Barriers to and facilitators for breast cancer screening among Lebanese women.

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Abstract

Background: In Lebanon, breast cancer (BC) is the most common cancer among females. Previous studies around the world have shown that early detection through screening can reduce BC mortality and increases the treatment choices. **Aim:** This thesis explores barriers and facilitators to Lebanese women's participation in BC screening services. **Methods**: This aim was achieved by using a mix of qualitative and quantitative methods. A knowledge, attitudes and practices survey was administered with 231 Lebanese women and 17 focus groups discussions were facilitated with 163 women living in eight governorates across Lebanon. 12 interviews were also conducted with key informants, in addition to six women survivors of BC. The health belief model was utilized to structure, guide and explain the thesis findings and analysis. **Results:** From the different methods used, I obtained some reliable findings regarding Lebanese women's perceptions, knowledge and beliefs of the barriers and facilitators in accessing BC screening services. Barriers to BC screening include family, knowledge and awareness, perceived susceptibility, healthcare system and experience, self-efficacy, psychological, social, cultural, economic, geographical, as well as religious and fear related factors. Facilitators to screening were related to family, self-motivation and practices, awareness campaigns and knowledge about BC, physicians and healthcare professionals, as well as economic, religious and social factors. Residing in urban areas and being employed, educated or insured influences also women's participation in BC. **Conclusion**: There are multiple intertwined factors and identified barriers that simultaneously influence Lebanese women's decision making process to seek screening. A woman would weigh the different factors, fears and expected outcomes, rather than each element separately. Even when the levels of "ever conducting a mammography test" were relatively high in certain occasions this behavior is not maintained but rather conducted intermittently or on one single occasion in a lifetime. Religion, age, geographical locations and health coverage also play a significant role in influencing women's decision towards screening. **Recommendations:** In order to increase women's participation in BC

screening, tackle the identified barriers and capitalize on the facilitators, policies, campaigns and programs can work towards tailoring awareness raising campaigns and adopting more personalized communication and messaging with women, increasing engagement of family members and community-based organizations, placing more attention on women in rural areas, providing psycho-social support for patients and women seeking screening, working on prevention in addition to early detection, encouraging breast self-examination and improving the comfort of mammography experience.

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1 Acknowledgments and Dedications

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This thesis is dedicated to my mother Mariette, my survivor who was my main inspiration since the beginning to enroll in this PhD program, to choose this research subject in particular, to share awareness around me and be able to complete my thesis. She has been fighting BC since 2014 and she doesn't know that by Staying Strong she is inspiring me every day.

2 Declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's regulations and Code of Practice for Research Degree Programs and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Any views expressed in the dissertation are those of the author.

3 Introduction

This section discusses the epidemiology of cancer and Breast cancer (BC), BC screening, and BC risk factors using worldwide statistics as well as from the Arab World and Lebanon specifically. It also elaborates on the context of the research and justifies the focus of the thesis.

3.1 Cancer worldwide

Cancer is classified as one of the leading causes of morbidity and mortality worldwide. More particularly, it is considered as the second leading cause of death after cardiovascular diseases (CVDs) in developed countries, and the third in developing ones. Approximately 8.2 million people are dying yearly from cancer, which consists almost 13% of all deaths worldwide. In 2012, the annual number of cancer cases was 14 million and it is expected to rise by about 70% within the next two decades. In 2015, cancer was responsible for 8.8 million deaths though it is considered as the second leading cause of death globally where nearly one in six deaths is due to cancer.[1]

More than 70% of all cancer related deaths occur in low- and middle-income countries, where resources available for prevention, diagnosis and treatment of cancer are limited or nonexistent. Nearly 40% of these deaths events can be prevented through risk factor management. Disease burden can, in fact, be

[1] World Health Organization, retrieved from WHO website: http://www.who.int/en/ retrieved 30/07/2018.

reduced by one-third with timely diagnosis and treatment.[2] A person's risk of developing cancer depends on many factors, including age, genetics, and exposure to several risk factors (including some potentially avoidable lifestyle factors). These risk factors are overall similar worldwide. Smoking, insufficient physical activity, alcohol consumption, unhealthy diet, overweight and obesity and infections contribute to an increasing proportion of cancers worldwide and in Lebanon as the figure 1 shows. Prevalence of different risk factors varies by region and country, this is partly why overall cancer incidence rates, and the most common types of cancer, do vary as well.

Figure 1: Adult cancer risk factors in Lebanon -World Health Organization – Cancer Country Profiles, 2014.

Risk Factors	Males	Females	Total
Current tobacco smoking (2011)	42.7%	21.9%	31.9%
Total alcohol per capita consumption, in liters of pure alcohol (2010)	3.9	0.8%	2.4
Physical inactivity (2010)	43.7%	34.2%	39.1%
Obesity (2014)	26.1%	35.7%	30.8%
Household solid fuel use (2012)	-	-	0.0%

3.2 BC worldwide

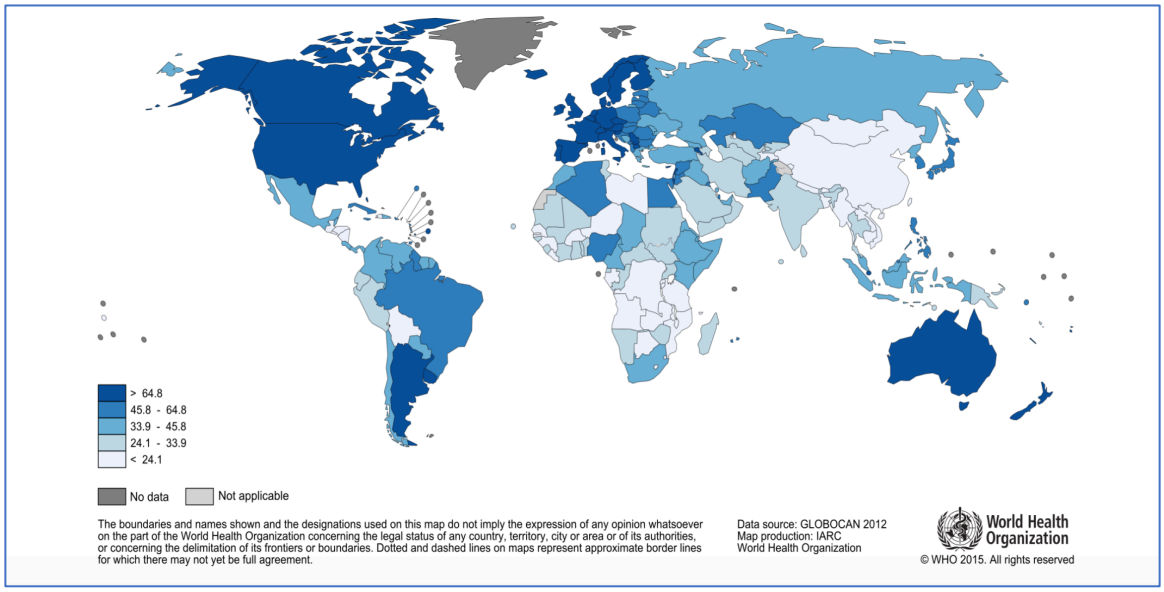
The incidence, mortality and economic costs of BC in women globally have been increasing as indicated in public health data. One over eight women worldwide can suffer from BC during their lifetime.[3] BC Incidence rates vary nearly four-fold

[2] World Health Organization WHO (2007), Cancer control: knowledge into action: WHO guide for effective programs ; module 2.

[3] DeSantis C, Ma J, Bryan L, & al, (2014). Breast Cancer Statistics, A Cancer Journal for Clinicians, Volume 64, Issue 1.

across the world regions, with rates ranging from less than 24.1 per 100,000 in Middle Africa and Eastern Asia to 92 in Northern America.[4,5,6]

Figure 2: Estimated Breast Cancer Incidence Worldwide in 2012 – Age Standardized Rates (World) per 100,000



BC is the most frequent cause of cancer death in women in less developed regions (324,000 deaths, 14.3% of total) and the second in more developed regions (198,000 deaths, 15.4%) coming after lung cancer. BC is also the most frequently diagnosed cancer and the leading cause of cancer death among females worldwide, accounting respectively for 25.2% of total cancer cases (excluding non-

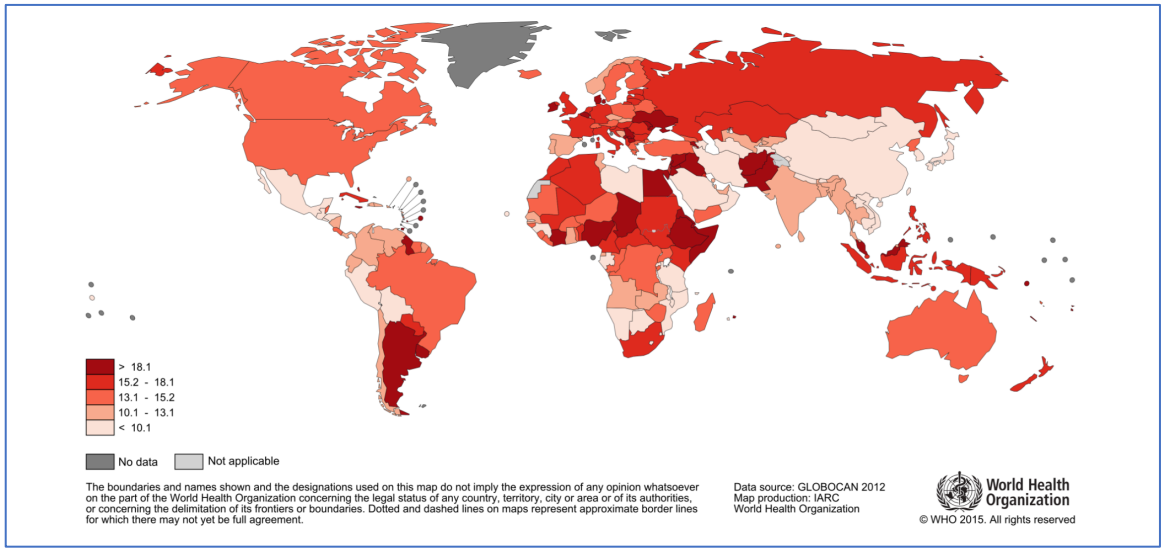
[4]Globocan 2012, IARC, Section of Cancer Surveillance, Retrieved from http://globocan.iarc.fr/old/FactSheets/cancers/breast-new.asp. retrieved June 15, 2017.

[5] World Health Organization. WHO Fight against Cancer: Strategies that Prevent, Cure and Care; 2007. Retrieved from http://www.who.int/cancer/ publicat/WHOCancerBrochure2007.FINALweb. pdf. retrieved April 14, 2017.

[6] Hortobagyi, G., De la Garza Salazar, J., Pritchard, K., et al. (2005) The global breast cancer burden: variations in epidemiology and survival. Clin Breast Cancer;6(5):391–401.

melanoma skin cancers) and 14.7% of cancer deaths in 2012.[7] It is considered as a major worldwide public health problem with an estimated 1,38 million women diagnosed yearly, and more than half a million of death cases.[8] At the same time, the burden of BC varies between countries and regions showing differences in incidence, mortality and survival.

Figure 3: Estimated Breast Cancer Mortality Worldwide in 2012- Age Standardized Rates (World) per 100,000



Incidence rates of BC are on the rise in developing countries. For Example, in the Arab world, it is the most common cancer among women, and its incidence and

[7] Ferlay et al, (2015). Cancer incidence and mortality worldwide: Sources, methods and major patterns in GLOBOCAN 2012. International Journal Of Cancer. Volume 136. Issue5.1 March 2015.Pages E359-E386.

[8] Al Nsour, M., Brown, D., Tarawneh, M., Haddadin, R. et al. (2007). Breast and Cervical Cancer Screening Among Women in Jordan: Findings from the Behavioural Risk Factor Surveillance System, The Open Breast Cancer Journal, 2012, 4, 1-7.

mortality rates have been consistently increasing during the last three decades.[9] In this region, BC constitutes between 13-35% of all female diagnosed cancers.[10] Despite this fact, low participation in BC screening activities has been reported among Arab women, who are now diagnosed at more advanced stages of the disease.[11] They develop BC at a median age of 49-52 which is significantly higher in comparison to other women from developed countries where it is 63 years old.[12]

3.3 BC in Lebanon

Lebanon is a small developing Arab country, located in the Middle East, with a total area of 10 452 Km^2 and an estimated total population of 3,759,137 in 2007 (of whom 50.6% are females).[13] It is an open and culturally diverse country. The level of literacy among Lebanese adults is relatively higher than that in the neighboring countries. The adult illiteracy rate was 89.6% in 2008–2012, with no major differences between men and women.[14] Its health indices are closer to the more

[9] Nojomi, M., Namiranian, N., Myers, R.E., et al. (2014). Factors Associated with Breast Cancer Screening Decision Stage among Women in Tehran, Iran. Int J Prev Med;5(2):196-202.

[10] El Saghir, N., Khalil, M., Eid,, T., et al. (2007) Trends in epidemiology and management of breast cancer in developing Arab countries: a literature and registry analysis. Int J Surg 5: 225-233.

[11] Al Nsour, M., Brown, D., Tarawneh, M., et al (2012). Breast and Cervical Cancer Screening Among Women in Jordan: Findings from the Behavioural Risk Factor Surveillance System 2007, The Open Breast Cancer Journal, 4, 1-7.

[12] Donnelly, T., Al Khater, A, Al-Bader, S., Al Kuwari, M., Al-Meer, N., Malik, M., Jong, F. (2013). Arab Women's Breast Cancer Screening Practices: A Literature Review. *Asian Pacific Journal of Cancer Prevention*, *14*(8), 4519–4528.

[13]Presidency of the council of ministers, Central Administration of statistics, retrieved from http://www.cas.gov.lb/index.php/about-lebanon-en retrieved June 5, 2018.

[14] United Nations Educational, Scientific and Cultural Organization (UNESCO) and UNESCO/UIS (UNESCO Institute of Statistics), including the Education for All 2000 Assessment retrieved from http://uis.unesco.org/country/LB.

developed countries: for example, the Infant Mortality rate (under 1) in Lebanon (in 2017), is 9 per thousand;[15] the Maternal Mortality ratio (2015) is 15 per 100,000 live births[16] and the Life Expectancy at Birth in 2017 was 79.4.[17]

In Lebanon, BC has been the most frequent cancer among women since data started being published in the late 1950s.[18] This prevalent type of cancer accounts for about 35 to 40% of all cancers seen in Lebanese women and 21% of overall cases among Lebanese cancer patients (males and females).[19]

Almost 2000 new cases are being diagnosed among Lebanese women on yearly basis as shown in chart 1, with half of them detected among women under the age of 50.[20] The latest statistics of the Lebanese National Cancer Registry (NCR) report accounts for 2574 new cases of diagnosed cancer in 2015.[21] More precisely and as illustrated in Table 1, Lebanon is renowned worldwide for having some of the highest age-specific incidence rates.

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[15] United Nations, Department of Economic and Social Affairs, Population Division (2017). World Mortality 2017: Data Booklet. New York: United Nations.

[16] WHO, UNICEF, UNFPA, World Bank Group, and the United Nations Population Division. (2015). Trends in Maternal Mortality: 1990 to 2015. Geneva, World Health Organization, 2015.

[17] United Nations, Department of Economic and Social Affairs, Population Division (2017). World Mortality 2017: Data Booklet. New York: United Nations.

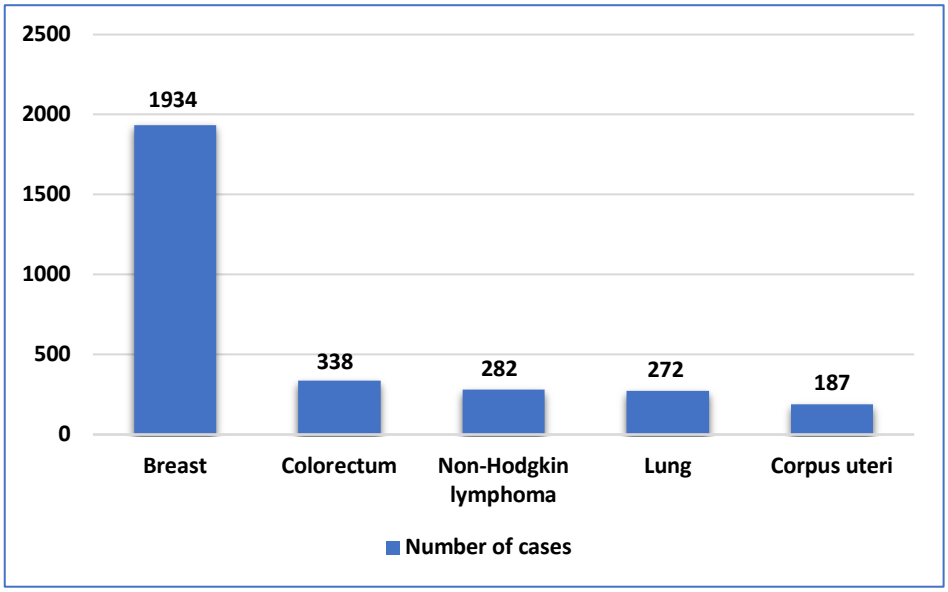
[18] Azar, H. (1962). Cancer in Lebanon and the near east. *Cancer*, *15*(1), 66–78.

[19] Doumit, M., AbuSaad, H., Kelley, J., El Saghir, N., et al. (2010). Coping With Breast Cancer: A Phenomenological Study. Cancer Nursing TM, Vol. 33, No. 2, n E33.

[20] El Saghir, N. (2017). 5th Annual Beirut Breast Cancer Conference, retrieved from article https://www.annahar.com/article/537530.

[21] Lebanese National Cancer Registry (2015), retrieved from www.publichealth.gov.lb on June 10, 2017.

Chart 1: Cancer incidence among Lebanese females in Lebanon - World Health Organization - Cancer Country Profiles, 2014



The age-specific rates of BC per 100.00 females were reported as follows: 32.8 for the age group 30-34 years old; 73.2 for the age group 35-39 years old; 160.8 for the age group 40-44 years old and 311.7 for the age group 45-49 years old.[22] Over 40 years old, the age-specific rates of BC per 100.00 females was reported in 2015 as 2543.1. A study by El Saghir et al. (2002) assessing the age distribution of BC in Lebanon, reported that a significant number of women were in younger age groups than those reported for western countries. To further investigate cancer incidence trends in Lebanon, Shamseddine et al. (2015) used the NCR data, used its trend to predict cancer incidence rates for the next decade. BC incidence

[22] Lebanese National Cancer Registry (2015), retrieved from www.publichealth.gov.lb on June 10, 2017.

projection in females were predicted to reach 146.1 per 100 000 for the year 2020.[23]

Table 1: Incidence rates of BC among Lebanese women per age groups- LNCR Application, Epidemiology Surveillance Program, Lebanese Ministry of Public Health, 2015

Age group	Year 2015 Female
0-4y	0.0
5-9y	0.3
10-14y	0.0
15-19y	0.4
20-24y	0.7
25-29y	10.0
30-34y	32.8
35-39y	73.2
40-44y	160.8
45-49y	311.7
50-54y	387.0
55-59y	352.2
60-64y	278.0
65-69y	308.7
70-74y	374.9
75+y	369.8
Crude Rate	**84.2**

3.4 Mortality rates of BC

The cancer mortality profile reported by the WHO in 2014 in Lebanon shows that 26.2% of deaths among Lebanese women were from BC.[24] As shown in Figure 4, the age-standardized death rate per 100,000 Lebanese females from BC dropped from around 34 in 2000 to less than 25 in 2012. This rate is notably higher than

[23] Shamseddine, D. (2015). Cancer Trends in Lebanon & Projections to 2020. *HUMAN & HEALTH*, (32). Retrieved from https://www.syndicateofhospitals.org.lb/Content/uploads/SyndicateMagazinePdfs/8217_8-11.pdf retrieved June 10, 2017.

[24] World Health Organization - Cancer Country Profiles (2014) retrieved from http://www.who.int/cancer/country-profiles/lbn_en.pdf.

the average of the world age-standardized rates reported in 2012 as around 15 per 100,000. The range in mortality rates between world regions is less than that for incidence, because of the more favorable survival of BC in (high-incidence) developed regions, with rates ranging from 6 per 100,000 in Eastern Asia to 20 per 100,000 in Western Africa, notably less than the same rates measured in Lebanon as Figure 5 shows.

