that the LCOWs had only 625 free mammography screening vouchers to offer to those who met the inclusion criteria, although 92% of the women aged 40 years or older reported at the baseline that they never had mammography before. Additionally, only 593 follow-up visits were conducted, thus, we had no reported post- test data for all the women who received a first visit.

7 CONCLUSIONS

This thesis aimed to explore women's and men's perceptions about breast cancer and breast health in Jordan and to assess the effectiveness of breast health promotion interventions in improving women's breast health knowledge and practices. The main conclusions to be drawn from the results are:

- Women had low breast health practices despite their considerable level of breast health knowledge.
- Culturally appropriate group educational lectures are effective in improving breast health knowledge among Jordanian women.
- Women showed ambivalence in prioritizing their own health and both men and women perceived that the husband had a supportive role in encouraging the wife to prioritize her own health.
- Jordanian men perceived themselves as having a positive role in supporting, guiding and encouraging their wives to seek breast health.
- Both men and women perceived breast cancer as a faraway risk or accepted it as a test from God.
- Women perceived breast cancer as an incurable disease and had fear of the risk of diminished femininity and husband's rejection, while men felt responsible for the family's health and were concerned about protecting the family from breast cancer.
- Men's views about other husband's rejection of a breast cancer inflicted wife were explained within the frame of their own perception of their masculine role and responsibility for the family's health.
- Both men and women perceived breast cancer as a stigmatizing illness.
- There were misconceptions among some women and men about breast cancer being contagious.
- Women reported some misconceptions among physicians towards mammography screening.
- Women and men preferred a female health provider for conducting CBE.
- Acquiring knowledge about breast cancer was perceived by women as a source of comfort and by men as an empowerment to face the culture of Eib (Shame).
- Community outreach home visits by trained LCOW that incorporate culturally appropriate education about breast cancer and breast health, in addition to offering free mammography screening vouchers can improve women's breast health knowledge and practices in less privileged areas.

8 POLICY AND RESEARCH IMPLICATIONS

- Women's ambivalence in prioritizing own health, their fear of diminished femininity and husband's rejection could be changed positively through mobilizing family and social support.
- The perceptions and attitudes of men towards breast cancer and breast health are fundamental and integral for the development of effective breast health promotion strategies. Thus, breast health awareness interventions should be gender conscious and should involve husbands to capitalize on family support.
- There is a need for breast health awareness interventions that address women's fears from breast cancer through emphasizing the good prognosis of the disease when detected early and involving breast cancer survivors to provide a living example of winning the survival battle against breast cancer.
- There is a need for educational interventions that address breast cancer stigma in the society and the misconceptions about breast cancer being contagious.
- There is a need for enhancing Jordanian women's access to breast screening services delivered by female health providers. In addition to conducting research to explore the perceptions of health care providers towards breast cancer and early detection examinations.
- There is a need for further qualitative research that explores the individual and contextual perceptions of women inflicted with breast cancer and their spouses to better understand the aspects related to husband's potential rejection of breast cancer inflicted wives.
- Although the community outreach interventions that we assessed in this thesis were associated with a significant improvement in women's breast health knowledge and practices, still there is a need for further research to assess their cost effectiveness and long term sustainability.
- Finally, as breast health practices are influenced by the socio-cultural context, I do believe that this doctoral research will enrich the literature by providing a better understanding of women's ambivalence towards breast cancer and breast health in Jordan. The findings of this doctoral research were used by the JBCP to design culturally appropriate breast health promotion interventions that were specifically tailored to overcome the barriers and catalyse on the facilitators in Jordan. In October 2011 JBCP designed a national campaign that for the first time addressed Jordanian men with the theme *"She'll listen to you…encourage her to get screened"*. I hope that recognizing the voices of Jordanian women could contribute to earlier detection of breast cancer and thus to higher survival rates.

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11 APPENDICES

Appendix 1: Article I, data collection instruments

a. Article I, group lecture pre-test questionnaire

Filled by the educator	Year		Educator name	
	Lecture date	/ /	Lecture number	
	Woman code		Governorate	

Filled by the woman	Marital Status		Single	Married	Divorced	Widow
	Age/ Date of Birth:					
	Work	Housewife	Gov. employee	Private employee	Other	

Assessment of practices:	
Do you know how to do breast self-examination? Yes No	Have you ever done breast self-examination? Yes No
Have you ever had Mammography screening? Yes No	Have you ever had clinical breast examination? Yes No
Have you ever attended a lecture on breast cancer? Yes No	When was your last mammogram?