Figure 4: Age-Standardized Cancer Mortality Trends among Lebanese women - World Health Organization - Cancer Country Profiles, 2014

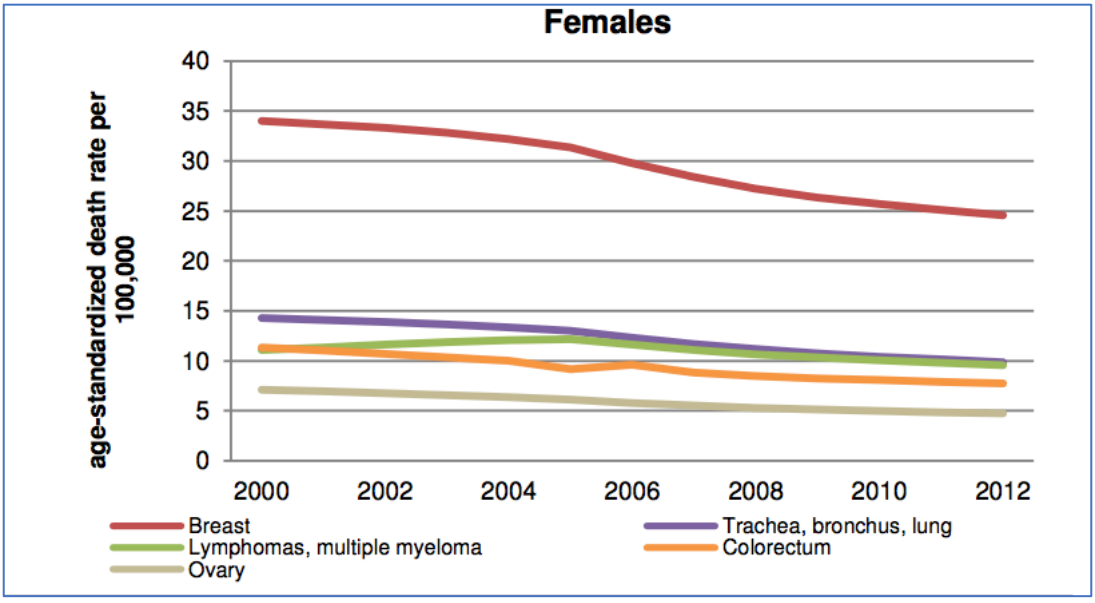
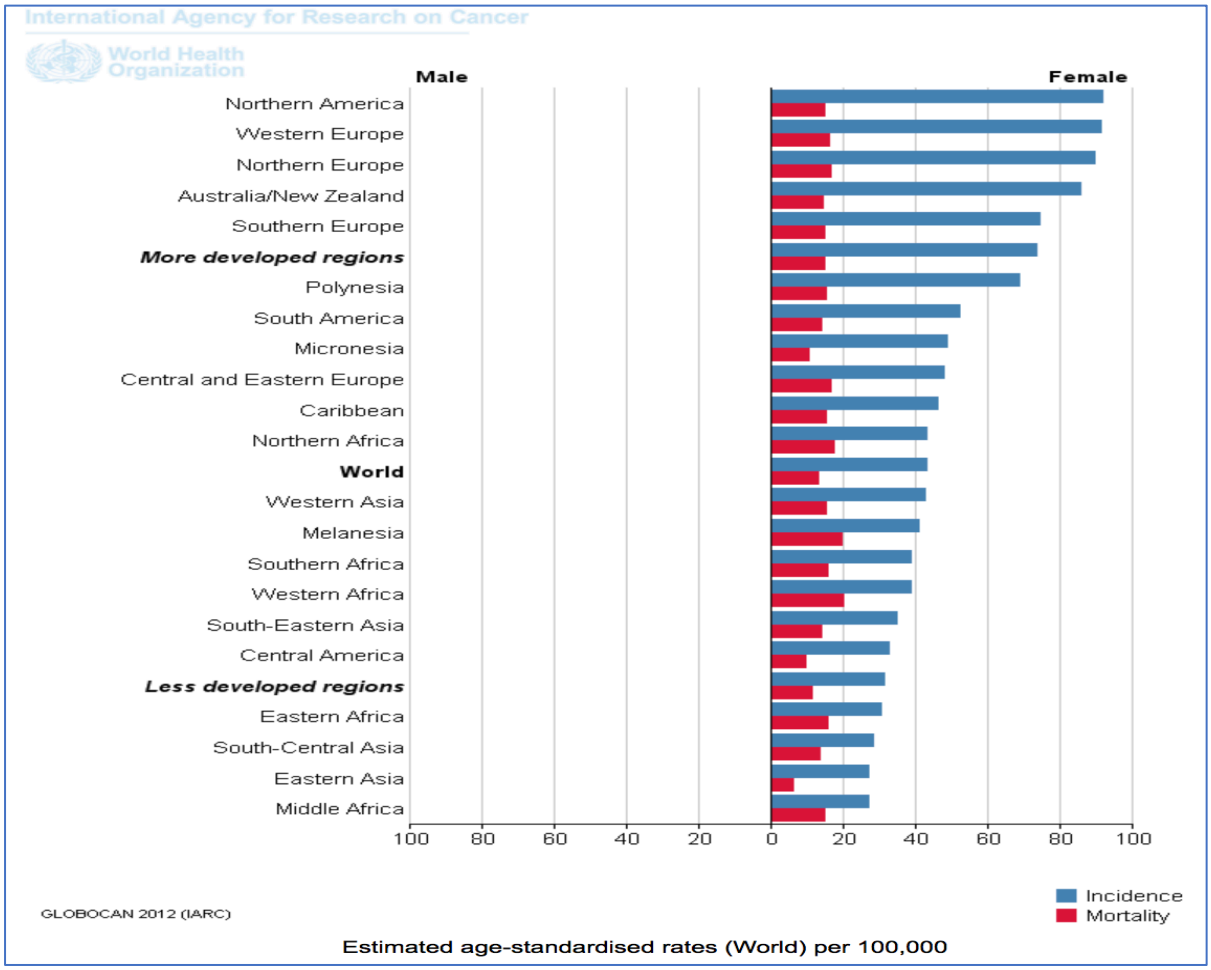


Figure 5: World Estimated age-standardized rates of incidence and mortality of BC among Females – World Health Organization, Globocan 2012 (IARC)



3.5 Early Detection of BC

Treatment modalities of BC have largely advanced during the last three decades which unquestionably affected survivors' quality of living, progression free survival and overall survival.[25] Similarly, mortality rates from BC have been dropping

[25] Adib, S., El Saghir, N., Ammar, W. (2009). Guidelines for breast cancer screening in Lebanon. Public Health Communication. Le Journal médical libanais. The Lebanese medical journal. 57. 72-4.

steadily since 1990. This was due to earlier detection and better treatment[26] which remains the most relevant prognostic factor for BC cure.[27]

Early detection of BC comprises two strategies: (1) early diagnosis and (2) screening. Early diagnosis consists of improved public and professional awareness of symptoms and signs of cancer. It allows the recognition of possible cases of cancer and taking immediate action and treatment at early stage. Early detection through screening tests and methods used to diagnose BC includes many tests such as screening mammography, breast ultrasound, breast MRI and clinical breast exam (CBE) and, to some degree breast self-examination (BSE).

Early detection is considered as the most effective method for reducing death and mortality rates caused by BC,[28] and it is highly recommended all over the world.[29] Mammographic screening were reported to reduces BC mortality by 23%.[30] When BC is detected at an early stage, women have higher chances of responding

[26] Boyle, P., Ferlay, J. (2005). Cancer incidence and mortality in Europe, 2004, *Annals of Oncology*, Volume 16, Issue 3, Pages 481–488.

[27] Adib, S., El Saghir, N., Ammar, W. (2009). Guidelines for breast cancer screening in Lebanon. Public Health Communication. Le Journal médical libanais. The Lebanese medical journal. 57. 72-4.

[28] Ibid.

[29] Javitt, M. (2012). Diagnosis and Management of High-Risk Breast Lesions: Aristotle's Dilemma. *American Journal of Roentgenology*, *198*(2), 246–248. https://doi.org/10.2214/AJR.11.7269.

[30] Wang, Y., Waters, J., Leung, M. L., Unruh, A., Roh, W., Shi, X.,Navin, N. E. (2014). Clonal Evolution in Breast Cancer Revealed by Single Nucleus Genome Sequencing. *Nature*, *512*(7513), 155–160.

successfully to treatment,[31] and be cured.[32] Survival rates have been significantly increasing, and for women living in developing countries, it is estimated that half of them living with BC, will survive for 5 years.[33] The early diagnosis of BC increases this five-year survival rate to 98%. The latter widespread use with the advancement in treatment are proven to be effective in reducing BC mortality among women (50 to 74 years old), and to a lesser extent among those aged between 40 to 49 years old.[34]

Improvements in BC screening and early detection can be better achieved with a wide-ranging understanding of the fundamental risk factors discouraging such behaviors. Many risk factors for BC reported in Lebanon, such as family history of BC, minor breast lacerations, smoking, obesity among post-menopausal women, the use of oral contraceptive pills, breastfeeding for very short durations, late age at first birth as well as late menopause, are found to be resembling those in other Middle Eastern countries and in the developed world.[35]

Furthermore, the introduction of advanced BC screening methods such as digital mammography, to the Lebanese market improved cancer detection rates, hence

[31]Bener, A., El Ayoubi, H., Moore, M., et al. (2009). Do we need to maximize the breast cancer screening awareness? Experience with an endogamous society with high fertility. Asian Pac J Cancer Prev,10, 1-6.

[32] Nojomi, M., Namiranian, N., Myers, R., et al. (2014). Factors Associated with Breast Cancer Screening Decision Stage among Women in Tehran, Iran. Int J Prev Med ;5(2):196-202.

[33] Stewart, B., Kleihues, P., (2003). World Cancer Report. World Health Organization. Lyon. IARC Press; 2003

[34] Division of Cancer Prevention and Control, Center for disease control and prevention (2007).

[35] Elias, N., Bou-Orm, I., Adib, S. (2016) Patterns and determinants of mammography screening in Lebanese women. Prev Med Rep. 2016;5:187–93.

contributing to the rise in incidence rates. Digital mammography is significantly more accurate than regular film mammography in detecting cancer in women under the age of 50 years, women with dense breasts, and premenopausal or peri-menopausal women.[3637]

The importance of improving diagnosis at earlier stages has led to many awareness campaigns and initiatives aiming at increasing screening by mammography. Each country implements guidelines differently depending on the disease's epidemiologic characteristics.

The United States Preventive Services Task Force (USPSTF) recommends biennial screening mammography for women aged 50-74 years and leaves the decision to initiate screening mammography for women aged 40 to 49 years for their personal decision.[38] Women who place a higher value on the potential benefit than the potential harms may choose to begin biennial screening between the ages of 40 and 49 years. More specifically, women with a parent, sibling, or child with

[36] Pisano, E., Hendrick, R., Yaffe, M., Baum, J., Acharyya, S., Cormack, J., Gatsonis, C. (2008). Diagnostic Accuracy of Digital versus Film Mammography: Exploratory Analysis of Selected Population Subgroups in DMIST. *Radiology*, *246*(2), 376–383.

[37] Hou, N., Hong, S., Wang, W., Olopade, O., Dignam, J., & Huo, D. (2013). Hormone Replacement Therapy and Breast Cancer: Heterogeneous Risks by Race, Weight, and Breast Density. *JNCI Journal of the National Cancer Institute*, *105*(18), 1365–1372.

[38] Final Update Summary: Breast Cancer: Screening. U.S. Preventive Services Task Force. Feb 2018. Retrieved from https://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/breast-cancer-screening.

BC are at higher risk for BC and thus may benefit more than average-risk women from beginning screening in their 40s.[39]

3.6 Lebanese BC Awareness campaign

During the last few years, many awareness campaigns around BC were launched in different Asian and Middle eastern countries that share similar cultural and religious characteristics, but the international targets are still far from being reached despite all the efforts.

The Lebanese Ministry of Public Health's (MoPH) recommendations, published in 2009, specified the age of 40 as a starting age for screening with an annual mammogram, while the duration remains as long as the woman is in good health,[40] whereas most western countries recommend starting the screening at the age of 50 years.[41][42] A particularity in Lebanon is the presence of relatively high age specific incidence rates at age groups younger than 50 years, which supports the current national recommendation of starting screening at the age of 40 years old.

[39] Adib, S., Sabbah, M., Hlais, S., Hanna, P. (2009). Research in action: mammography utilization following breast cancer awareness campaigns in Lebanon 2002-05.

[40] Ibid.

[41] Forouzanfar, M., Foreman, K., Delossantos, A., Lozano, R., Lopez, A., Murray, C., et. al (2011). Breast and cervical cancer in 187 countries between 1980 and 2010: a systematic analysis, The Lancet, Volume 378, Issue 9801,2011,Pages 1461-1484,ISSN 0140-6736.

[42] Youlden, D., Cramb, S., Dunn, N., Muller, J., Pyke, C., Baade, P. (2012). The descriptive epidemiology of female breast cancer: An international comparison of screening, incidence, survival and mortality, Cancer Epidemiology. Volume 36, Issue 3,2012,Pages 237-248,ISSN 1877-7821.

Since 2002, the Lebanese MOPH has launched annual BC campaigns during the month of October. During recent years it extended to four months instead of only one. The latest 2017 MOPH BC awareness campaign started in October 2017 and ended in January 2018, it was entitled: “No excuses, do the mammography”.

During this annual campaign, mammograms are offered for free at governmental hospitals and for a reduced price at private ones reaching 40.000 Lebanese Lira (L.L.) an equivalent to 26.5$. Moreover, breast ultrasounds are offered at a reduced price at both governmental hospitals for 30.000 L.L (20$) and private ones at a price of 40.000 L.L. (26.5$).[43]

Women who participate to mammography tests in public hospitals during the awareness campaign, complete a questionnaire which is used by the MoPH to monitor and count the number of women participating in the screening tests. Therefore, this method constitutes the only type of assessment accounting for the number of yearly participants by the MoPH. From 2009 till 2016, the number of women benefiting from the MoPH’s offer for mammography has been consistent and reached 10.000 participant according by the director of the public relations and health education departments at the Lebanese MoPH. In 2017, the reported number of women participating in mammography tests in public and private hospitals across Lebanon, increased from 10.000 to 21.500 women (16.000 were reported from public hospitals).

[43] Ministry of Public health in Lebanon, retrieved from http://www.moph.gov.lb/Pages/Home.aspx.

In 2017 the duration of the duration of the campaign increased by an additional 1 month (reaching a total of 4 months) and the opening ceremony campaign was different from the previous years. It was held in a public football field on a Sunday, with less public officials and celebrities. The participants included public-school students mainly (aged between 12 and 17 years old) in an attempt to mobilize the youth. Each one of them went back home with a message from the Ministry written on a football specifying the need to remind mothers to go do the mammography during the upcoming 4 months.

The overall number of Lebanese women screened has increased due to the national campaign since it was launched,[44] but this rate is still considered to be low. An evaluation of the first three years of this program revealed that repeated mammograms are still less common than first screening. By 2013, ever-utilization of mammography had reached 43% and recent mammography 20% nationwide. Utilization was significantly more important in the age group 50-59 compared with the age group 40-49 or ≥60. While recent rates have increased nationwide, they have reached a plateau of about 25% in greater Beirut area (GB) and are tending to the same level in other areas.[45]

[44] Ministry of Public health in Lebanon, retrieved from http://www.moph.gov.lb/Pages/Home.aspx.

[45] Haddad, F., Hampig, K., Salim, A. (2015). Trends in mammography utilization for breast cancer screening in a Middle-Eastern country: Lebanon 2005–2013. Cancer Epidemiology. 39. 819-824. 10.1016/j.canep.2015.09.015.

Additionally, the rate of women screened for BC by mammograms is still lower than the rate in the developed countries.[46] As per the director of the public relations and health education departments at the Lebanese MoPH, the increase was most marked in the capital Beirut and its surrounding area where it went from 39% in 2005 to 52.7% in 2013. In other regions, the increase went from 23.9% in 2005 to 40.6% in 2013.[47]

[46] Pace, L., Keating, N.. (2014). A Systematic Assessment of Benefits and Risks to Guide Breast Cancer Screening Decisions. *JAMA.* 2014;311(13):1327–1335. doi:10.1001/jama.2014.1398.

[47] Haddad, F., Hampig, K., Salim, A. (2015). Trends in mammography utilization for breast cancer screening in a Middle-Eastern country: Lebanon 2005–2013. Cancer Epidemiology. 39. 819-824. 10.1016/j.canep.2015.09.015.

4 Aim and objectives of the thesis

This study aims at identifying and exploring both barriers and facilitators of BC screening among Lebanese women. The significance of this study is in it being a cumulative report combining, both, quantitative and qualitative methods, to examine barriers and facilitators to BC screening among Lebanese women from different regions, backgrounds and cultural characteristics.

The limited body of research available in Lebanon around this topic shows the lack of utilization of related healthcare services. As such, there is limited data that corresponds to the low levels of demand for screenings and why Lebanon has not achieved higher adoption rates for these screenings as compared to other developed countries.

To fulfil this aim, my thesis included the following objectives:

- Exploring Lebanese women's knowledge about screening services of BC.
- Assessing the barriers and facilitators Lebanese women face when accessing BC screening services.
- Exploring Lebanese women's experiences when accessing screening services
- Addressing potential solutions of how to make screening of cancer more accessible through policy and programmatic recommendations.

The intention of this research is to generate an in depth understanding of both the barriers and facilitators in order to guide future health promotion and public health

policies and awareness building efforts. The results will be shared and disseminated with health policy makers in Lebanon to influence and adapt service provision accordingly. Hopefully, this study will have an importance in improving diagnosis at earlier stages and will lead to more targeted awareness campaigns and initiatives aiming at increasing the participation of screening services, and thus reducing the morbidity rate associated with BC in Lebanon.

5 Problem Statement

BC among Lebanese women is one of the leading diseases in terms of morbidity and mortality rates. Early diagnosis is the most relevant prognostic factor for the cure of BC and reduced related death; the problem, in Lebanon, remains in its late identification. This is despite the efforts lead by the MoPH, in collaboration with, local and international non-governmental organizations to raise the awareness of women on the importance of regular screening. These services are typically provided free of charge or at a reduced rate during certain periods of the year so as to drive adoption of such programs. However, despite these efforts, these campaigns, along with the offered incentives, have not managed to significantly raise the participation of women in screening services.

6 Factors influencing women's participation in BC screening

Several studies have been conducted to better understand the reasons hindering women from accessing early detection services. Having knowledge and generating positive attitudes, is one of the factors influencing the decision of women to participate in screening programs.[48]

6.1 Knowledge

Lack of knowledge around BC screening methods has been found to be an important barrier for many women particularly associated with the lack of use of screening services in low-income and poorly educated minorities and elderly women. For example, in Jordan the low level of mammography usage could be partially attributed to lack of knowledge or awareness about its importance.[49] At the same time, there are similar studies that have found that even among Arab women with sufficient knowledge, their participation in screening activities remained very low.[50] Furthermore, in Kuwait, a survey concluded that early campaigns for screening BC should be recommended to eliminate the confusion

[48] Tang, T., Solomon, L., Yeh, J., Worden, J. (1999). The Role of Cultural Variables in Breast Self-Examination and Cervical Cancer Screening Behavior in Young Asian Women living in the United States. *J Behav Med*. 1999;22:419–436.

[49] Al Nsour, M., Brown, D., Tarawneh, M., Haddadin, R. and Walk, H. (2007). Breast and Cervical Cancer Screening Among Women in Jordan: Findings from the Behavioural Risk Factor Surveillance System - 2007, The Open Breast Cancer Journal, 2012, 4, 1-7.

[50] Taha, H., Halabi, Y., Berggren, V., et al. (2010). Educational intervention to improve breast health knowledge among women in Jordan. Asian Pac J Cancer Prev, 2010, 11, 1167-73.

of wrong perceptions about malignant mammary disease.[51] In Iran, the most common cause given for not doing BSE was the lack of knowledge on how to perform it.[52]

Another study conducted in the United Arab Emirates (UAE) examined the determinants of BC screening behavior and found that many encouraging factors included feeling of vulnerability, great level of knowledge in some of the participants, attitudes and beliefs about person responsibility for health, and the support from the social surrounding.[53] The same study discussed how the lack of knowledge about screening programs can act as a barrier to BC examination. Women who do not want to know if they have BC or feel neutral about it are less motivated to participate in screening activities.[54] Lower education has also been found to be an additional factor that may contribute to poor knowledge and infrequency of performing BC screening.[55]

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[51] Saeed, R., Bakir, Y., Ali, L. (2014). Are Women in Kuwait Aware of Breast Cancer and Its Diagnostic Procedures? Asian Pacific Journal of Cancer Prevention, Vol 15, 2014 , 6307-6313.

[52] Parsa, P., Kandiah, M. (2005). Breast cancer knowledge, Perception and breast self-examination practices among Iranian women. Int Med J, 4, 17-24.

[53] Elobaid, Y., Aw, T., Grivna, M., Nagelkerke, N. (2014). Breast Cancer Screening Awareness, Knowledge, and Practice among Arab Women in the United Arab Emirates: A Cross-Sectional Survey. PLoS ONE 9(9): e105783. doi:10.1371/journal.pone.0105783.

[54] Al-Qattan, M., Al Saleh, K., Al-Musallam, S., Masoud, G. (2008). Knowledge and factors affecting breast self- examination. Kuwait Medical Journal,2008, 40, 103-9.

[55] Al Nsour, M., Brown, D., Tarawneh, M., Haddadin, R., Walk, H. (2007). Breast and Cervical Cancer Screening Among Women in Jordan: Findings from the Behavioural Risk Factor Surveillance System - 2007, The Open Breast Cancer Journal, 2012, 4, 1-7.

There are barriers and facilitators to BC screening that extend beyond the level of knowledge. Such examples include personal, psychological, social and economic factors.[56]

6.2 Fear and cultural related factors

Cultural factors also play an important role in shaping women's attitudes towards screening. This finding has been well-established during a study analyzing a screening mammography program among Arab women.[57] Additionally, a study in Iran revealed that other reasons influencing women's decision to participate in screening services included forgetfulness, fear of finding a mass, doubting its value, and lack of time.[58]

Another study in Malaysia showed that the major barriers to BSE among urban women were the fear of being diagnosed with the disease and the lack of awareness.[59] Additional study in Egypt showed that the most frequent cited reason for not practicing the BSE was the fear of finding a lump followed by forgetfulness. Other stated reasons included lack of time, cultural and health beliefs and the

[56] Theisen, C. (2004) In Different Cultures, Cancer Screening Presents Challenges. JNCI Journal of National Cancer Institute 96 (1): 10-12.

[57] Akhtar, S., Nadrah, H., Al Habdan, M., El Gabbani, S., El Farouk, G., Abdelgadir, M., Al Saigul, A. (2010). First organized screening mammography programme in Saudi Arabia: preliminary analysis of pilot round. *Eastern Mediterranean Health Journal*, *16*(10), 1025-1031. doi:10.26719/2010.16.10.1025.

[58] Parsa, P., Kandiah, M. (2005). Breast cancer knowledge, Perception and breast self-examination practices among Iranian women. Int Med J, 4, 17-24.

[59] Al-Dubai, S., Ganasegeran, K., Alabsi, A. M., Manaf, M. R. A., Ijaz, S., Kassim, S. (2012). Exploration of Barriers to Breast-Self Examination among Urban Women in Shah Alam, Malaysia: A Cross Sectional Study. Asian Pacific Journal of Cancer Prevention, 13(4), 1627–1632. https://doi.org/10.7314/APJCP.2012.13.4.1627.

dislike to touch one's own breasts.[60]

In a study in UAE too, fear was described to be an important factor influencing women's participation in BC screening tests[61]. Similarly, a study in Yemen highlights fear of BC being detected as a major barrier to its screening.[62] The fear of pain and gossip were also mentioned in another study in Jordan focusing on women's health beliefs about mammography.[63]

Some other fear and cultural related barriers that prevent women from doing mammography were fear of the test itself, fear of the treatment in case of diagnosis and the needed permission of the husband to act which needs to be tackled with a way that considers culture and religion.[64] Besides, other factors mentioned in a study in Iran included the profession and family members.[65]

[60] Seif, N., Aziz, M. (2000). Effect of breast self- examination group of working women. J Egypt Natl Cancer Inst, 12, 105-15.

[61] Anagnostopoulos, F., Dimitrakaki, C., Fitzsimmons, D., Potamianos, G., Niakas, D., & Tountas, Y. (2012). Health beliefs and illness perceptions as related to mammography uptake in randomly selected women in Greece. Journal of Clinical Psychology in Medical Settings, 19(2), 147–164. https://doi.org/10.1007/s10880-011-9272-1.

[62] Ahmed, B. (2010). Awareness and practice of breast cancer and breast self-examination among university students in Yemen. Asian Pac J Cancer Prev, 11, 101-6.

[63] Petro-Nustas, W. (2001). Young Jordanian women's health beliefs about mammography. J Community Health Nurs,18, 177-94.

[64] Parsa, P., Kandiah, M., Abdul Rahman, H., Zulkefli, N.M.,(2006). Barriers for breast cancer screening among Asian women: a mini literature review, Asian Pacific Journal of Cancer Prevention : APJCP.

[65] Nojomi, M., Namiranian, N., Myers, R.E., et al. (2014). Factors Associated with Breast Cancer Screening Decision Stage among Women in Tehran, Iran. Int J Prev Med;5(2):196-202.

6.3 Socio-economic factors

Literature also showed a significant role that socio-economic factors play in affecting women's decision to seek screening services. Inequalities in availability and affordability were described in different studies as important factors influencing women's decision to seek medical care and to participate in BC screening activities.[66] For example, a study focusing of such factors among Asian women demonstrated the significance of knowledge, perception and socioeconomic barriers in women's decision on acceptance of such services.[67] Cases from turkey, Jordan and Iran revealed that the cost and lack of health insurance presented significant barriers to participation in BC screening.[68] On a more structural level, the availability of health insurance and affordability of such services have also been identified as barriers to screening.[69] Women with poor access to health care services and facilities are less likely to undergo mammography.[7071]

6.4 Perceived importance of screening

Studies also showed that women who do not want to know if they have BC or feel

[66] Adib, S., Sabbah, M., Hlais, S., Hanna, P. (2009). Research in action: mammography utilization following breast cancer awareness campaigns in Lebanon 2002-05. East Mediterr Health J, Jan-Feb;15(1):6-18.

[67]Parsa, P., Kandiah, M., Abdul Rahman, H., Zulkefli, N.M.,(2006). Barriers for breast cancer screening among Asian women: a mini literature review, Asian Pacific Journal of Cancer Prevention : APJCP.

[68] Cohen, M., Azaiza, F. (2010). Increasing breast examinations among Arab women using a tailored culture based intervention. Behav Med, 36, 92-9.

[69] Amin, T., Al Mulhim, A., Al Meqihwi, A. (2009). Breast cancer knowledge, risk factors and screening among adult Saudi women in a primary health care setting. Asian Pac J Cancer Prev, 10, 133-8.

[70] Schueler, K., Chu, P., Smith-Bindman, R. (2008). Factors associated with mammography utilization: a systematic quantitative review of the literature. J Womens Health (Larchmt)17: 1477-98.

[71] Von Euler-Chelpin, M., Olsen, A., Njor, S., Vejborg, I., Schwartz, W., Lynge, E. (2008). Socio-demographic determinants of participation in mammography screening. Int J Cancer 122: 418-23.

neutral about it, are less motivated to participate in screening activities.[72] According to a population based-survey in Greece, a less consistent understanding of BC was associated to more perceived barriers to mammography uptake and less perceived benefits of mammography screening. The same study also revealed that the benefits of the mammography screening are correlated with beliefs about the importance of the treatment, the perceived serious consequences of BC, scarcer barriers to screening with mammography and greater self-efficacy.[73]

6.5 Personal and Psychological factors

Evidence on existing barriers to BC screening in the Arab World can also include personal, psychological, religious and environmental characteristics.[74] Discouraging factors include anxiety, denial,[75] embarrassment and shyness.[76] Such barriers might include, women finding it unacceptable to touch their breasts, embarrassment of discussing it with others (family and relatives), bad impression about what others might think about it, stigma following the diagnosis, breast

[72] Al-Qattan, M., Al Saleh, K., Al-Musallam, S., Masoud, G. (2008). Knowledge and factors affecting breast self-examination. Kuwait Medical Journal, 40, 103-9.

[73] Anagnostopoulos, F., Dimitrakaki, C., Fitzsimmons, D., Potamianos, G., Niakas, D., Tountas, Y. (2012). "Health Beliefs and Illness Perceptions as Related to Mammography Uptake in Randomly Selected Women in Greece." Journal of Clinical Psychology in Medical Settings19(2): 147-164.

[74] Theisen, C. (2004) In Different Cultures, Cancer Screening Presents Challenges. JNCI Journal of National Cancer Institute 96 (1): 10-12.

[75] Elobaid, Y. E., Aw, T. C., Grivna, M., & Nagelkerke, N. (2014). Breast cancer screening awareness, knowledge, and practice among arab women in the United Arab Emirates: A cross-sectional survey. PLoS ONE, 9(9).

[76] Petro-Nustas, W. (2001). Young Jordanian women's health beliefs about mammography. Journal of Community Health Nursing, 18(3), 177–194.

examination is considered a taboo by the community and women might feel ashamed to uncover their breasts for examination or mammography.[77]

6.6 Healthcare and healthcare professionals

Arab women have been found to be more likely to participate in screening activities if recommended to do so by their health care provider.[78] At the same time, a study conducted in the UAE has found that the lack of proactive health care provider involvement in providing education or offering screening was a major barrier to BC activities.[79] In another study, Arab women shared that mistrust of health care and belief in predestination as a barrier to ongoing a mammography.[80] The absence of specialized centers as a study in Egypt shows, also influences negatively on women's decision to participate in BC screening tests.[81]

[77] Abdel-aziz, S., Smin, T., Al-gadeeb, M., et al. (2018). Perceived barriers to breast cancer screening among Saudi women at primary care setting. Journal of Preventive Medicine and Hygiene. 2018;59(1):E20-E29. 9.

[78] Lamyian, M., Hydarnia, A., Ahmadi, F., Faghihzadeh, S., Aguilar-Vafaie, M. (2007). Barriers to and factors facilitating breast cancer screening among Iranian women: a qualitative study. East Mediterr Health J, 2007,13, 1160-9.

[79] Bener, A., Alwash, R., Miller, C., Denic, S., Dunn, E. (2001). Knowledge, attitudes, and practices related to breast cancer screening: a survey of Arab women. J Cancer Educ,16, 215-20.

[80] Elobaid, Y., Aw, T., Grivna, M., Nagelkerke, N. (2014). Breast Cancer Screening Awareness, Knowledge, and Practice among Arab Women in the United Arab Emirates: A Cross-Sectional Survey. PLoS ONE 9(9): e105783. doi:10.1371/journal.pone.0105783.

[81] Seif, N., Aziz, M. (2000). Effect of breast self- examination group of working women. J Egypt Natl Cancer Inst, 12, 105-15.

7 Theoretical Framework

The Health Belief Model was used to inspire the quantitative and quantitative tools utilized in the study, as well as the analysis of the data generated and the proposed recommendations.

7.1 Behavioral Model

Beliefs play a key role in the explanation and determination of actions and behaviors. The Health Belief Model (HMB) developed by a group of social psychologists in the U.S Public Health Service: Hochbaum, Leventhal, Kegeles, and Rosenstock. It was originated in the 1950[82] and has been since then, one of the most used as conceptual frameworks in health behavior. This model has been applied in several research studies to explain change and maintenance of health-related behaviors and to guide the development of health interventions to change behaviors.

The HBM theory is used to predict a person's behaviors and attitudes concerning health issues, it is essentially a cognitive approach employed by an individual in preventive health behavior if he feels threatened by a health condition and believes

[82]Janz, N. K., Champion, V. L., & Strecher, V. J. (2002). The Health Belief Model. In K. Glanz, B.K. Rimer, & F.M. Lewis (Eds.), Health Behavior and Health Education: Theory, Research, and Practice 3rd Edition (pp.45-66). Jossey-Bass. San Francisco, CA.

that the benefits of taking preventive action outweigh the barriers to or costs of said action.[83]

The HBM theory is a method that has been developed through the years for evaluation and explanation of individual differences in preventative health behavior and the willingness to change one's behaviors in relation to health concerns. It focuses on the degree of fear of illness related to the potential benefits of taking health action and how he will comply with prescribed therapies.[84] There are six main constructs in the current HBM, and they are: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy. All of the concepts of the HBM are addressed during this study. The HBM's constructs are explained by the theory that individuals will behave and act for prevention, for screening, or to control conditions of ill-health if the individual perceives herself as susceptible to the condition, believes potentially serious consequences are present, believes that a particular action available to her would

[83] Rosenstock, I. M. (1974). The health belief model and preventive health behavior. Health Education Monographs, 2, 354-386.

[84] Janz, N. K., Champion, V. L., & Strecher, V. J. (2002). The Health Belief Model. In K. Glanz, B.K. Rimer, & F.M. Lewis (Eds.), Health Behavior and Health Education: Theory, Research, and Practice 3rd Edition (pp.45-66). Jossey-Bass. San Francisco, CA.

be beneficial in decreasing susceptibility or severity of the condition, and if she believes that the benefits of taking the action outweigh its anticipated barriers.[8586]

7.2 Components of the HBM

7.2.1 Perceived Susceptibility

Perceived susceptibility is defined as a subjective perception of the risk of contracting a health condition. One's belief regarding the chances of being diagnosed with a medical condition can be applied by defining populations at risk and risk levels. Risk could then be personalized on personal characteristics or behavior.[87] In relation to BC, perceived susceptibility may be seen as the chances of being diagnosed with BC, in the long term or immediate future, as felt by the individual.

7.2.2 Perceived Severity

Perceived severity is one's belief and personal feelings about the seriousness of contracting a medical condition and the sequence of events after diagnosis, or of leaving it untreated including both medical and clinical or social consequences. Possible medical consequences may include death, disability, and pain; possible

[85] Champion, V., Maraj, M., Hui, S., Perkins, A.J., Tierney, W.M., Menon, U., et al. (2003). Comparison of tailored interventions to increase mammography screening in nonadherent older women. Preventive Medicine. 36(2):150–158.

[86] Janz, N. K., Champion, V. L., & Strecher, V. J. (2002). The Health Belief Model. In K. Glanz, B.K. Rimer, & F.M. Lewis (Eds.), Health Behavior and Health Education: Theory, Research, and Practice 3rd Edition (pp.45-66). Jossey-Bass. San Francisco, CA.

[87] Ibid.

social consequences consist of effects on work, family life, and social relations. The merging of susceptibility and severity is also called perceived threat or perceived seriousness by the individual. For BC, the perceived severity is defined as perceived seriousness of the diseases through its level of morbidity and mortality.[88]

7.2.3 Perceived Benefits

Perceived benefits refer to a person's opinion of the effectiveness of a new behavior or action related to a specific health outcome to reduce the disease threat or seriousness of impact. It is also termed as perceived benefits of taking health action and clarifying the positive effects to be expected. Perceived benefits of BC screening behaviors include BSE and CBE for early detection of breast diseases. Consequently, educating individuals regarding benefits of early detection and treatment associated to greater survival rate could rise the chances of participation, more willingly, in screening activities.

7.2.4 Perceived Barriers

Perceived barriers refer to potential negative aspects of or obstructions to undertaking a recommended health action. This is one's belief about physical and psychological costs that may act as impediments to taking the advised health action. An internal cost benefit analysis occurs, weighing the health action's

[88] Janz, N. K., Champion, V. L., & Strecher, V. J. (2002). The Health Belief Model. In K. Glanz, B.K. Rimer, & F.M. Lewis (Eds.), Health Behavior and Health Education: Theory, Research, and Practice 3rd Edition (pp.45-66). Jossey-Bass. San Francisco, CA.

expected effectiveness against perceptions that it may become an obstacle such as financial expense, danger, pain, difficulty, upset, inconvenience, and time-consumption.[89] Thus, "the combined levels of susceptibility and severity provide the energy or force to act and the perception of benefits (less barriers) provide a preferred path of action".[90]

7.2.5 Cues to Action

Cues to action are the strategies taken to activate one's readiness to take health action such as bodily events or by environmental events such as media publicity. It refers to internal impulse for living a healthy lifestyle.[91] Cues to action for performing BC screening behaviors relate to BSE, BCE, mammograms, more specifically in providing how-to information, promoting awareness and employing reminder systems.

7.2.6 Self-Efficacy

Bandura defined self-efficacy as one's belief in one's ability to succeed in specific situations or accomplish a task. Rosenstock, Strecher, and Becker proposed in 1988, to add to the HBM's original concepts: susceptibility, severity, benefits and

[89] Janz, N. K., Champion, V. L., & Strecher, V. J. (2002). The Health Belief Model. In K. Glanz, B.K. Rimer, & F.M. Lewis (Eds.), Health Behavior and Health Education: Theory, Research, and Practice 3rd Edition (pp.45-66). Jossey-Bass. San Francisco, CA.

[90] Rosenstock, I. M. (1974). The health belief model and preventive health behavior. Health Education Monographs, 2, P. 332.

[91] Janz, N. K., Champion, V. L., & Strecher, V. J. (2002). The Health Belief Model. In K. Glanz, B.K. Rimer, & F.M. Lewis (Eds.), Health Behavior and Health Education: Theory, Research, and Practice 3rd Edition (pp.45-66). Jossey-Bass. San Francisco, CA.

barriers the self-efficacy.[92] This means that confidence in lifestyle modification is vital before fruitful change is possible.

Therefore, the HBM claims, that the success of the behavior change of a person occurs only if the person senses threat from her current behavioral patterns through perceived susceptibility and severity and supposes that the change of her behavior will result in a valued outcome at acceptable cost. Overcoming perceived barriers in taking action requires that individuals feel competent or self-efficacious.[93] Self-efficacy involves how effective BSE and BCE are to detect breast abnormalities.

7.3 Breast Cancer Screening Behaviors with Health Belief Model

The HBM has been used in several studies as a theoretical framework to study BSE and other BC detection behaviors[94][95][96][97] and it is the conceptual framework for this study. Factors that determine the participation of women, in low-income

[92] Janz, N. K., Champion, V. L., & Strecher, V. J. (2002). The Health Belief Model. In K. Glanz, B.K. Rimer, & F.M. Lewis (Eds.), Health Behavior and Health Education: Theory, Research, and Practice 3rd Edition (pp.45-66). Jossey-Bass. San Francisco, CA.

[93] Ibid.

[94] Hoeman, S. P., Ku, Y. L., & Ohl, D. R. (1996). Health Beliefs and Early Detection among Chinese Women. Western Journal of Nursing Research, 18(5), 518–533.

[95] Barron, C. R., Houfek, J. F., & Foxall, M. J. (1997). Coping style, health beliefs, and breast self-examination. *Issues in Mental Health Nursing*, *18*(4), 331-350.

[96] Mikhail, B. I., & Petro-Nustas, W. I. (2001). Transcultural adaptation of Champion's health belief model scales. Journal of Nursing Scholarship, 33(2), 159–165.

[97] Al-Abadi, N. (2001). Factors influencing BSE practice among Jordanian nurses. Unpublished master's [thesis]. Irbid (JO): Jordan University for Science and Technology.

countries, to mammography screening included perceived susceptibility and barriers related to fear, embarrassment and costs.[98]

Applying the HBM to BC, a woman who perceives that she is susceptible to BC and believes that BC is a serious disease, would be more likely to perform regular BSE. Similarly, a woman who perceives more benefits of and fewer barriers to BSE would be more likely to perform breast examination. A woman who has an internal cue (body perception) or who has been exposed to an external cue (e.g., the positive influence of a health care provider or the media or a friend) would also opt for BSE as would a woman who wants to improve her health and who is confident of positive results.[99]

[98] Thompson, B., Montaño, D.E., Mahloch,J., Mullen, M., Taylor, V., (1997) Attitudes and beliefs toward mammography among women using an urban public hospital. J Health Care Poor Underserved. 1997 May; 8(2): 186–201.

[99] Champion, V. (1993). Instrument refinement for breast cancer screening behaviors. Nurs Res; 42:138-43.

8 Research Design, Methods and Procedures

8.1 Introduction

This study is based on a combination of mixed quantitative and qualitative methods. Mixed methods research was first used in the social sciences and has recently extended into the health and medical sciences including fields such as nursing, family medicine, social work, mental health, and others.[100]

A comprehensive literature review focusing on BC in general and particularly in Lebanon, screening behaviors and behavioral and environmental determinants in Lebanon, the Arab world and developing countries was conducted. It provided key factors for further investigation in the Lebanese context, as well as missing gaps in terms of body of research available. Based on available literature, research tools and methods have been designed and pre-tested.

In previous studies, FGDs, key informant interviews and surveys have been used extensively to study factors influencing BC screening among American women,[101] African American women,[102] Mexican women,[103] Asian American

[100] Creswell, J. W., & Plano Clark, V. L. (2011). Designing and Conducting Mixed Methods Research (2nd ed.). London: Sage Publications Ltd.

[101] Coughlin, S. S., Uhler, R. J., & Blackman, D. K. (1999). Breast and cervical cancer screening practices among American Indian and Alaska Native women in the United States, 1992-1997. *Preventive Medicine*, *29*(4), 287-295.

[102] Hoffman-Goetz, L., Gerlach, K.K., Marino, C., Mills, S.L. (1997) Cancer coverage and tobacco advertising in African-American women's popular magazines. J Community Health. 1997 Aug; 22(4): 261–270.

[103] Suarez, L., Nichols, D. C., Pulley, L., Brady, C. A., & McAlister, A. (1993). Local health departments implement a theory-based model to increase breast and cervical cancer screening. Public Health Reports, 108(4), 477–482.

women[104] and Arab women.[105]

Three main data collection methods were used in this study: (1) focus group discussions (FGDs), (2) semi-structured interviews and (3) a quantitative Knowledge, Attitudes and Practices survey (KAP). The integration of a mixed method permits a more complete and synergistic utilization of data than do separate quantitative and qualitative data collection and analysis.[106]

The benefits to conducting mixed-methods research studies comprise the benefit of triangulation of research results, provision of a more holistic picture of the phenomenon studied by approaching it in different ways and provision of stronger explanations of a phenomenon.[107] Initially, FGDs and semi-structured interviews helped me develop a better understanding of Lebanon related factors which has helped as well in tailoring the survey accordingly.

[104] Tang, N. L. , Pang, C. P. , Yeo, W. , Choy, K. W. , Lam, P. K. , Suen, M., Law, L. K. King, Johnson, W. W. P., Hjelm, M. (1999 May 19). Prevalence of mutations in the BRCA1 gene among Chinese patients with breast cancer. J Natl Cancer Inst. 91(10): 882–885.