Pre-test, assessment of breast health knowledge ***Question***	***True***	***False***
The probability of the woman getting breast cancer increases at the age of 40		
Breast cancer is a curable disease		
Breast cancer curability and survival rates depends on the stage of the detection of the disease weather it is early detection or late		
All breast lumps are malignant		
Breast secretions are normal regardless of the colour		
Breast cancer is always associated with pain		
Getting breast cancer means mastectomy		
Breast feeding protects the woman from breast cancer		
There is an association between breast cancer and obesity		
If the woman feels any abnormality in the breast she must seek the doctor advice		
Monthly BSE helps the woman to notice any abnormal changes in the breast as soon as they occur		
Breast self-examination includes checking the armpit		
A woman is advised to practice breast self-examination starting from age 20		
A woman is advised to practice clinical breast examination starting from age 20		
A woman is advised to do a mammogram once every one or two years starting from the age 40		

b. Article I, group lecture post-test questionnaire

Date: Educator name: Lecture number: Woman code: Governorate: Area:		
Post- test, assessment of breast health knowledge		
Question	**True**	**False**
The probability of the woman getting breast cancer increases at the age of 40		
Breast cancer is a curable disease		
Breast cancer curability and survival rates depends on the stage of the detection of the disease weather it is early detection or late		
All breast lumps are malignant		
Breast secretions are normal regardless of the colour		
Breast cancer is always associated with pain		
Getting breast cancer means mastectomy		
Breast feeding protects the woman from breast cancer		
There is an association between breast cancer and obesity		
If the woman feels any abnormality in the breast she must seek the doctor advice		
Monthly BSE helps the woman to notice any abnormal changes in the breast as soon as they occur		
Breast self-examination includes checking the armpit		
A woman is advised to practice self-breast examination starting from age 20		
A woman is advised to practice clinical breast examination starting from age 20		
A woman is advised to do a mammogram once every one or two years starting from the age 40		

Notes about the lecture:

Appendix 2: Article II, focus group guide

- What is your assessment of your general health status over the past year?
- Are there certain practices you do to stay healthy? What are they?
- From where do you acquire your knowledge about health issues?
- When you think about approaching healthcare, who would you ask or consult before you seek health care?
- What comes to your mind when you think about breast cancer?
- What could happen to a woman who gets diagnosed with breast cancer?
- What things do you think makes the woman more susceptible to breast cancer?
- Can the woman protect herself from breast cancer? How?
- What do you know about ways to detect breast cancer at an early stage? From where did you gain this knowledge?
- Have you experienced any constrains in practicing breast cancer early detection examinations? Why? What are these constrains?
- What can make it easier for you to practice breast cancer early detection examinations? In your opinion what could influence your decision to seek breast cancer early detection examinations?

Appendix 3: Article III, semi-structured interview guide

- What comes to your mind when you think about breast cancer? Why?
- Do you think that the women within your family (wife, mother, sister, daughter) are susceptible to breast cancer? why?
- Did you ever know or hear about a woman who had breast cancer? In your context, what could happen to a woman who gets diagnosed with breast cancer?
- Can the woman protect herself from breast cancer? How? Did you previously hear or see anything about breast cancer early detection? what? where?
- What is your role in the health of the women within your family? Do the women within your family comply with periodic breast examinations? How do you feel about that?

Appendix 4: Article IV, data collection instruments

a. Article IV, first home visit pre-test questionnaire

Personal Information			
Home code: Woman code:		Educator Name:	Date :
Address:			
Marital Status: □ Single	□ Married	Divorced □	□ Widow
Family Income :	Husband Occupation:		
Type of health Insurance :□ RMS □ Public		□ Private □ No Insurance	Age/Date of birth:
Educational Level :		Husband Educational Level:	
Nature of work □ House Wife □ Public Sector □ Non -Governmental Sector			□Other, Specify:
Are you pregnant: □ yes □ No	If the answer is yes	Date of last menstruation	