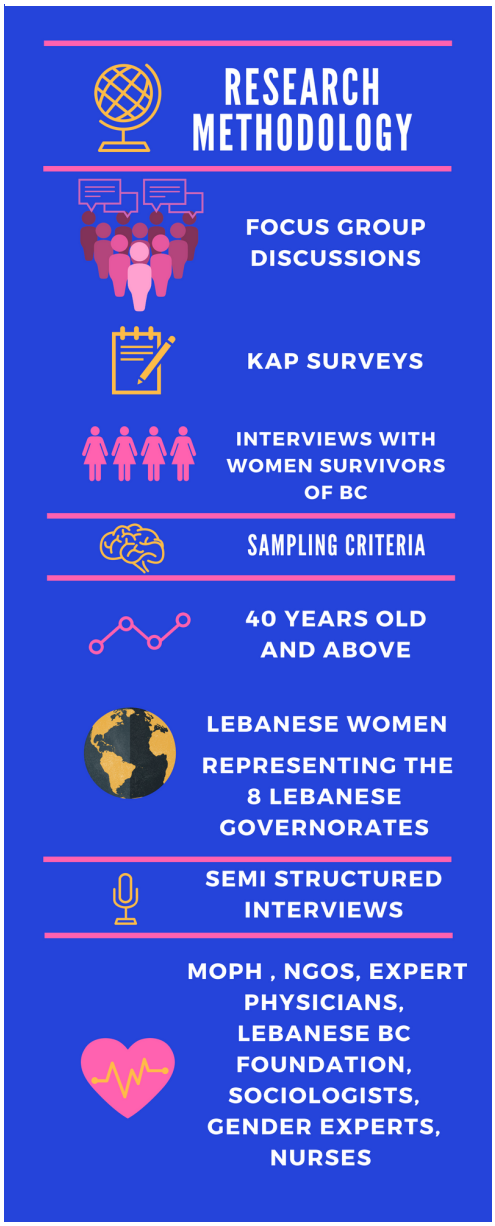
[105] Bener, A., Honein, G., Carter, A. O., Da'ar, Z., Miller, C., & Dunn, E. V. (2002). The Determinants of Breast Cancer Screening Behavior: A Focus Group Study of Women in the United Arab Emirates. Oncology Nursing Forum, 29(9), E91–E98.

[106] Wisdom, J., Creswell, J.W. (2013) Mixed Methods: Integrating Quantitative and Qualitative Data Collection and Analysis While Studying Patient-Centered Medical Home Models. Rockville, MD: Agency for Healthcare Research and Quality. AHRQ Publication No. 13-0028-EF.

[107] Rachel, (2018). Mixed-Methods Research: The Integration of Qualitative and Quantitative, Complete dissertation by Statistical Solutions retrieved from http://www.statisticssolutions.com/mixed-methods-research-the-integration-of-qualitative-and-quantitative.

Therefore, the findings from the FGDs helped me in designing the questionnaire to better measure Lebanese women's attitudes towards BC screening quantitatively. This method of triangulation allowed the integration of Lebanon specific factors that were not evident in other research on the issue in Lebanon and abroad.

Figure 6: Infographic of Research Methodology



8.2 Methods

A total of 163 Lebanese women participated in 17 FGDs, 231 respondents, six BC survivors all aged above 40 years old, in addition to 12 key informants were reached through the following qualitative and quantitative methods.

8.2.1 Qualitative Methods

Qualitative Health Research is a research approach to exploring health and illness as they are perceived by the people themselves, rather than from the researcher's perspective.[108] In research and specifically in this one, qualitative methods are

[108] Morse, J. (1992) Qualitative Health Research: Creating a Discipline, 1st Edition, 17-30.

used to elicit emotions, perspectives, beliefs, values, actions, behaviors, and to understand the participants' responses to health and BC and the meanings they construct around their experience with it.

8.2.1.1 Focus Group Discussions

Focus group interviewing has been used considerably to observe a variety of healthcare-related topics, belief, attitudes, and practices. Focus group methodology is particularly effective in collecting information about sensitive topics, such as BC, because it breaks barriers of shyness and silence through group interaction,[109][110] participants may challenge each other leading to more realistic responses to different issues and in the same time this will create kind of a group support for the participants. Moreover, FGDs allowed me to assess the response of different groups from different locations across Lebanon and different socio-economic backgrounds towards their participation in BC screening methods. Usually, small group discussions of eight to twelve persons are held in neutral and nonthreatening situations to allow for the collection of subject-generated data and "group norms" that are not caught by quantitative methods.[111]

In this research, FGDs were facilitated with a total of 17 groups of women including

[109] Black, E., & Smith, P. (1999). Princess Diana's meanings for women: Results of a focus group study. Journal of Sociology, 35(3), 263–278.

[110] Galina-Tessaro, P., Ortega-Rubio, A., Alvarez-Cardenas, S. and Arnaud, G. (1999). Colonization of Socorro Island (Mexico) by the tropical house gecko Hemidactylus frenatus (Squamata: Gekkonidae). Revista de Biologia Tropical 47(1–2): 237 – 238.

[111] Morgan, D. L. (1995). Why Things (Sometimes) Go Wrong in Focus Groups. *Qualitative Health Research*, *5*(4), 516–523.

163 participants from the different regions covering all the eight governorates in Lebanon until saturation was reached. The focus was on deconstructing from first-hand accounts the perceived barriers and facilitators to BC screening. Table 2 summarizes the list of FGDs locations and the number of participants in each one of them.

Table 2: List of FGDs locations and number of participants

Governorate	Location	Number of Participants
Greater Beirut (GB)	Jdaide	10
	Dekwane	8
	Dahye	11
Mount Lebanon (ML)	Barbara	8
	Bejje	8
	Halat	9
	Batloun	12
Northern Lebanon (NL)	Arde	10
	Mina	9
	Kalamoun	8
Akkar (AG)	Bebnin	10
	Der Dalloum	12
Southern Lebanon (SL)	Bezouriye	11
	Abba	9
Nabatiye (NG)	Hasbaya	8
Baalback El Hirmel (BHG)	Hallaniye	12
Beqaa (BG)	Karak Nouh	8
Total		**163**

A pilot FGD was carried out, using a convenience sample of nine participants, the purpose of which was to test the interview guide and evaluate, firstly, the most appropriate number of participants and, secondly, the length of time required to obtain rich and meaningful data. Topics were covered in depth for around one hour and I had no difficulties in facilitating the FGD.

The interview guide required no alteration as the questions were understood and answered satisfactorily. I moderated the group, and I did not find it challenging. The pilot interview provided rich descriptions and was much more successful than anticipated.

The whole FGDs were audio-taped (after the women's consent) and notes were recorded, transcribed and translated from Arabic to English and analyzed thematically. Each interview was coded so that only myself have knowledge of the individuals who participated. Participants were assured of confidentiality.

8.2.1.2 Semi-Structured Interviews with experts

Semi-structured interviews are often arranged at a certain time and location outside of everyday events. They are the sole data source for a qualitative research project.[112] In such interviews, the interviewer sets predetermined open-ended questions for the interviewee. Other questions might emerge from the

[112] Adams, W., McIlvain, H., Lacy, N. et al. (2002). Primary care for elderly people: why do doctors find it so hard? Gerontologist;42(6):835–42.

dialogue between them. In qualitative research, semi-structured interviews are the most broadly used interviewing format. They are usually conducted once and take between 30 minutes to an hour to complete.

The individual in-depth interview allows the interviewer to delve deeply into social and personal matters.[113]

Semi-structured interviews were conducted with experts in order to develop a better understanding of the structural barriers and facilitators facing women. These interviews were organized throughout the study with the following list of key informants: NGOs working on awareness raising against BC, Lebanese Breast Cancer Foundation, sociologists and Gender Based Violence trainers/researchers, expert physicians (gynecologist, oncologists), Lebanese Ministry of Public Health-National Awareness Program, Faculty and researchers from the Faculty of Health Sciences at the American University of Beirut, registered nurses, Lebanese cancer society. Table 3 provides detailed information on interviewed key informants throughout this research.

Audio recorders (after the key informant's consent) were used to record the discussions after that they were transcribed, translated and analyzed thematically.

[113] Rubin, H., Rubin, I. (2005). Listening, hearing and sharing social experiences. Qualitative Interviewing: the Art of Hearing Data. Thousand Oaks, California: Sage; 1–18.

Table 3: List of Key informants interviewed

Name	Position	Organization
1. Gulnar Wakim	Sociologist	Lebanese University, Beirut
2. Rima Dandachi	Founding president	May Jallad Foundation, Beirut
3. Ann Frangieh	Founding president	Faire Face Foundation, Beirut
4. Krystel Tabet	Gender expert	Beyond Reform and development, Beirut
5. Rasha Hamra	Ph.D., Director of public relations and health education departments	Lebanese MoPH, Beirut
6. Nagi El Saghir	MD, Oncologist	American University of Beirut Medical Center (AUBMC), Beirut
	Founding president	Lebanese Breast Cancer Foundation (LBCF), Beirut
7. Myrna Doumit	Ph.D., RN, FAAN, Assistant Dean, Head of the Lebanese syndicate of nursing	Lebanese American University (LAU), Byblos
8. Salim Adib	MD, DrPH, Professor	American University of Beirut (AUB), Beirut
9. Habib Barakat	Gynecologist	Notre Dame De Secours Hospital, Byblos
10. Sonia Zavzavadjian	Member	Lebanese cancer society, Beirut
11. Linda Harris	Registered nurse (RN)	American University of Beirut Medical Center (AUBMC), Beirut
12. Latifa Shihab	Registered nurse (RN)	American University of Beirut Medical Center (AUBMC), Beirut

8.2.1.3 Semi-Structured Interviews with BC survivors

Semi-structured interviews were conducted with six Lebanese women survivors of BC in order to develop a better understanding of the essential barriers and

facilitators facing women in Lebanon and what were possible factors that facilitated their access to mammography, their healthcare experience after and before being diagnosed BC. Additionally, BC survivors revealed their thoughts and experience with BC throughout their treatment, and cited their possible recommendations for Lebanese women regarding the importance of BC screening for early detection.

8.2.2 Quantitative Methods

In this study, I used the data collected from the FGDs and semi-structured interviews to support the development of appropriate instruments for the KAP survey that provided accurate measures of the exploratory data. Qualitative exploration through FGDs and semi-structured interviews with BC survivors and experts helped me to assess what constructs should be measured to best understand factors influencing women's decision in seeking BC screening activities.

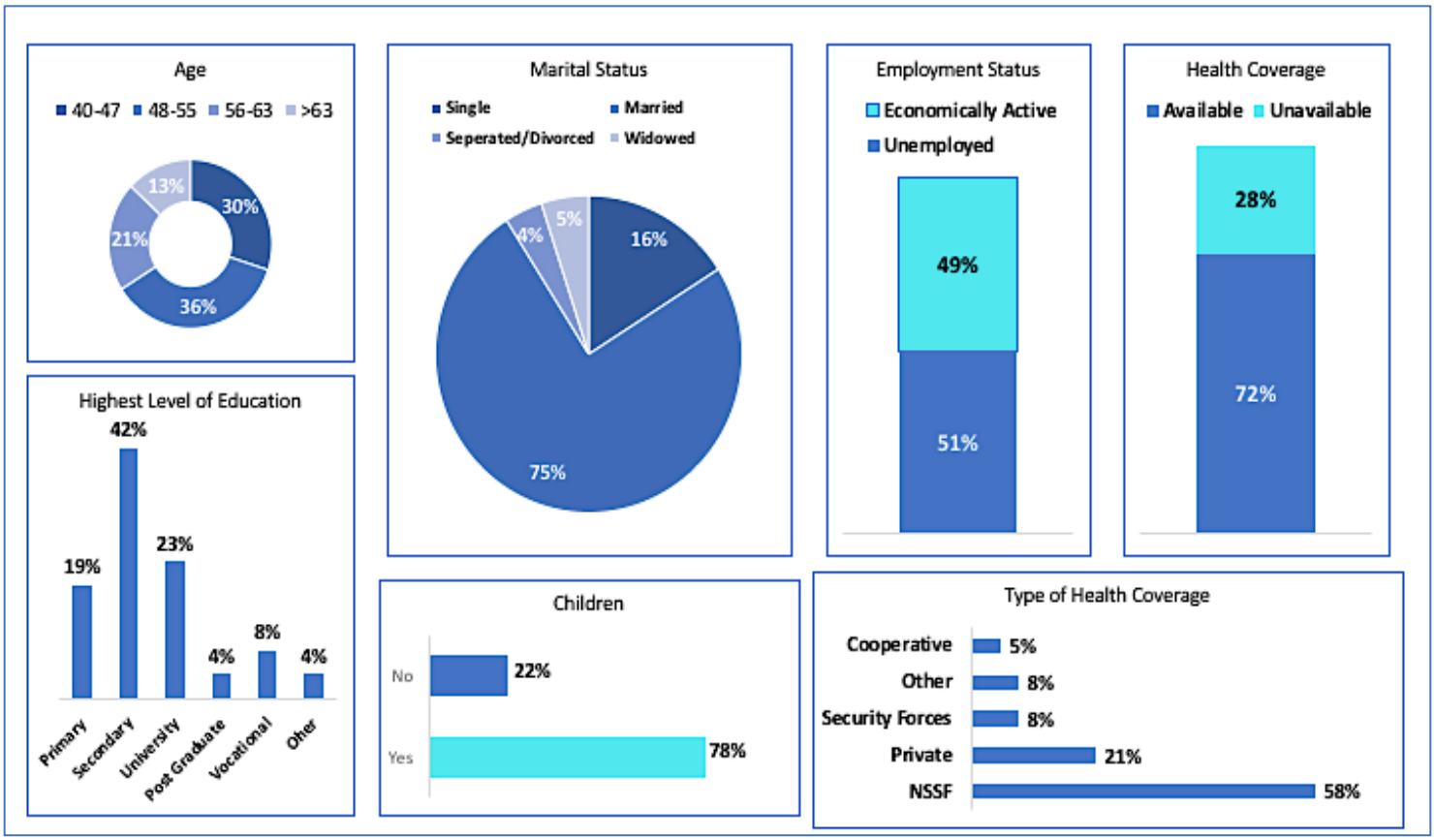
8.2.2.1 Demographic Characteristics of KAP survey Respondents

A total of 231 females were reached through the KAP survey. They were distributed over the eight Lebanese governorates and the majority were married and have children. 42% of them have reached secondary education and 51% were unemployed. The majority of them, 72% also have one of the different types of health coverage. Tables 4 and Figure 7 present a clear description of the various demographic characteristics of survey respondents.

Table 4: KAP Survey respondents per Governorate

Governorate	Number of Respondents
Greater Beirut (GB)	14
Mount Lebanon (ML)	56
Northern Lebanon (NL)	34
Akkar (AG)	25
Southern Lebanon (SL)	22
Nabatiye (NG)	21
Baalback El Hirmel (BHG)	21
Beqaa (BG)	38
Total	**231**

Figure 7: Demographic characteristics of KAP survey respondents



8.2.2.2 Instrument and variables

After collecting qualitative exploratory data, analyzing the information, and using the findings to develop a KAP survey well adapted to the sample under study, the KAP survey questionnaire was piloted and finalized based on the feedback of a sample of participants. Additionally, consent forms were developed in English then translated into Arabic together with the final version of the questionnaire. The final version was pilot tested with 15 Lebanese women who met the eligibility criteria of the study. The purpose of the pilot was to assess for clarity, length, and comprehension of the translated survey. No further changes were recommended. The instrument used was a self-administered questionnaire, it consisted of four parts:

-A socio-demographic component which included variables such as place of residence, age, marital status, number of children, educational level (elementary, secondary, post-graduate, vocational and university), employment status, socio-economic status (SES), Insurance/Health coverage status and type.

- A knowledge component which included 10 questions related to the source of information around health in general and BC specifically, knowledge about warning signs of BC, mammography, BC awareness campaign of the MoPH and Family history of BC.

- An attitudes component which included eight items, measured on a 5-point Likert scale ranging from strong agreement (1) to strong disagreement (5) and some of them inspired from the HBM such as perceived susceptibility of BC, perceived seriousness of BC, perceived benefits of mammography (perception of efficacy of the test), perceived barriers: fear, perceived support from family members and cues to action.

- A practices component which included 14 items related to healthcare, screening behavior, mammography practice and BSE.

8.3 Sampling Framework

Given the sensitivity of the topic and some of the limitations later described in the relevant section related to access and willingness of women to participate in similar research activities I followed a convenient sampling methodology during my research, which was based on the following parameters:

8.3.1 Location

Female participants were selected from the different Lebanese regions. Lebanon is administratively divided according to two main levels. The first includes eight Mohafazat (governorates). In the second layer, the eight governorates include a

total of 26 cazas. Governorates and cazas are then followed by municipalities, which may sometimes correspond to villages.[114]

After the civil war extending from 1975 to 1990 in Lebanon the majority of these regions became more and more religiously and culturally segregated. This segregation was the result of war-induced internal and international population movements.[115]

Greater Beirut (GB) is the urban agglomeration comprising the city of Beirut (Beirut governorate) and the adjacent municipalities over the ML governorate. Even though, GB does not constitute a single administrative unit, it does assemble people from different denominations and religions, SES, socio-cultural backgrounds, who share similar geographical factors and accessibility to healthcare centers and hospitals. This is why the research was aligned with previous studies conducted in the country which considered GB instead of Beirut only.

[114] Presidency of the council of ministers, Central Administration of statistics, retrieved from http://www.cas.gov.lb/index.php/about-lebanon-en retrieved June 5, 2018.

[115] Faour, M. (2007) Religion, demography, and politics in Lebanon, Middle Eastern Studies, 43:6, 909-921.

FGDs were conducted and surveys were collected from different areas and regions across Lebanon. Locations reached by this study included:

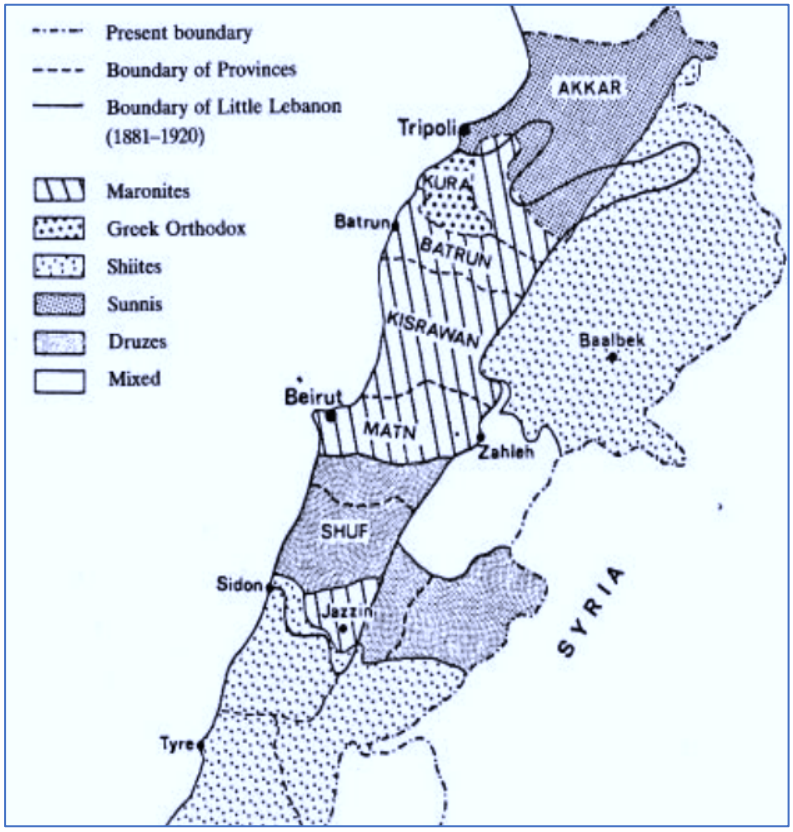
Table 5: Characteristics of locations reached through FGDs

Governorate	Location	Characteristics
1. Greater Beirut	Dahye,	Urban, Muslim Shiaa
	Jdaide	Urban, Christian
	Dekwane	Urban, Christian
2. Akkar	Bebnin	Peri-urban, Muslim Sunni
	Der Dalloum	Rural, Christian
3. Northern Lebanon	Tripoli	Urban, Muslim Sunni
	Arde	Rural, Christian
	Kalamoun	Rural, Muslim Sunni
4. Mount Lebanon	Bejje	Rural, Christian
	Halat	Urban, Christian
	Barbara	Rural, Christian
	Batloun	Rural, Druze
5. Southern Lebanon	Bezouriye	Rural, Muslim Shiaa
	Abba	Rural, Muslim Shiaa
6. Beqaa	Karak Nouh	Rural, Muslim Shiaa
7. Baalback El-Hermel	Hallaniye	Rural, Muslim Shiaa
8. Nabatiye	Hasbaya	Rural, Druze

8.3.2 Religion

In Lebanon there are 18 officially recognized sects most of which belong to one of two large clusters: Muslims and Christians. Religions play a vital function in Lebanon because they are the 'primary social organization through which political security has been maintained'.[116] The ethno-religious geographical distribution of Lebanese in the country has remained relatively constant since 1930. As shown in Figure 8.[117]

Figure 8: Religious distribution across Lebanon



[116] Hudson, M.C.(1985). The Precarious Republic: Political Modernization in Lebanon. Boulder, CO: Westview Press, p.21.

[117] Soffer, A. (1986). Where Demography Is the Core of Politics and Life. Middle Eastern Studies, 22 (2), p. 203.

8.3.3 Age

This study followed the guidelines of the Lebanese MoPH specifying the age of 40 years old as the starting age for annual BC screening. Therefore, only women aged 40 years and above were included in the study. This is greatly due to the different Lebanese demographic, where the median age of diagnosis in 2004 was 52.5,[118] with 47% cases diagnosed below the age of 40 years in 2010.[119]

8.3.4 Socio-economic

In each district, the cazas selected presented specific socio-cultural particularities to ensure that all subgroups of the diversified Lebanese population are represented.

8.3.5 Access and mobilization

Access to women from the different governorates and regions was facilitated through active local NGOs and complemented by convenient sampling through key community figures or contacts. The aim was to have an equal representation and understanding of different religious and sectarian denominations, socio-economic, cultural and regional characteristics and disparities.

[118] Lakkis, N. A., Adib, S. M., Osman, M. H., Musharafieh, U. M., & Hamadeh, G. N. (2010). Breast cancer in Lebanon: Incidence and comparison to regional and Western countries. *Cancer Epidemiology*, *34*(3), 221–225.

[119] Lebanese Ministry of Public Health, (2010). Data retrieved from a newspaper article https://www.annahar.com/article/645423.

8.4 Data Analysis

Quantitative surveys were entered and analyzed using The Statistical Package for Social Sciences (SPSS Inc., Chicago, IL, USA), Version 24. Thematic analysis was used for analyzing focus group discussions and semi-structured interviews. Themes were based on literature review and tendencies identified in the surveys and the different discussions. It included a segregation of barriers and facilitators on the family related factors, economic, social, cultural, healthcare system and experience, religious, geographical, knowledge and awareness, Self-efficacy and psychological factors, perceived susceptibility, self-motivation and practices levels. Quantitative and qualitative findings were triangulated, analyzed and reported jointly.

9 Research Limitations

The limited studies available on BC in Lebanon along with the weak surveillance system for the Lebanese MoPH (especially when cases are detected in private healthcare institutions) do not provide a comprehensive background on the issue.

The limitations of this study relate to the design itself. A cross- sectional study such as this one is carried out at a single point in time, or over a short period of time at most. It provides a snapshot of the outcomes and its related characteristics, at that specific point, and results could have been different had another time frame been chosen.[120]

In some of the FGDs, couple of women added some of their thoughts only once I turned off the recording machine. This shows the level of embarrassment and shyness they feel about the topic, and the unwillingness to deal with the issue as a common subject. Another limitation was related to the interviews with survivors and participants during the FGDs. They might have exhibited some bias (even inadvertently) in reporting information about themselves that they perceived as quite intimate.

Furthermore, I was not able to include in the KAP survey a question to assess the religious denomination of the respondents. Although its importance as a main parameter it was not used for two reasons. The first is because religion remains

[120] Doumit, M.A., Fares, S., & Arevian, M. (2017). Knowledge , Practices , and Attitudes of Women Towards Breast Cancer in Lebanon.

quite a sensitive issue among Lebanese citizens, and I wanted to avoid having respondents questioning the lines of enquiry and benefit of my research if my research is seeking to know about their religion. Second, was to avoid affecting the respondents' choices of answers and make them think of the link between the possible answers and their religion.

In different areas, various women groups refused to attend a FGD once they heard about the subject of the discussion (BC). This even happened with an NGO working for the empowerment, leadership and rights of women, and girls. Due to this limitation faced at the beginning of my research I switched the way I framed the invite for the FGD to -a discussion around women's health in general-.

During some of the FGDs, certain women were afraid or embarrassed to talk from the beginning and open up, it happened mostly with women who had cases of BC in the family.

10 Ethical Considerations

My mother is a BC patient and since this PhD started with a question I asked her "Why did you refuse to do any mammography while noticing a change in your breast? And why you refused to do it even after you noticed having a lump in your breast?". This fact however did not impact my objectivity throughout my research and directed my efforts towards the collection of viable results, data and recommendations to be used by health policy makers and community health promoters to benefit Lebanese women who, like my mother, lack motivation, knowledge, awareness and support on different scales.

The study aimed at assessing barriers and facilitators of BC screening among Lebanese women only. Although it will cover systemic and administrative factors on the national level, it was not be able to include populations of refugees (Syrians, Iraqis, Palestinians and Sudanese among many others living in Lebanon), and domestic workers who are also using the Lebanese healthcare system. These two categories of people residing in Lebanon unfortunately do not benefit from the services of the MoPH and especially the free or diminished prices of BC screening methods. Therefore, they do not fit the rationale of this research which aimed at assessing low demand for BC screening methods even when the direct economic barrier is potentially taken away.

The administered survey was anonymous and contained a consent form, a detailed description of the research study along with its objectives, and the contact details of the researcher. The FGDs were facilitated by the researcher who is of

the same sex and mitigated cultural and religious challenges related to access of the women.

11 Results

The results section reports on the findings of the various research activities conducted with Lebanese women in different locations across Lebanon. It provides a clear insight on socio-demographic, economic, cultural, psychological, and personal (attitudes, beliefs and practices) factors, facilitators and barriers influencing the demand, participation or decision of Lebanese women regarding BC screening activities. Furthermore, it highlights structural elements, related to the national health system affecting Lebanese women's access and use of BC screening services.

11.1 Overall Use of BC Screening Services

Before going into an-depth discussion of barriers and facilitators, it is important to elaborate on the current practices and usage of screening services among women met during the research.

Qualitative and quantitative findings reveal that a significant number of women have actually done a mammography, but the majority have done it once in their lifetime so far, or mostly not on a regular basis. 70% of the survey respondents have ever done a mammography, yet 30% of them perform the test "intermittently and not on regular basis". Further results from the survey show that 30% of the respondents have never done a mammography, and 15% of them mentioned that they do not do it because they usually perform tests only if requested by their physician, and until now he did not. For example, as one participant in Abba

described, she did the mammography only once so far, but she does not believe in its added value which is why she did not repeat it afterwards.

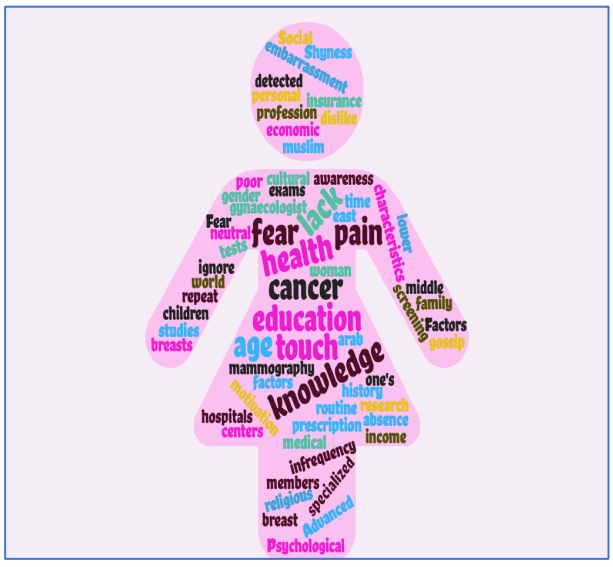
In its turn, BSE is less practiced among the participants of this research. There is only 53% of the survey respondents who reported doing it. Half of these 53% perform the BSE irregularly or occasionally. Respondents mentioned two major reasons preventing them from performing such examination, not knowing how to do it (21%) and forgetting (14%). It needs to be noted that the MoPH's National awareness campaign does not highlight enough the importance of BSE as it does for mammography during the campaign (on billboards or on social media). The campaign includes information about BSE only on leaflets or during informative appearances on TV shows.

11.2 Barriers to BC screening activities:

11.2.1 Family related barriers

I have found through my research that many women undervalue their own life's worth for the sake of their family and that the support they get from their family members, especially their husbands, influences their decision in participating in BC screening activities.

Figure 9: Word generator from barriers to BC screening



11.2.1.1 - Undervalue their own life's worth for the sake of their families

Through this research, I have discovered that many Lebanese women take less care of themselves because they believe that the life of other family members are more important than their own, and specifically more important than their own health. This leads them to prioritizing their children and their family over their own needs and well-being.

According to the findings of the KAP survey 50% of the respondents agreed and strongly agreed about their family's health being more important than their own. As one of the participants in the FGD in Kalamoun (NL), stated "Priority in life is to take care of the family, work in the house and prepare food. All this makes us forget about ourselves".

Family comes first. Which means that family members, husbands, parents or kids, are always the Lebanese women's main priority until their own health is at risk. One of the participants from Mina (NL) stated, "I would not take care of myself until I fall". Before that happening, like a participant from Hasbaya (NG) mentioned, they usually hide any change they notice in their body or any notable variance in own health.

Taking care of the family, comes in parallel also with taking care of the house chores (essentially preparing food for family members and cleaning the house). Many participants in this study consider these chores more important than themselves and their own well-being. According to the sociologist interviewed,

women are culturally programmed to think less of their own health and well-being and rather think of their role as a mere caretaker for other male family members.

My FGDs show also that numerous women do not want to be a burden or a bad influence on their family especially their children. Many participants mentioned that they worry about not being able to fulfil the role of the "good" mother or wife at the house if they are ever diagnosed. They consider that being possibly diagnosed would stop them from seeing their children grow and could prevent them from "watching" them fulfill their dreams throughout their life, such as graduating and getting married. One of the participants also mentioned during the FGD in Jdaide (GB) that she lives for her children and that she would never imagine them living without her.

11.2.1.2 - Lack of support from family members

The results from the FGDs and some of the interviews show that women who perceived having negative or neutral spousal or familial support were less likely to ever-obtain a mammography. Specifically, the role of husbands in encouraging or obstructing women's access to screening has been described as an important factor in traditional societies, by a study investigating the health beliefs and practices related to cancer screening among Arab Muslim women in an urban community.[121]

[121] Khlood, F.S. (2012). Health Beliefs and Practices Related to Cancer Screening Among Arab Muslim Women in an Urban Community. Health care for women international. 33. 45-74.

Additionally, I have found that sometimes the absence of a family member(s) motivating the woman or taking an active role in facilitating her access in screening services, as participants in FGDs in both Halat (ML) and Dahye (GB) mentioned, acts as a barrier to her participation in BC screening tests. This could possibly happen when she is not aware of what is the best for them, or of the steps that she should take to safeguard her health.

This occurs, more likely, in families that lack information about the importance of BC screening tests and early detection as mentioned by one BC survivor interviewed. Another example is the case of one of the participants in Halat (ML), who feels that her family, especially her husband, never motivated her to take care of her health, therefore never reached the stage to seek a mammography.

11.2.1.3 - Negligence from family members and relatives

Women feel neglected and less supported when family members do not notice any changes in their behavior or attitudes or ignore these changes if ever noticed. Ignoring any variations (physical or emotional) seen in a woman or not taking them seriously if noticed acts as barrier to her participation in BC screening tests. The lack of information about BC comes together with family members not supporting the woman in her decision in doing or not a mammography.

The lack of seriousness given to BC in case a woman is diagnosed, as stated by the gender expert, makes her also feel neglected and not supported by her family. One of the BC survivors interviewed stated that receiving phone calls from relatives

telling her that “the chemotherapy is nothing, and BC is just like any normal flu” was not supportive at all for her during her treatment.

11.2.1.4 - Presence of a cancer patient within the family

Findings show that the presence of a cancer patient within the family discourages women from seeking BC screening so not to live through the same experience and stages of the disease with all its negative effects that were witnessed on the family member affected. More specifically, taking care of a family member surviving cancer can also act as a significant barrier to being tested for BC.

For instance, existing family cases diagnosed with BC, like a mother, sister or daughter, makes the woman feel more vulnerable, which results sometimes in avoiding doing the screening test. The loss of a family member to cancer or a close friend, in many cases, acts as an obstacle to women’s participation in BC screening. During the FGD in Dekwane (GB), one of the women said: “I do not want to know if I have BC or not because I lost my mother 18 years ago and I still feel it as if it happened 18 minutes ago”.

Having a family case of cancer creates a situation of fear of being diagnosed and tortured by cancer. In Jdaide (GB), participants described how seeing parents in pain and fighting the sickness could prevent them from checking themselves for BC. This occurs especially in cases of BC defined as hereditary type of cancer. According to the founder of May Jallad Foundation, family members who suffer from BC (mothers, sisters, aunts or cousins), can hide their sickness sometimes from society and in many cases also from their relatives, especially at earlier

stages of diagnosis. This matter could also negatively contribute in delaying other female relatives from initiating mammography and getting themselves checked the earliest possible.

Previous studies also show that women and men with a family history of BC, especially a first-degree relative (parent, child, or sibling), are at increased risk for the disease. Compared to women without a family history, risk of BC is about two times higher for women with one affected first-degree female relative, and three to four times higher for those with more than one first-degree relative.[122] Risk is further increased when the affected relative was diagnosed at a young age or if the cancer was diagnosed in both breasts.

11.2.2 Geographical related barriers

The association of ever using and/or repeating a mammography test with geographical related factors were mentioned by participants from different regions and locations as well as key informants from different domains. Principally, the location of participants' homes and their distance from medical centers and hospitals together with the difference between rural and urban areas were linked directly to BC screening activities and acted as barriers to women's participation in BC screening tests.

[122] Collaborative Group on Hormonal Factors in Breast Cancer. (2001). Familial breast cancer: collaborative reanalysis of individual data from 52 epidemiological studies including 58,209 women with breast cancer and 101,986 women without the disease. *Lancet (London, England)*, *358*(9291), 1389–99.

11.2.2.1 Location of homes and distance from medical centers and hospitals

Participants perceived the availability of prestigious healthcare institutions as concentrated in the capital Beirut, which influenced negatively on their accessibility to healthcare services. This was also specifically described as a limiting barrier to their participation in BC screening tests. Some participants from the FGDs in NL, complained about the distance of their villages to main healthcare centers, and the lack of transportation means in the regions, which they describe as barriers limiting their access to BC screening services. Being far from major clinics and hospitals was not the only barrier discussed by participants in NL. They have also described how the lack of trust in healthcare centers when available in certain areas also limits their decision in performing a mammography.

Similar findings were mentioned by participants in FGDs in other locations throughout the country as well. In Hallaniye (BHG) the distance from public healthcare facilities from this rural area to Zahle, an urban area located in BG is around 20 Km. Similarly, in Batloun located in rural ML, the closer main public hospital is situated in Sidon (SL) 46 Km away. This geographical barrier is considered by women living in these areas as a factor limiting their accessibility to healthcare services and therefore preventing them from participating in BC screening tests.

The mentioned findings concerning the location of homes and distance to hospitals were also mentioned by the interviewed BC researcher and epidemiologist. He stated that the main matter women face is the accessibility to the screening services especially when they do not own a car or live in areas where centers or

hospitals in which these screening services are offered cannot be reached by public transportation.

Furthermore, during the interview he also added that the accessibility issue is remarkable in both Akkar and Bekaa governorates that are both large cazas in Lebanon together with Chouf caza, a smaller caza where the difficulty in accessibility is due to its geographical composition of valleys and mountains.

11.2.2.2 Difference between urban and rural areas

The capital of Lebanon, Beirut, where the majority of the healthcare facilities are located, brings along with that, a noted perceived effectiveness and high trust in healthcare centers located in central urban areas and mostly in GB. Previous studies on the frequency of mammography screening on the national scale indicated that levels in GB were higher than those in rural areas, which the authors attributed to a difference in availability of screening tests, and more concentrated awareness campaigns, among other factors.[123][124] These findings were also exhibited in my research as well.

As many participants highlighted, the need to reach Beirut when seeking medical care together with the difficulty of transportation from rural areas to healthcare

[123] Adib, S., El Saghir, N., Ammar, W. (2009). Guidelines for breast cancer screening in Lebanon. Public Health Communication. Le Journal médical libanais. The Lebanese medical journal. 57. 72-4.

[124] Haddad, F., Hampig, K., Salim, A. (2015). Trends in mammography utilization for breast cancer screening in a Middle-Eastern country: Lebanon 2005–2013. Cancer Epidemiology. 39. 819-824. 10.1016/j.canep.2015.09.015.

facilities perceived more efficient in Beirut and GB, act as barriers to participation in BC related tests.

In Bazouriye (SL), women mentioned their distance from Beirut as a barrier to BC screening, “being far from GB and from most of the clinics and the big hospitals.” Differences between urban and rural utilization of BC screening tools have been observed in multiple previous studies as well.[125] These differences were greatly attributed to decreased accessibility.[126]

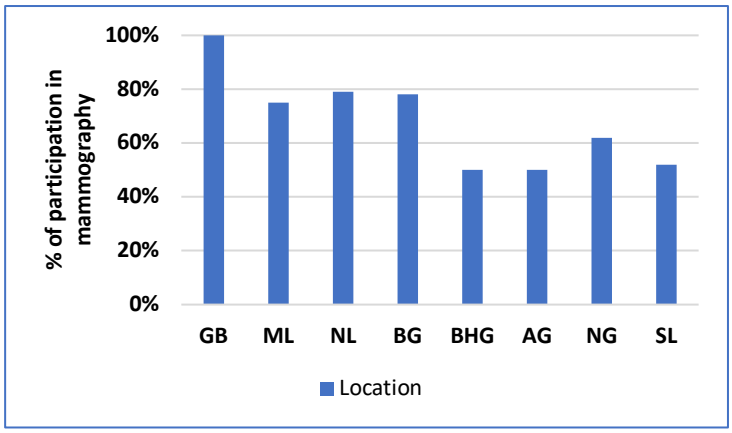
A study around the Patterns and Determinants of Mammography Screening in Lebanese Women published by Salim Adib et. Al in 2016, describes how outside of GB, accessing a mammography requires finding culturally accepted means of transportation for targeted middle-aged women. Henceforth the importance of a male family member supporting the woman and facilitating her access to healthcare services mainly when coming from outside GB. Similar to that finding, the Gender expert mentioned the need of women to be accompanied by a male family member in order to commute to a healthcare facility outside of the region as an important barrier to having a mammography.

[125] Abu-Helalah, M., Al-Hanaqta, M., Alshraideh, H., Abdulbaqi, N., & Hijazeen, J. (2014). Quality of life and psychological well-being of breast cancer survivors in Jordan. *Asian Pacific Journal of Cancer Prevention : APJCP*, *15*(14), 5927–36.

[126] Kim, J. I., Oh, K. O., Li, C. Y., Min, H. S., Chang, E. S., & Song, R. (2011). Breast cancer screening practice and health-promoting behavior among Chinese women. *Asian Nurs Res (Korean Soc Nurs Sci)*, *5*(3), 157–163.

The participation in BC screening differs, for all the previously mentioned reasons, between urban and rural areas especially in SL, AG, NG and BHG (rural areas). As chart 2 shows, location of respondents of the KAP survey influences on their participation in mammography. All respondents from GB (urban area) have done a mammography at least once. Participation in mammography was found to be also high among respondents from NL (79%), ML (75%), BG (78%) and NG (62%). Additionally, the percentage of participation in mammography for respondents residing in SL, AG and NG resulted less than in the previously mentioned locations accounting 52% in SL, and 50% in both AG and NG.

Chart 2: Correlation between location and participation in mammography



As per the founder of the NGO Faire Face as well, in rural areas, where the infrastructure and public transportation are close to being inexistent, women face much more barriers to attend awareness raising activities related to BC awareness, visit medical centers and hospitals and do the required tests for BC screening. For instance, only 8% of the surveyed women selected NGOs as a source of information about BC and 10% get their information about BC from their participation in conferences and awareness sessions.

In addition, participants of FGDs in different locations, revealed a high perception of apathy exhibited by physicians in areas outside of Beirut and specifically in rural areas. This reflects the preference of women from many rural areas to potentially access mammography within the GB urban area.

11.2.3 Knowledge and Awareness

Other barriers to women's participation in BC screening are knowledge and awareness. These factors are directly related to the source of information of women about health in general, BC and BC screening. Additionally, the influence of awareness and the limited availability, reach or effectiveness of awareness raising campaigns and initiatives in rural areas remain an important factor affecting women's participation in BC tests.

11.2.3.1 - Source of information about health and BC

As the incidence of BC increases worldwide, understanding women's knowledge of, attitude toward, and behaviors engaged in regarding to BC screening is essential, because screening is a first step toward early detection. As previous studies emphasized, better knowledge of BC, and better beliefs and attitudes towards the disease and its management may contribute considerably to health-related help-seeking behaviors and are correlated with better screening.[127][128][129]

[127] Haddad, F., Hampig, K., Salim, A. (2015). Trends in mammography utilization for breast cancer screening in a Middle-Eastern country: Lebanon 2005–2013. Cancer Epidemiology. 39. 819-824. 10.1016/j.canep.2015.09.015.

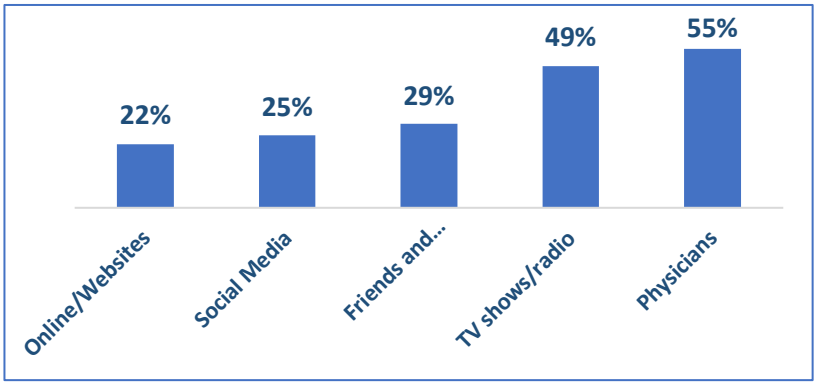
[128] Institute NC. Breast cancer screening (PDQ®)–health professional online version NIH; 2016 retrieved from https://www.cancer.gov/types/breast/hp/breast-screening-pdq.

[129] Elias, N., Bou-Orm, I., Adib, S. (2016) Patterns and determinants of mammography screening in Lebanese women. Prev Med Rep. 2016;5:187–93.