Assessment of the risk factors			
Are there any previous or current cases in your family of one of the following types of cancer :			
	Breast	Ovarian	Prostate
Relative degree			
Age of diagnosis			

Did you undergo breast biopsy before?	□ Yes	□ No	□ Not Sure
Did you have breast cancer before?	□ Yes	□ No	□ Not Sure
What is the stage at which the disease was discovered?			
Did you have any other type of cancer?	□ Yes	□ No	□ Not Sure
Type of Cancer:			
Do you take any oestrogen containing hormonal therapy?	□ Yes	□ No	□ Not Sure
Specify: □Alternative hormones after menopause □ For treatment of osteoporosis □ Contraceptives (when) (for how long) □ Other reasons …			
Did you have late onset of menopause after the age of 55 years (at a late age)?	□ Yes	□ No	□ Not Sure
Did you give birth to your first child after the age of 35 years old?	□ Yes	□ No	□ Not Sure
Have you started menstruation before the age of 12 years?	□ Yes	□ No	□ Not Sure
Did you breastfeed your children?	□ Yes	□ No	□ Not Sure
Number of children who were breastfeed	Average breast feeding duration for each child:		
Where you exposed to radiation therapy?	□ Yes	□ No	□ Not Sure
Specify : □			
Are you eating a lot of fatty foods? (Such as lamb or butter)	□ Yes	□ No	□ Not Sure
Do you continuously practice exercise or have physical activity	□ Yes	□ No	□ Not Sure
Do you smoke?	□ Yes	□ No	□ Not Sure

Pre-test, assessment of practices:
Do you know how to do breast self-examination : □ Yes □ No
Have you ever done a clinical examination of the breast? □ Yes □ No
Have you ever Mammography of the breast? □ Yes □ No
When is the last time you did breast mammography?
Have you ever attended any lecture about breast cancer? □ Yes □ No

Pre-test, assessment of breast health knowledge	**True**	**False**
The probability of the woman getting breast cancer increases at the age of 40		
Breast cancer is a curable disease		
Breast cancer curability and survival rates depends on the stage of the detection		
All breast lumps are malignant		
Breast secretions are normal regardless of the colour		
Breast cancer is always associated with pain		
Getting breast cancer means mastectomy		
Breast feeding protects the woman from breast cancer		
There is an association between breast cancer and obesity		
If the woman feels any abnormality in the breast she must seek the doctor advice		
Monthly BSE helps the woman to notice any abnormal changes in the breast as soon as they occur		
BSE includes checking the armpit		
A woman is advised to practice BSE starting from age 20		
A woman is advised to practice CBE starting from age 20		
A woman is advised to do a mammogram once every one or two years starting from the age 40		
Early detection examinations are recommended only for married women		

The result of the session		
Action: Referral to mammography □ Yes □ No		Notes
Need to follow up visit	□ Yes □ No	
Number of women who attended the session ( ) including the one filled this form		Referral Voucher form No.:

b. Article IV, post-test questionnaire that was used for data collection in the after six months follow-up visit

Form number: Home code: Woman Code :	Educator name:	Date:

Post-test, assessment of breast health knowledge after six months of the visit	True	False
The probability of the woman to get breast cancer increases at the age of 40		
Breast cancer is a curable disease		
Breast cancer curability and survival rates depends on the stage of the detection		
All breast lumps are malignant		
Breast secretions are normal regardless of the colour		
Breast cancer is always associated with pain		
Getting breast cancer means mastectomy		
Breast feeding protects the woman from breast cancer		
There is an association between breast cancer and obesity		
If the woman feels any abnormality in the breast she must seek the doctor advice		
Monthly BSE helps the woman to notice any abnormal changes in the breast as soon as they occur		
BSE includes checking the armpit		
A woman is advised to practice BSE starting from age 20		
A woman is advised to practice CBE starting from age 20		
A woman is advised to do a mammogram once every one or two years starting from the age 40		
Early detection examinations are recommended only for married women		

Post-test, assessment of practices after six months of the first home visit
Do you know how to do BSE: □ Yes □ No Did you practice regular BSE during the last six months: □ Yes □ No
Did you do a CBE during the last six months? □ Yes □ No
Did you do mammography of the breast during the last six months? □ Yes □ No

Barriers of breast health practices in the six months after the first visit

Barrier	**Notes**