Frequent screening was associated with better survival and earlier detection. Similar to what has been found in previous studies with Arab women.[130] Lebanese women who participated in this research, gather information about health and BC mainly from Mass media (TV shows, social media, websites), their healthcare providers or friends.

Findings from the survey show that knowledge about health in general is obtained from physicians (54%), TV shows (53%), friends and neighbors (31%) and social media (26%). Information about BC specifically were found to be collected from physicians (55%), TV shows/radio (49%), friends and neighbors (29%), social media (25%) and online/websites (22%) as Chart 3 shows.

Chart 3: Participants' source of information about BC



Participants in Dahye (GB) stated that not everyone is reached by mass communication like websites and social media since many persons still do not have access to the internet or are not capable of doing it.

[130] Montazeri, A., Vahdaninia, M., Harirchi, I., Ebrahimi, M., Khaleghi, F., & Jarvandi, S. (2008). Quality of life in patients with breast cancer before and after diagnosis: an eighteen months follow-up study. *BMC Cancer*, *8*, 330. http://doi.org/10.1186/1471-2407-8-330.

11.2.3.2 - Lack of knowledge and awareness about BC and BC screening

In my research I have noticed that women have minimal knowledge about BC in general and specifically its symptoms and available screening tests for it. Participants in different locations stated that physicians are not providing sufficient or adequate information around BC, even though many women considered their physicians as a main source of information about their main health and BC.

Knowledge about the benefits of BC screening is an important determinant of BC screening behavior[131][132] and this knowledge is reportedly low in many Arab countries.[133][134] Compared to these last mentioned studies from 2010 and 2011, a growing knowledge about BC in Lebanon has been noted in this study where 90% of the respondents agree or strongly agree that early detection can increase the possibility of recovery and effectiveness of the treatment, yet limited action is being recorded. This is where the importance of this research that identifies and

[131] Bener, A., Honein, G., Carter, A. O., Da'ar, Z., Miller, C., & Dunn, E. V. (2002). The Determinants of Breast Cancer Screening Behavior: A Focus Group Study of Women in the United Arab Emirates. Oncology Nursing Forum, 29(9), E91–E98.

[132] Soskolne, V., Halevy-Levin, S., & Cohen, A. (2007). The socio-cultural context of family caregiving and psychological distress: A comparison of immigrant and non-immigrant caregivers in Israel. Aging and Mental Health, 11(1), 3–13.

[133] Cohen, M., Azaiza, F. (2010). Increasing breast examinations among Arab women using a tailored culture based intervention. Behav Med, 36, 92-9.

[134] Aghamolaei, T., Tavafian, S.S., Madani, A. (2011) Prediction of Helmet Use Among Iranian Motorcycle Drivers: An Application of the Health Belief Model and the Theory of Planned Behavior. Traffic Injury Prevention. 2011;12(3):239–43.

reconstructs barriers beyond the mere level of knowledge and awareness about the benefit of early detection.

Moreover, like stated in a case during the FGD in Dahye (GB), there is a misconception about early detection. Some persons think that it is better and preferable to keep the cancer “sleeping in the body” and not to awaken it by any procedure. Similarly, in Dekwane (GB), participants believe that even when found, cancer should not be treated with chemotherapy because it will cause its dispersion in the body, "it is like fireworks”. This finding has been reported in among Muslim and Christian participants alike.

Another misconception uncovered during the FGDs is the preference of not doing the mammography because the x-rays are thought to be harmful for the body. Women usually are not aware that the dose of radiation they get from the mammography is very low, and that for most of them, the benefits of regular mammograms outweigh the risks posed by this amount of radiation. Also, the BC mortality reduction due to screening greatly outweighs the risk of death due to radiation-induced cancers as found in a study published in England in 2016.[135]

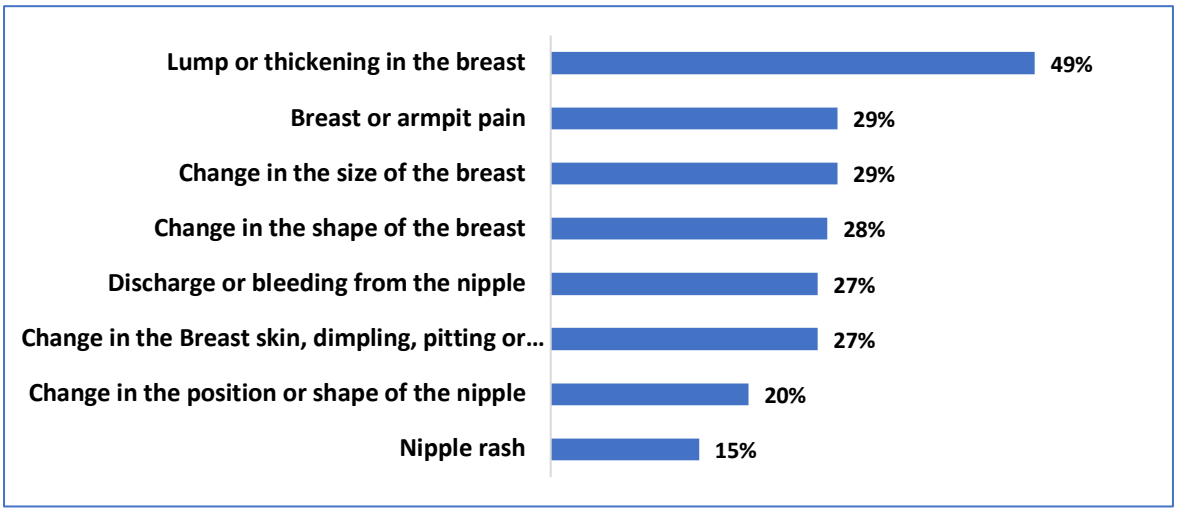
Other women do not perceive the mammography as an important method for BC screening and consider BSE as a sufficient practice on its own. Lack of knowledge

[135] Warren, L. M., Dance, D. R., & Young, K. C. (2016). Radiation risk of breast screening in England with digital mammography. The British Journal of Radiology, 89(1067), 20150897. http://doi.org/10.1259/bjr.20150897.

about early detection of BC and how it can be achieved by proper awareness around performing BSE, and by accessing CBE by health providers, along with mammography[136] might be valid roots for these misconceptions.

When asked “Are you aware of the warning signs of BC?”, 65% of respondents answered “yes”. When they think that they have increased awareness around the warning signs of BC, in reality they have very low knowledge and understanding of the signs specifically. As the chart 4 below shows, the highest percentage of correct answers was on “Lump and thickening in the breasts” and it only reached 49% of the respondents.

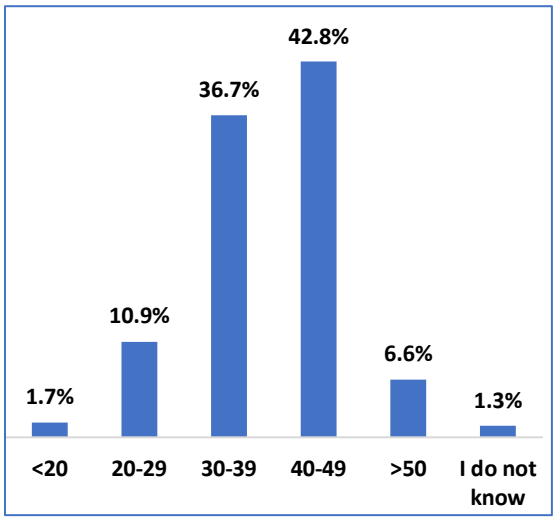
Chart 4: Respondents' knowledge around the warning signs of BC



[136]Bener, A., Alwash, R., Miller, C., Denic, S., Dunn, E. (2001). Knowledge, attitudes, and practices related to breast cancer screening: a survey of Arab women. J Cancer Educ,16, 215-20.

Moreover, results from the survey showed a lack of knowledge around the age at which a woman should start having routine mammograms. Only 43% of the respondents chose the category of 40-49 years old, 37% of them indicated 30-39 years old and 11% thought that women should start having mammography between 20 and 29 years old as chart 5 shows.

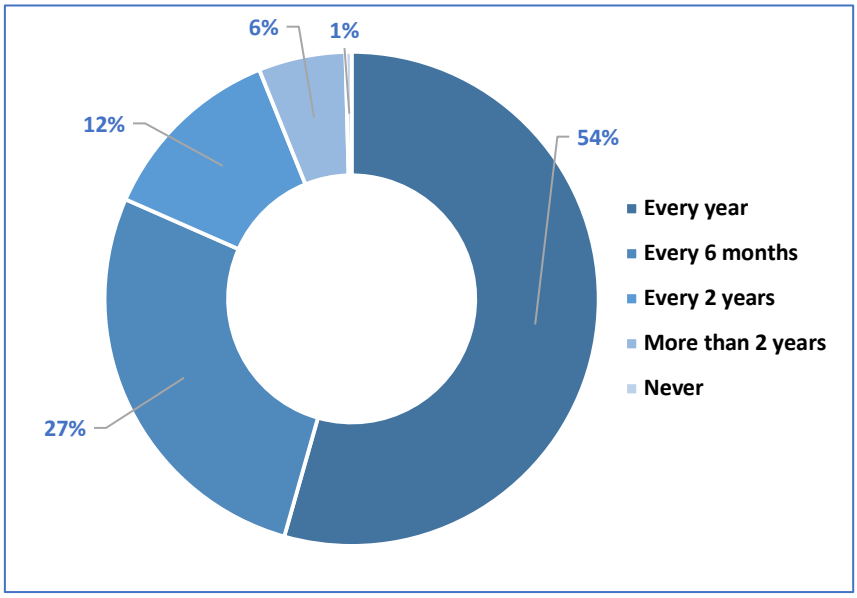
Chart 5: Respondents' knowledge around the age at which a woman should start having routine mammograms



I also remarked that many women do not know when exactly the mammography should be done during their menstrual cycle. This was reflected during several FGDs and supported by the interview conducted with the Head of the Lebanese syndicate of nursing who specified that women do not know that the mammography should be done three days after the period (or at least during the week after the period).

Survey questions related to when the mammography should be done and if it needs to be repeated show that 54% of the respondents consider that the mammography should be done yearly, 27% mentioned that it has to be done twice per year and 12% think that it should be repeated every two years. In the FGD conducted in Mina Tripoli (NL), the participants stated that there is a lack of awareness on importance of repeating yearly the mammography (Chart 6).

Chart 6: Respondents' knowledge around when mammography should be repeated



11.2.3.3 - Limited availability, reach or effectiveness of awareness raising campaigns or initiatives especially in rural areas

Lebanon is currently actively involved in promoting awareness of BC and the necessity of screening at a national level; however, it is important to signal that this research is not an attempt at evaluating the awareness campaign of the MOPH itself.

The MoPH's yearly campaign promotes awareness around the importance of undertaking mammography and echography, yet to a lesser extent around BSE as specified by the Head of the Lebanese syndicate of nursing. Survey results show that 47% of the respondents have never done the BSE for two main reasons. The first is because they do not know how to do it (21%) and the second one is they

forget do it (14%). When respondents mentioned that they do the BSE, 29% of them stated that they perform it irregularly and 21% of them do it occasionally.

A lack of awareness raising initiatives or campaigns on national or local level was noticed in different locations reached by this study as in the example of the group of women met in Barbara (ML). Women consider that there is a limited awareness about the screening methods, what they are, when, where and how they should be performed. Many women do not know that they need to reserve during the national awareness campaign which fallout in a rush of women to public hospitals, or at others not managing to book appointments as mentioned by the founder of Faire Face. Other women mentioned that they do not know where exactly they can participate to screening tests and benefit from the offers provided by the MOPH. They do not even know where to find a clear list of public hospitals and medical centers in each region collaborating with the MoPH.

Similar findings were noticed also in Jdaide (GB), Mina Tripoli (NL), Kalamoun (NL) as well as in Bebnin (AG) which is distant from the two major urban hubs Halba (AG, 12 Km away) and Tripoli (NL, 19 Km away). The difficulties resulting from the distance from homes to healthcare centers have been discussed in section 11.2.2.

In rural areas, results show a limited reach of awareness campaigns initiatives or lack of availability of public medical centers like the case of Abba (NG, 84 Km away from Beirut). Bebnin (AG) is another example of a rural city, with almost 25 000 residents, that lacks the presence of a public primary healthcare center or a medical service collaborating with the MoPH under the campaign. Even in the case

of its existence, participants from Bebnin (AG) were not aware of it. This supports the fact that, even when the service is available and affordable (free of charge), there are women who are not aware of its provision.

81% of the surveyed women were aware of the BC awareness campaign organized by the MOPH yearly, but only 31% of them have ever benefited from the offers on the mammography during this campaign. This means that the knowledge about the campaign is high but too many barriers act against benefiting from it, especially in rural areas.

Other barriers to participating in BC screening activities when reached by the awareness campaigns and the offers on mammography tests provided by the MOPH include the fear of possible results as it will be discussed in section 11.2.10. Furthermore, another barrier to BC screening activities during the awareness campaign is women's perceived susceptibility (that will be discussed more in section 11.2.7) mentioned by the Founder of Rima Jallad foundation who considers that the awareness campaigns are reaching a wider audience of Lebanese women (very few do not have a TV, nor a phone) but they are not doing the mammography mostly because they do not care or they do not think that they need to do it.

These barriers are also linked to a general limited awareness raising interventions on structural levels such as in schools and TVs, and insufficient and ineffectiveness of messages or channels used for awareness raising. These results may be due to campaigns focusing more on detecting cancers through its symptoms rather than focusing on its curability. The gender expert interviewed

considers that awareness campaigns should not be the same to the two million women, as they are different, which means that awareness campaigns should be tailored accordingly.

11.2.4 Self-efficacy and psychological factors

Different psycho-social factors act as barriers to Lebanese women's participation in BC screening tests. This includes negligence and lack of motivation, lack of priority given to health together with the burden of women's childhood stress and its effect on their current psychological and physical condition. Another aspect revealed in this study is women not accepting the probability of having BC and how they worry about how they will face it in case they were diagnosed.

11.2.4.1 - Negligence and not giving importance to own-health

The stress of women's daily lives makes them forget about themselves and prevents them from seeking medical care. Many women mentioned that they do not do mammography tests because of an overwhelming sense of negligence towards themselves and they do not feel motivated in life in general.

They describe themselves as always stressed about their life problems and sometimes feeling depressed. In Dahye (GB) for example, a region affected by the last war in Lebanon in 2006 during which many houses were demolished, and also in SL, participants talked about the stress they lived as residents in these regions and how this makes them mentally "unstable" and overwhelmed by the smallest health issues such as fever. For women of these regions seeking BC screening is not perceived as important.

Furthermore, the childhood of many women who lived with economic instability, being obliged to work to help their family and taking responsibilities at very young ages, make them currently feel “the heaviness” of these old days. All these responsibilities continue to affect them mentally and physically. They consider themselves stressed and exhausted and not encouraged to take any step towards their own well-being, and thus BC screening.

63 years old participant from Bazouriye (SL)

- *"I got married when I was 13 years old, took all the responsibility of the house, the kids, the schools, worked in different places until the age of 45 when my health problems started showing. My situation aggravated with the loss of my son during war followed the loss of my parents. All these issues decreased my ability to resist and fight in life. Nothing mattered anymore."*

11.2.4.2 - Worry of how to face BC If ever diagnosed

Many participants refuse to hear about cancer in general or about other people diagnosed. “If I see on TV anyone talking about cancer I would change the channel” one of the participants in Dahye (GB) said.

Not supporting the idea of the probability of having BC is another finding from the FGDs. Women thought that BC diagnosis might affect negatively the psychological well-being of the affected person, her relationship with her husband and their sexual life. Many of them consider that the fate of BC is ultimately “death”. For example, a participant in Bebnin (AG) mentioned that if she ever notices anything wrong in her breast she will lend herself to fate and death and will not act towards seeking medical advice or treatment.

11.2.5 Social and cultural barriers

11.2.5.1 - Negative image of BC in the society and importance of external appearance

In this research, many women highlighted cases of people hiding the presence of BC patients in their families, and others avoiding knowing that they have BC because they would be embarrassed to tell people about it. Remarkably, in Lebanon, people use words like "pity" when describing cancer patients which could have negative influences on the patient. The society can be harsh on people. As one of the BC survivors described, a woman would avoid getting diagnosed so she would not be treated with pity and stigmatized by the society as a “cancer patient”. According to a member of the Lebanese Cancer Society, society has a negative attitude towards BC, people look at patients with pity, with negativity and lack of respect to survivors and people who are attaining cancer treatment.

Additionally, and according to the founder of May Jallad Foundation, there is always a need to hide from the society when diagnosed with BC, especially after starting chemotherapy and losing the hair. The physical transformations that the BC patient faces result in shyness and embarrassment. The Head of the Lebanese syndicate of nursing also mentioned that people say out loud the name of other diseases like diabetes for example, but they avoid pronouncing the word “cancer”, calling it “that disease”. She adds, "if a mother has BC, she does not speak out loud about it for fear of scaring men who wish to marry her daughter". BC patients have a guilt feeling about BC especially towards their family. As she describes in her study too, BC patients are found to have guilt feelings which is emphasized by

their perceived genetic predisposition for BC implying high vulnerability for their female relatives.[137]

Other barrier to doing the tests is to avoid being obliged to perform a mastectomy alongside all its negative effects on a woman's personality and mental state as well as the changes that her kids and husband might sense. Women are usually proud of their feminism and of having two breasts "outside" of their bodies. During the FGDs, the effect of the mastectomy has been described as "crucial" on BC patients. One of the participants in Bazouriye (SL) stated that "If a woman does any operation to remove hidden organs in her body, she would not be affected like this."

One of the BC survivors also mentioned that a woman who must to do mastectomy "loses half of herself and half of her beauty" even if she makes a reconstruction of the breasts, her body will never return to how it was before. According to the founder of May Jallad Foundation, women in the Lebanese society prefer to take care only of the external image and hide any signs of BC. Similarly, the Gender expert stated that "The body and the looks of a person, especially women, is very important in our society which makes it harder in case of diagnosis and treatment for the patient. They would prefer to die and not look different. This is very well seen in Lebanon, a country famous with plastic surgeries where women want to

[137] Doumit, M. A. A., El Saghir, N., Abu-Saad Huijer, H., Kelley, J. H., & Nassar, N. (2010). Living with breast cancer, a Lebanese experience. *European Journal of Oncology Nursing*, *14*(1), 42–48.

remain young forever by taking care of their appearance and forgetting about their organs."

11.2.5.2 Self-medication and acting upon their neighbors' medical advices

Lebanese have the culture of self-medicating or asking friends and neighbors what medications to take when feeling any pain instead of seeking professional medical advice. This comes also with getting advices from neighbors about when to do the mammography for example. In many cases, neighbors would give recommendations about the importance or lack of it of mammography testing and when to visit the physician if necessary.

Sometimes women seek friends' opinion after feeling a change or pain in the breast. Consequently, this act prevents them from getting checked and doing a mammography in most cases. As found in the FGDs conducted during this study, advices from neighbors would include their decision making in response to treatment options as well as their strategies for coping with and making sense of BC.

11.2.5.3 Embarrassment and shyness

Embarrassment and shyness have also been found to be significant barriers to BC screening in relation to being checked by gynecologists, technicians and healthcare professionals, especially males and specifically in cases among older and unmarried women. Several studies showed that embarrassment and shyness

are found to be barriers to CBE, mammography, and even to BSE.[138][139] This has been found in studies in other Middle Eastern countries such as Jordan where unmarried women mentioned shyness as a barrier to seeking breast healthcare.[140] In Hallaniye (BHG), the lack of presence of female physicians in Beqaa governorate increases the shyness and embarrassment of women obliged to visit a male gynecologist similarly to what Jordanian women mentioned in the previous study.[141]

Even if the mammography is being performed by a female physician or technician, some women feel shy and embarrassed as one of the participants from Jdaide (GB) mentioned "when I did it once, I was dying to leave the room, I felt so embarrassed".

Previous studies in Saudi Arabia, another Arab country, have discovered that the lack of female physicians was found to be an important barrier to BC screening for Saudi Arabian women.[142] In another study in UAE, 97% of the women participants

[138] Seif, N., Aziz, M. (2000). Effect of breast self- examination group of working women. J Egypt Natl Cancer Inst, 12, 105-15.

[139] Bener, A., El Ayoubi, H., Moore, M., et al. (2009). Do we need to maximize the breast cancer screening awareness? Experience with an endogamous society with high fertility. Asian Pac J Cancer Prev,10, 1-6.

[140] Taha, H., Al-Qutob, R., Nyström, L., Wahlström, R., & Berggren, V. (2012). " Voices of Fear and Safety" Women's ambivalence towards breast cancer and breast health: A qualitative study from Jordan. BMC Women's Health, 12.

[141] Ibid.

[142] Akhtar, S., Nadrah, H., Al Habdan, M., El Gabbani, S., El Farouk, G., Abdelgadir, M., Al Saigul, A. (2010). First organized screening mammography programme in Saudi Arabia: preliminary analysis of pilot round. Eastern Mediterranean Health Journal, 16(10), 1025-1031. doi:10.26719/2010.16.10.1025.

reported preference for a female physician[143] when given the choice to choose between female or male physicians.

Furthermore, one of the BC survivors interviewed described how “The most terrifying thing about having to go back after my BC recurrence is removing my clothes in front of the male physician." Another BC survivor who was asked to remove her clothes while being checked, said to the physician: "is my body for everyone? Does not it belong to me only?".

54 years old participant from Jdaide (GB)

- *"Routine visits is a common thing among women but I , personannly do not visit my gynecologist because I am very shy, I can never remove my clothes in front of a physician even when it is a female one"*

11.2.5.4 Gender inequality and women’s relationship with men

Another concern that could act as a barrier to being diagnosed with BC is the possible discrimination women could be treated with by their husbands after their surgery and/or treatment. Women in this study expressed how they felt men in general are “selfish”, even if they love their women, after mastectomy they would look at other women who have real breasts. A perception from a BC survivor “in our society if the man gets cancer, his wife would stay next to him, but contrary men would not stand next to their wives, they would even cheat on them the next day.”

[143] Bener, A., Alwash, R., Miller, C., Denic, S., Dunn, E. (2001). Knowledge, attitudes, and practices related to breast cancer screening: a survey of Arab women. J Cancer Educ,16, 215-20.

Furthermore, FG participants mention that in a patriarchal society such as the in Lebanon, in cases of which both parents are sick, the priority of getting a treatment goes to the father who is in charge of the family and needs to be healthy to work and bring money to the house. This also sometimes prevents women from even declaring that they have an illness or disease so not to influence their family's survival. The gender expert mentioned that this patriarchal system does not give importance to women's health and considers them to be caring persons, taking care of their families, supporting them and giving from their own time.

The male influence on women was mentioned also in the FGD in Bazouriye (SL) where participants cited that sometimes it is not possible for a woman to go by herself to seek medical care, she needs to be accompanied by a male person and has to find him available when she is in need. These women also mentioned that, this gender inequality and the need to be always accompanied by a male is the result of gender discrimination they lived during their childhood and adolescence. For example, one of the participants added "At the age of 10, girls were not allowed to attend schools, it was considered "shame" in SL and in many other Lebanese regions".

11.2.6 Economic Factors

Results from the current study suggest that economic factors not only act as barriers to women's participation in BC screening activities but also on their decision to repeat the test on yearly basis or when needed. In Lebanon, where

51.7% of the population does not benefit from any form of medical coverage, the access to such services is already limited.[144]

During the FGD in Mina, Tripoli (NL), women stated that even if the mammography or the screening tests is covered by the MOPH, the additional perceived cost, limits women from seeking the mammography in the first place to avoid any follow-up or unforeseen cost of additional required tests. A woman from Bazouriye (SL) also stated that “awareness campaigns cover only the mammography, but who will help the diagnosed patient economically and psychologically?”.

Also, in many cases, physicians request the repetition of the mammography more than once a year, as for example, every three or six months. This need of repeating some tests more than once per year, together with the absence of social security or any type of medical coverage makes the woman skip her tests and not doing them on time.

Even in public medical centers where usually women go because visits are free of charge or very cheap, some of the tests required after the first visit are very expensive. Participants in the FGD in Mina described how they are living in a “very bad economic situation, our salary is already under the minimum wage, it does not

[144] National Health Statistics Report in Lebanon Institute of Health Management and Social Protection (IGSPS) at Saint-Joseph University and coordinated by Dr. Kosremelli, M.A. with the technical support of the WHO office in Beirut and the Lebanese Ministry of Public Health and the financial assistance of the WHO office in Beirut, 2012 retrieved from https://igsps.usj.edu.lb/docs/recherche/recueil12en.pdf.

cover our food expenses and rent, we cannot pay medical services at all.” They also added how during the awareness campaign, sometimes technicians ask for an additional echography that costs 30,000 L.L (20$). In most of the cases, they are going to do the mammography when it is free without having money to do any additional tests like the echography.

52 years old participant from Abba (SL)

- *"If I need to be operated for BC, my husband would need to sell his house so we can pay the medical expenses including tests and drugs."*

During the remaining months of the year, these services are offered at their original price. At private medical centers and hospitals, a mammography an echography would cost 60,000 L.L (40$) each. In public hospitals, the mammography costs 50,000L.L (33$) and the echography 60,000 L.L (40$). Noting that the minimum wage in Lebanon is 675,000 L.L (450$), a mammography and an echography would cost 16% of a minimum wage salary at a public hospital and 18% at a private one.

Lack of economic resources, social security or any type of medical coverage can lead to postponing the woman's needs in general, health issues and participation in BC screening tests in particular. Many patients would even stop their treatment once they cannot afford the price of the chemotherapy anymore.

The National Social Security Fund (NSSF) in Lebanon provides employees from any sector with insurance coverage for sickness and maternity care. It also covers family allowances, end of service pension, and work related accidents and

diseases. In the FGD conducted in Arde (NL) participants mentioned that sometimes they cannot afford medical expenses, even when NSSF is available, as they are unable to cover the remaining 15% that is not covered by the NSSF nor the cost of further required tests or medical procedures.

Women's concern is also related to treatment affordability if diagnosed with BC. They worry in the case that the MoPH does not cover all cancer drugs they would not find someone to help them, if diagnosed, in buying the drugs and paying for any required chemotherapy, radiotherapy or additional medical procedures. As per the director of public relations and health education departments at the Lebanese MoPH, the economic burden on BC patients is real. The ministry does not cover the outpatient's services, nor the fees of physicians and diagnostic. This issue is extremely difficult to be changed since it requires law modifications, and a lot of resources that the ministry does not have.

At the same time, it is worth noting that between 2014 and 2016, a total of approximately $140 million was spent through the MoPH free cancer drug dispensing program.[145] Complete coverage remains a challenging procedure as the average cost of drugs per patient per year measured across all cancer types

[145] Elias, F., Bou-Orm, I. R., Adib, S. M., Gebran, S., Gebran, A., & Ammar, W. (2018). Cost of Oncology Drugs in the Middle-Eastern Country of Lebanon: An Update (2014-2016). *Journal of Global Oncology*, (4), 1–7.

increased from $7,000 in 2014 to $8,400 in 2016 as per the study on the cost of Oncology Drugs in Lebanon last updated for the period 2014-2016.

The cost of transportation from homes to hospitals or medical centers acts also as a barrier to women's participation in BC screening activities. This was clarified by participants in Hasbaya (NG) who cannot afford the price of a taxi to arrive to the closest hospital. Transportation cost is directly linked to the geographical factors presented previously in section 11.2.2. As an attempt to reduce the effect of transportation as a barrier to BC screening, the MoPH is planning to collaborate with municipalities, especially in rural areas, to offer public transportation for women from their homes to the closest public hospital as mentioned by the director of public relations and health education departments at the Lebanese MoPH starting October 2018.

Finally, when economic resources are limited, many women prefer not to spend money on taking care of themselves therefore, not doing mammography when needed. They prioritize their family's needs and house expenses to their health and to access medical services. More on the how the undervalue of women's own life's worth for the sake of their families has been discussed previously in section 11.2.1.

11.2.7 Perceived susceptibility

Psychosocial elements of the Health Belief Model such as higher perceived susceptibility of BC, and higher perceived benefits were all significantly associated

with life-time performance.[146] Perceived susceptibility is the subjective perception of the risk of contracting a health condition. Associated to BC, it may be seen as the chances of being diagnosed with BC, in the long term or immediate future, as felt by women.

Stubbornness, denial and refusing the possibility or the idea of being diagnosed with BC was noted as a barrier to women taking a mammography test. Similarly, 17% of the respondents agreed to the fact that they prefer not to know if they have BC. 33% of the respondents to the survey agreed and strongly agreed on the notion that “A woman only needs a mammogram when she experiences breast pain”. Subsequently, 48% agreed and strongly agreed that “A woman only needs a mammogram when she notices changes in her breast”.

50 years old participant from Halat (ML)

- *"I do not do the test, I prefer not to know if I have BC"*

FGDs participants talked about feeling denial in regards to BC. Many women consider that BC is not going to happen to them personally, and do not perceive themselves as targets. As mentioned by the founder of Faire Face, numerous women keep saying that “it [BC] could happen to my neighbor but not me”.

54 years old participant from Hasbaya (NG)

- *"I will not get BC, I know that, this is why I do not do the mammography"*

[146] Haddad, F., Hampig, K., Salim, A. (2015). Trends in mammography utilization for breast cancer screening in a Middle-Eastern country: Lebanon 2005–2013. Cancer Epidemiology. 39. 819-824. 10.1016/j.canep.2015.09.015.

One of the BC survivors interviewed also explained how she used to think before being diagnosed that cancer can happen to others but not to her. She used to think that BC could never affect her especially that she used to exercise, eat healthy food and never smoked.

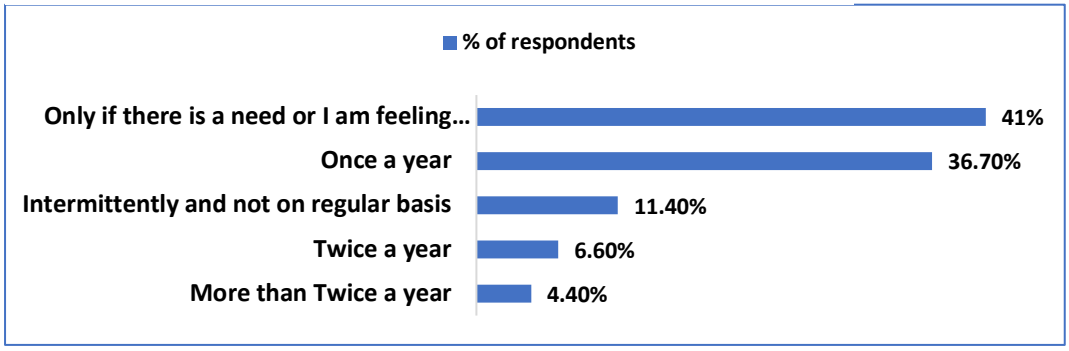
41 years old participant from Jdaide (GB)

- *"How will I see myself without a breast if it will ever happen to me? We always say that loving life is imporatnt but it is scary if we think of it happening to us"*

Another finding from this study is that women do not feel the need to do screening tests when they are feeling well, not feeling pain or any signs of illness and specifically not seeing any perceived signs of BC. According to one of the participants in Batloun (ML), “not feeling anything means I am fine”.

In Der Dalloum (AG), participants mentioned that they leave their health to God. When not feeling that there is anything wrong with their own health, they would visit their physicians only in case of emergencies and irregularly. For these women, repeating the mammography yearly is very far from being a routine. Likewise, one of the participants in the FGD in Karak Nouh (BG) mentioned having done the mammography once in her lifetime precisely three years ago. She was convinced that she does not need to repeat it anytime again as she does not feel the need to it. Additionally, 41% of the respondents to the KAP survey, go for check-ups and visit their physician or gynecologists only if there is a need or when they are feeling something wrong as shown in the chart 7.

Chart 7: Frequency of medical visits and routine check-ups



During the FGD in Hallaniye (BHG), participants mentioned that if the mammography is not requested by their physician they would not do it. The same idea was mentioned by the director of public relations and health education departments at the Lebanese MoPH, who considers not being advised by the physician to do the mammography an important barrier to her involvement in BC screening methods.

11.2.8 Healthcare system and experience

Lack of trust in the Lebanese medical system in general and in the services provided during the awareness campaign have been found to act as barriers to BC screening activities by this research. Another health experience related barrier is women's perceived knowledge about BC therapies, their personal experience with previous participation in mammography or their friends' experience.

11.2.8.1 Lack of trust in the Lebanese medical system and bad previous experiences

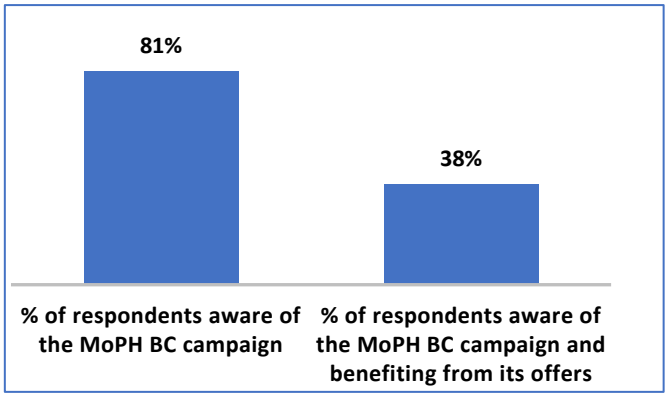
During this research, many women have mentioned having little trust in the Lebanese medical system, physicians and healthcare centers. They think that "the new generation of physicians" for example, work differently nowadays. In

particular, accessibility to physicians, communication, trust and personal relationship with them has been described as “different and not very comfortable”. Furthermore, perceived lack of transparency and compassionate communication with the patients has been recorded as one of the mentioned barriers to women’s participation in BC screening tests throughout this study.

This lack of trust perceived by participants applies also to technicians working in the medical centers who were described as “treating patients inhumanly”. As a result to this approach, participants feel a lack of respect in regard to the patient and the patient's family members. Participants added that the disrespect is felt mostly from the medical body in the hospitals including technicians, nurses and physicians.

As per the Head of the Lebanese syndicate of nursing, women do not trust the government in general, nor the medical services provided. They are afraid of catching infections in hospitals. One of the participants in Batloun (ML) stated "you arrive to the hospital for a reason, and you end up sick if not dead, from another reason". This statement arises from previous experiences with participants’ family members. The lack of trust in the public medical system in Lebanon could be noted in the KAP survey results that show that even

Chart 8: Comparison between participants ‘ knowledge about the MoPH’s awareness campaign on BC and their participation in offers on mammography during the campaign



though 81% of the respondents are aware of the BC awareness campaign organized by the MoPH as the chart 8 shows.

Moreover, as described by the gender expert, another reason to the lack of trust in medical service providers, is the lack of confidentiality in public hospitals and the perceived lack of respect of the patients. Most of the participants in the FGDs mentioned not trusting hospitals and therefore not seeking medical care in general and specifically for BC for the lack of privacy in the hospitals. One of the participants in the FGD in Arde (NL) stated “when being on the desk and talking to the nurse or technician, other people or visitors might stay and hear all the conversation which is uncomfortable for the patient or patient's family member”.

A common finding from different FGDs conducted, is that there is a decreasing level of trust towards physicians. Women sometimes underestimate the value of mammography when requested by their physicians as they believe that there is a growing trend in the country of physicians asking for tests or operations only to benefit from commissions. Participants in Jdaide (GB) talked about getting recommendations from physicians to do the mammography in a specific center rather than in another which raised the issue of trust and the benefits that a physician gets from the medical center (commission) or from the pharmaceutical companies in case a treatment is needed.

The lack of trust towards physicians explains the growing trend of increased level of trust and care sought directly from a pharmacist. Women and BC patients interviewed believe that pharmacists provide more time for patients, answer their questions about subscribed drugs, listen to them and provide them advices for their medical cases. Even though, some of the participants mentioned not trusting even pharmacists since some of them are being caught for selling fake chemotherapy for cancer patients.

57 years old participant from Arde (NL)

- *"Running from a place to another to get the approval for the medication is an attempt for the human dignity"*

Additionally, the burden of doing all the paper work requested by the MoPH and the hospital in case of diagnosis and when a treatment is needed, has negative effect on their dignity. Participants find that witnessing first-hand experience or hearing about a humiliating experience from others who have dealt with the MoPH's system to obtain cancer drugs, pushes women to avoid doing any tests and therefore knowing if she has BC to avoid this humiliation.

11.2.8.2 Lack of trust in services during the awareness campaign

Findings from the FGD in Hallaniye (BHG) express the lack of professionalism at the medical centers and public healthcare institutions especially during the awareness campaign. Participants talked about the lack of trust in services provided during the campaign and the perceived inefficiency and corruption in public medical centers. In Kalamoun (NL), participants talked about not trusting free services in public hospitals because of having previous bad experiences. Other participants in this study, revealed that the discrimination felt by the MoPH's

dispensaries operators as well as the lack of proper documentation in the MoPH constitute important challenges to accessibility to the ministry's services.

For instance, experiences of false diagnosis in public hospitals acts as an important barrier to participation in BC screening tests. For example, one participant in the FGD in Mina (NL) talked about bad medical experiences that makes her never go back to the public medical centers; and without affording going to a private hospital she prefers not to go at all. This lack of trust in results of mammography done during the awareness campaigns due to a perceived negligence, ineffectiveness and unprofessionalism of healthcare staff working in the public sector when overloaded with work, prevents women from seeking BC screening tests in public healthcare centers especially during the yearly BC awareness campaign.

43 years old participant from Halat (ML)

- *"I do not trust the hygiene of the machinery used during the awareness campaign when the tests are provided for free. That is why I pay for my mammography test when I need to do it"*

Many women consider that the national awareness campaign is offered for short periods during the year which makes it more difficult for them to manage booking appointments if ever they decide to. Even if they know and hear about it, very few choose to go to the public hospitals or healthcare centers and tolerate the burden of waiting for hours to do the tests or waiting for months to book an appointment.

Healthcare centers' limited capacity to receive high numbers of women delays the appointments (maybe for one month) which makes women sometimes choosing not to go anymore instead of waiting. In Hallaniye (BHG), participants also talked

about the favoritism experienced during the awareness campaigns, when persons from the public medical centers and hospitals contact particular women that they know (especially relatives and friends), in order to book them appointments and to remind them about the offers of the MOPH.

11.2.8.3 Previous bad experience with mammography

Previous experience in performing a mammography acts as a barrier to repeating it again yearly (or when required) as found in this research. Bad experience related to previous participation in BC screening tests as described in the FGD in Jdaide (GB) in many cases is the outcome of poorly trained technicians at the centers offering mammograms, which can result in errors or obligations to repeat the mammography twice in the same day.

The majority of women interviewed defined their experience with mammography as “painful” or “disturbing”. Participants in the FGD in Bejje (ML) in particular, described the mammography as a very annoying test. Same definition has been described in Batloun (ML) where participants added that mammography creates a lot of physical and psychological discomfort. One of the participants in the FGD in Jdaide (GB), who is 54 years old, has done the mammography once in her life and has found it very painful so she would never think of repeating it ever again. She said "It felt like my breasts were getting smashed, and I felt that I was about to faint". Results from the survey also show that 30% of respondents who have ever done a mammography, have done it more than two years ago and other 10% of them do not even remember when was the last time they did it.

During the FGD in Bazouriye (SL) participants mentioned that in many centers and hospitals, the presence of a male physician or technician doing the test is a huge barrier, some women take the appointment but will not do the mammography if they find that it would be done by a male person. In particular, what has been described by participants as “annoying” is mostly having the breast pressed into the machine and the male physician or technician touching it.

11.2.8.4 Different recommendations for mammography

Another barrier to women’s participation in BC screening activities is not having clear recommendations on when to do the mammography and how frequently it should be done. This was described during the FGD in Jdaide (GB) by participants stating that the recommendations differ from a center to another, as well as from a physician to another. For example, when requested by their physician, some women go to repeat the mammography after having done one less than a year ago, and they find a technician who interferes in saying “why are you repeating it? you do not need to”.

11.2.8.5 Perceptions about BC therapies

Many participants interviewed consider that the chemotherapy kills the cancer cells and the normal cells which causes a decrease in the immunity system. They try to avoid doing the tests, so they would not be diagnosed and be obliged

51 years old participant from Dahye (GB)

- *"I do not want to suffer, I prefer to die directly rather than doing all the chemotherapy"*

to take the only cure for BC cancer containing “killer” chemicals in the chemotherapy as participants in the FGD in Halat (ML) described.

11.2.9 Religious factors

Women in Lebanon have a fatalistic relationship with sickness in general and not only with BC. This was consistently expressed among participants from both religions and all denominations. For example, a Muslum Sunni participant from Kalamoun (NL) mentioned that “Whatever happens to me is from God, I am in God's hands". In Hasbaya (NG), Druz women consider health as a religious matter. They mentioned during the FGD "why do I need to do anything to my body, whatever will happen is going to happen". As per the sociologist interviewed, many Lebanese women even consider sickness as a punishment from God.

62 years old participant from Abba (SL)

- *"I have never done any BC screening test in my life. If I ever notices any signs on my breasts, I will only cover it with some anointed oil and pray for it to heal."*

Leaving life in God's hands prevents some women from doing mammography and taking actions in an attempt to respect what (He) has planned for them. Many women interviewed consider that whatever God wants for them will happen, and they respect His decision. A participant in Bazouriye (SL) mentioned that “nobody will die before the end of his life”. Another participant from Jdaide (GB) mentioned that “living in a country where everything is polluted (food, air), we breath the garbage every second, so whatever God has "written" for us will happen for us no matter what”. She adds, that we just

40 years old participant from Mina (NL)

- *"Age is limited and defined, we can not change anything about it. When it is our time to die we will die."*

need to keep our life in God's hands instead of paying tons of money in Lebanese hospitals.

11.2.10 Fear

The most important barrier to obtaining a screening mammography across all regions, ages and educational levels is fear of discovering the possibility of having BC. When discussing the barriers that prevent them from obtaining a mammogram, FGDs' participants replied with expressions related to fear such as fear of finding out something is wrong from the mammogram, fear of discovering the disease, fear of knowing I have BC, it's a scary disease, I'm afraid of knowing, I prefer not to know, and I do not want others to know.

Some women consider that they do not have the strength and the power to face BC. They are afraid from the psychological and physical pain that they would feel if diagnosed. Generally, cancer is perceived by women to be a menacing illness.

47 years old participant from Jdaide (GB)

- *"If the cancer is in the body not even God can remove it"*

Some of the FGDs participating in this research are afraid because they still believe that there is no cure to cancer. As one of the participants in Abba (SL) stated, "If I will know that I have BC, I would be afraid, I will have to see the physician and will have to take chemotherapy no one took chemotherapy and got better".

Other fear related barriers perceived by participants is the fear of uncertainties if diagnosed, dying and leaving their family and husband. A participant in Bazouriye

(SL) stated “what will happen if I will be diagnosed?”. This fear of change of habits and change of external looks (food intake, physical activity) in case of diagnosis makes women ignore the importance of the screening.

Furthermore, the fear of being diagnosed is accompanied with the fear of the chemotherapy, losing hair, and “their feminine image after mastectomy” as per the founder of Faire Face. Participants revealed that the fear of being stigmatized by the society as BC patient is a factor influencing their participation in BC screening tests. Similarly, the Head of the Lebanese syndicate of nursing talks about women’s fear of being labeled and pitied for having BC.

Previous studies in the Arab World have showed that the fear of gossip and the belief that a woman’s potential for a good marriage could be negatively affected have been described as a barrier to BC screening.[147] Other studies in the Middle East talk also about the fear of the social stigmatization and how it prevents women from obtaining mammography.[148]

57 years old participant from Baalback (BHG)

- *"Women who are married are more motivated to doing the mammography for fear of losing their husband"*

Lebanese women who participated in this study mentioned also the fear of losing their husband as a barrier to obtaining a mammography. In the FGD in Hallaniye (BHG), participants focused on the fear of being diagnosed and getting left by the

[147] Cohen M, Azaiza F. (2005). Early breast cancer detection practices, health beliefs, and cancer worries in Jewish and Arab women, Preventive Medicine,Volume 41, Issues 5–6,2005,P.P 852-858, ISSN 0091-7435.
[148] Azaiza, F., & Cohen, M. (2008). Between traditional and modern perceptions of breast and cervical cancer screenings: A qualitative study of Arab women in Israel. Psycho-Oncology, 17(1), 34–41.

husband who will be marrying someone else. Additionally, an interviewed BC survivor mentioned being in constant fear of losing her husband after she did the mastectomy.

In this research, the fear of medical procedures has also been found to be an important barrier to women's participation in BC screening which includes the fear of radiation from the mammogram, fear of the pain felt during mammography, similarly to what has been found in a previous study in Abu Dhabi.[149] Participants also mentioned the fear of operations if ever needed, fear of medical interventions in general and fear of cancer treatment and its effect as factors influencing on mammography practices.

Finally, many women notice changes and signs of BC in their breasts, but they try to hide them from their family members and from their friends, neighbors and relatives. All this is for fear of being diagnosed and for not knowing how important the early detection is and for the lack of knowledge about signs of BC. Consequently, women might ignore changes in the breast that are benign thinking that they are tumors as mentioned previously in the knowledge section in 11.2.3.

[149] Abu-Helalah, M. A., Alshraideh, H. A., Al-Serhan, A. A. A., Kawaleet, M., & Nesheiwat, A. I. (2015). Knowledge, barriers and attitudes towards breast cancer mammography screening in Jordan. Asian Pacific Journal of Cancer Prevention, 16(9), 3981–3990.

11.3 Facilitators for BC screening

11.3.1 Family

11.3.1.1 - Love of family

As there are numerous factors affecting BC screening behaviors, many of it act as facilitators and motivators to women's participation in mammography. Some of the women participating in this research have expressed that an important factor influencing their decision to do a mammography is their own love for their families. They described how it pushes them to take care of themselves to remain healthy, be able to support their family and therefore minimize the burden of their own health on their children and husband.

Although this finding was also covered in the barriers section 11.2, the love and dependency of the family on the mother can itself act as a facilitator or a barrier depending on the mother's own framework of thought. The more positive it is, the more it is oriented towards maintaining her own health for the well-being of her family members.

Relatedly, some of the participants mentioned how they take care of their own well-being in order to avoid obliging their family members to take care of them. As one of the participants in the FGD in Bejje (ML) described, having family members as a back-up, motivating and supporting her in case anything would happen to her, brings serenity and courage for her to face BC if she is ever diagnosed. Another participant in Jdaide (GB) mentioned that "children are a great motivator,

specifically when the mother feels indispensable to them and that they would never be able to live without her". Being indispensable to her family, intensify the woman's will to stay alive to see her children and grandchildren grow.

58 years old participant from Arde (NL)

- *"I thought of my family, if I will not be well, they will have to take care of me and I will be a burden."*

In several locations, participants described how the fear of losing their husbands if they found out that they are diagnosed with BC acted as a barrier, however some other participants in different locations such as Halat (ML), Arde (NL) and Jdaide (GB), felt that this would be a call for action to maintain their own health for the same sake of keeping their husbands.

11.3.1.2 Support from family

I have found in this research that motivation from husbands and family members, encourages women to take care of themselves and conduct general health related tests including mammography. For example, in the FGDs in Barbara (ML) and in Bazouriye (SL), participants talked about how some of their children reserve appointments and cover the cost of their mother's regular medical check-ups. In Dekwane (GB), participants even mentioned that their children would take the appointment and oblige them to go (sometimes only once but in other cases every year). A participant in Hasbaya (NG) also described how

53 years old participant from Barbara (ML)

- *"I used to neglect my health, I never took care of myself until I did one test and found out that my situation was critical, then I realized that I should start changing my lifestyle especially my diet. All this happened because my son kneeled on his feet and begged me to go with him and see a physician."*

her father used to oblige her and her sister, since they were young, to do yearly regular check-ups and medical exams. This has facilitated her routine yearly participation in mammography.

Sometimes, friends and relatives also play a positive role in reminding some women to do the mammography. As per the director of public relations and health education departments at the Lebanese MoPH, women need to be reminded by one of their family members to do a mammography, this is why, for the past three years, the national awareness campaign of the Ministry focused on this aspect.

Family members, friends and relatives can act as a reminder, and even in better situations they also in some cases go together to obtain a mammography and motivate each other. This has been mentioned by participants in Hallanie (BHG) and Barbara (ML) who go together during the awareness campaign to obtain mammography tests. As per the gender expert, women who go together express solidarity among them, which could facilitate their participation in BC screening tests and decreases the burden of taking appointments, waiting time at the hospitals or for the results.

11.3.1.3 Family experience with mammography and family history of BC

A family member's positive experience with mammography encourages her own relatives to seek for it. In this study I have found that women get influenced by other family members' positive experience. They get motivated to do the mammography when hearing how easy it was to take an appointment, do the test, not finding it painful, or being afraid of it. Additionally, feeling at ease in a certain

medical center rather than another and getting negative results after performing the tests encourages relatives to go through the same process.

Family history also plays a determinant role in the perception of severity of BC. Some of the participants, with an existing family member with BC tend to get routine checkups and go for a mammogram on a regular basis. This motivation to do routine check-ups, and seek early detection when having a mother, daughter or sister diagnosed with BC, is a finding that has been noticed between participants from different locations. Results from the KAP survey show that 38% of the respondents have one of their family members or relatives diagnosed with BC. Moreover, 78% of the respondents who have family members or relatives previously diagnosed with BC have previously done a mammography. This is eight per cent higher than the overall finding from all respondents. This shows the significance of family history of BC in contributing in an increased participation of women in mammography.

48 years old participant from Dekwane(GB)

- *"When we started talking specifically about cancer today, I wanted to leave this discussion, I felt that I can't hear the conversation, but I stayed only to respect the host. Usually if I hear two times the word cancer I faint. I lost my brother, my sister and my relative all in one year, cancer destroyred me, but i till take preventions and do my tests regularly."*

Participants in Batloun (ML) mentioned that hearing about BC survivors sharing their experiences with BC, meeting survivors, watching them on TV or living with them, affects positively on their decision to seek mammography especially if they were diagnosed 20 or 30 years ago with BC and continue to live normally and healthy.

Furthermore, losing a family member or relative for BC, motivated some of the participants to start visiting the gynecologist and to start doing the mammography. It has been described by one of the participants in Bejje (ML) as a facilitator to BC screening for prevention and for early detection.

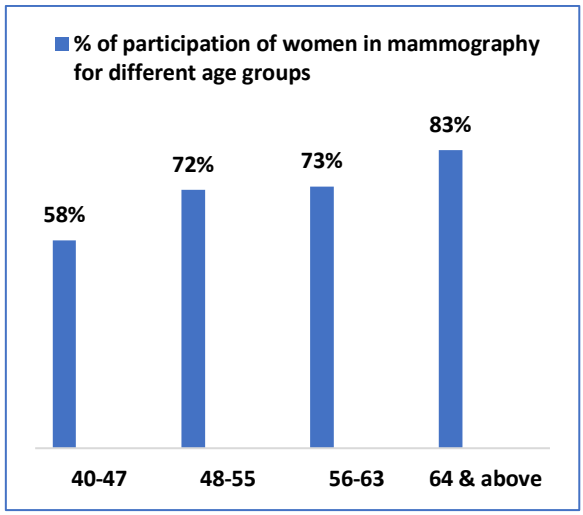
11.3.2 Self-motivation and practices

A significant number of participants in this study described how their own love for their self, motivates them to take care of their well-being, which in many cases could include conducting the BSE and mammography among other preventative measures and practices. Self-motivation as described by participants in the FGDs, includes also reaching for centers and hospitals collaborating with the national campaign to benefit from the MoPH's offers on mammography.

Findings from this research also show how participants who notice any change in their breasts through BSE, take the initiative to do the mammography. A participant from Kalamoun (NL) performs BSE bimonthly. She considers it as a preventive measure to BC and mentioned that she would definitely perform a mammography if she ever finds a change in her breast while doing the BSE.

This research shows that the need of participants to take care of own self increases with age. As the chart 9 shows, there is a notable correlation between the age of women and their participation in mammography. Similarly, during FGDs in several locations, women stated that, with age, they would feel that taking care of own health is increasingly important which motivate them to routinely do the mammography.

Chart 9: Correlation between women's participation in mammography and age



When asked about "why do you perform mammography" 61% of the respondents answered "for prevention purposes". This reasoning was found to be notably higher among respondents aged 64 years and above (72%) when compared to other age groups such as 56-63 years old (57%), 48-55 years old (57%), 40-47 years old (60%).

60 years old participant from Dahye (GB)

- *"Only when I reached 50 years old I started doing routine chek-ups"*

Another facilitator and motivator for BC screening mentioned by women during this study is their love of life. "Not willing to die" is their prime motivation and consolation to accept doing and repeating tests described as painful such as the mammography, for the sake of taking care of themselves. For an attempt to show their love of life, women mentioned changing their behaviors to reduce BC risk factors, such as exercising plus eating healthy foods. In the FGD in Barbara (ML),

participants shared how it is important for them to take care of themselves and handle BC as any other disease such as diabetes for example.

Moreover, in many FGDs, participants believed that the fear of being diagnosed with BC especially after seeing or hearing about other women diagnosed, acts as an essential facilitator to their participation in BC screening tests.

11.3.3 Awareness campaigns and knowledge about BC

During my research I have found that the more women are aware and convinced of the importance of the screening methods in detecting BC, of BC risk and hereditary factors and types of treatment for BC, the more they are willing to take action and seek BC screening methods. Furthermore, the higher women think about BC as curable the more they are motivated to do the mammography and to screen for BC. Additionally, as per the Head of the Lebanese syndicate of nursing, the higher women perceive themselves susceptible to BC the more they participate in screening activities.

For instance, this research has found also that the more women are reached by national and local awareness raising campaigns the more they have a higher knowledge about the importance of the screening methods and about the types of services provided. Participants mentioned that they do the mammography because they have information about BC in general. A participant in the FGD in Dekwane (GB) mentioned that “BC is considered an easy cancer so prevention should be a routine for women.”

Additionally, hearing about the increased incidence of BC in Lebanon and how it is possible to prevent it motivates Lebanese women, as they describe in this research, to perform yearly mammography. In Hasbaya (NG), Batloun (ML) and Arde (NL) for example, participants mentioned gathering information about BC from TV programs, conferences and seminars done by local NGOs.

There are many Lebanese women such as participants in Karak Nouh (BG), who wait for the Ministry's yearly campaign to do the mammography test. As per the director of public relations and health education departments at the Lebanese MoPH, the private sector and companies across Lebanon are also reminding women about doing the mammography through billboards and TV commercials and by marketing BC specific offers during the whole period of the awareness campaign. The Ministry's 30 seconds TV clip is considered as women's first source of information and reminder about BC screening, followed by the SMS that the Ministry sends to the Lebanese citizens in collaboration with the Ministry of Telecommunication.

As per the founder of the NGO Faire Face, knowledge about BC from TV and billboards increases the BC awareness in Lebanon, encourages women to talk about BC freely and to participate in conferences and activities related to BC organized by local NGOs across the country. She adds that Faire Face, in an attempt to spread awareness on BC, made available a mobile mammography in some rural areas to facilitate women's access to BC screening tests. The outcome

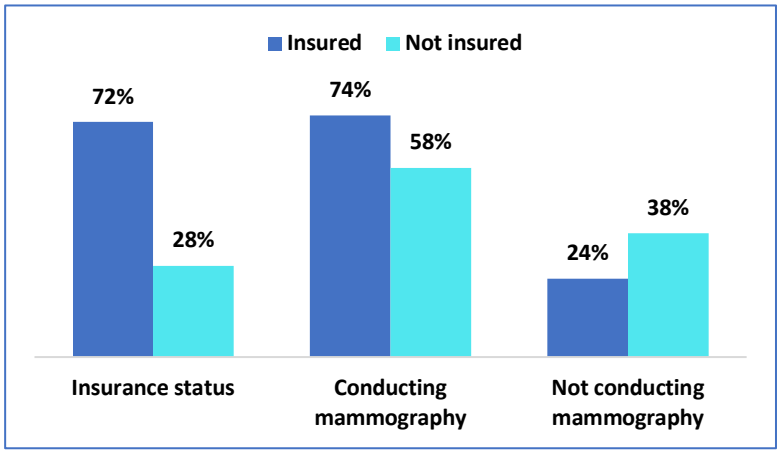
of these campaigns have been noticed from one year to another. Specifically, the number of women doing the mammography has increased remarkably and the age of participants augmented likewise. Furthermore, she added that during such campaigns women in rural areas were encouraging each other's to participate in the screening, which was observed in different locations and religious groups even the most conservative ones.

11.3.4 Economic factors

Having the possibility to do a mammography for free or at a reduced price acts as a motivator to participation in BC screening tests. As described in the section of economic factors 11.2.6, the lack of economic resources, or lack of any type of social security acts as barrier to women's participation in BC screening services. On the other hand, many participants in the FGDs in different locations, mentioned doing mammography because it is one of the routine tests that they do on regular basis since they are insured and/or have a health coverage.

Many participants do mammography tests regularly and on a yearly basis for they are insured. The KAP survey results show that 74% of the insured respondents have performed at least once the mammography previously. The correlation

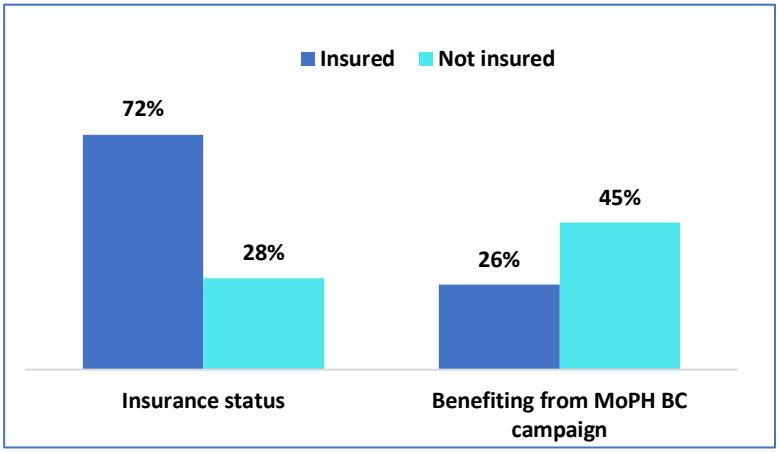
Chart 10: Correlation between availability of insurance and participation in mammography



between being insured and conducting mammography is well shown in chart 10, being insured increases the participation of respondents in mammography tests. 74% of respondents are insured and they conduct mammography, a higher number than the respondents who are not insured but they conduct mammography (58%). Furthermore, KAP survey results show that 24% of the respondents are insured but they do not practice mammography.

One of the participants in Dahye (GB), shared how since she is insured she does all her regular medical check-ups including the mammography once per year. Also in Bebnin (AG), participants found that having a social security is a motivator to their participation in BC screening. Many of them would wait for the awareness campaign starting October of each year to benefit from the offers and reduced prices of mammography.

Chart 11: Correlation between availability of insurance and participation in the MoPH's awareness campaign



Similarly, this campaign is managing to decrease the economic barrier facing women from accessing screening tests. As the following Chart 11 shows, 45% of respondents who are not insured, have benefited from the MoPH's BC awareness campaign, a higher number than those who are insured and have ever benefited from the MoPH's campaign (26%).

Meaning that when economic burdens are lifted, there are more women who would be encouraged to opt for such free screening measures.

It is worth noting as well that in case a woman is diagnosed with BC, the MoPH would potentially cover her treatment (and drugs in certain cases) when she is not covered by any type of medical insurance. Participants in Bejje (ML) explained that a facilitator for doing mammography is having the security that the MoPH would cover the cost of the treatment. In particular, the National health statistics report in Lebanon (2012) shows that the number of BC cases treated in 2009 according to the drug dispensing center at the MoPH accounts for the 36.9% of the overall cancer cases treated.[150]

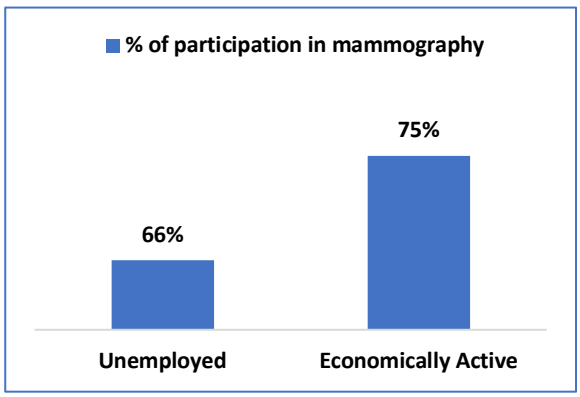
Besides, for many women, knowing that the cost of the reconstructive surgery could be covered by the MoPH would more likely influence positively on their decision to do the mammography. One of the BC survivors interviewed mentioned that the breasts reconstruction is being approved by the MoPH and this influences positively on women's decision in participating in BC screening.

Similarly, KAP survey results show that the employment status influences on Lebanese women's participation in BC screening activities, but it is not a strong predictor to it. As chart 12 shows, when respondents are employed or economically

[150] National Health Statistics Report in Lebanon Institute of Health Management and Social Protection (IGSPS) at Saint-Joseph University and coordinated by Dr. Kosremelli, M.A. with the technical support of the WHO office in Beirut and the Lebanese Ministry of Public Health and the financial assistance of the WHO office in Beirut, 2012 retrieved from https://igsps.usj.edu.lb/docs/recherche/recueil12en.pdf.

active (employed, freelancer or runs a business) they tend to participate more in BC screening tests (75%) than unemployed respondents (66%).

Chart 12: Correlation between participation in BC screening and employment status



Finally, an indirect economic support received by women and facilitating participants' involvement in BC tests is the support they get for transportation or for paying the cost of transportation from their homes to the healthcare services centers. For example, in Batloun (ML), participants talked about the importance of their municipality's role in providing transportation means from the village to the medical centers during the BC awareness campaign and how this minimizes the burden of covering their own transportation expenses (commuting by bus or taxis).

11.3.5 Social factors

Nowadays, BC is increasingly being treated as a socially accepted disease among the Lebanese community. It is less considered as a taboo among some groups and many women. The more mass media talks about BC (especially TV and social media), the more people and particularly women discuss it among each other's, find courage to go and test themselves and treat BC as an ordinary disease.

As per the founder of May Jallad foundation, the taboo of saying the word "cancer" and showing images of breasts of BC patients on brochures, has finally started diminishing. During awareness raising sessions they organize they feel more at

ease to share information about BC including pictures of breasts, showing the sings of BC and explain how the BSE should be performed.

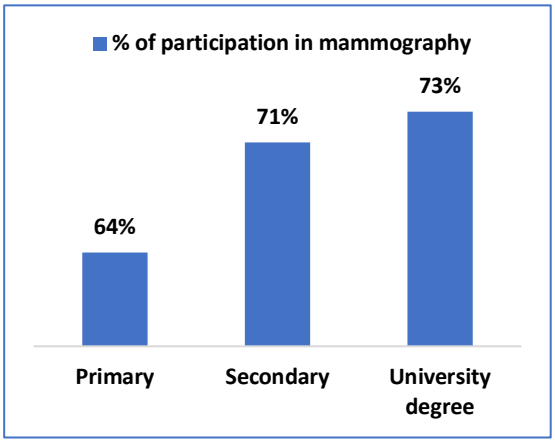
Furthermore, the Head of the Lebanese syndicate of nursing explains how hearing BC survivors talk positively about their experience with BC would influence other women and motivate them to do BC screening tests. Examples of information that could be shared by a BC survivor that would encourage women to participate in BC screening are how they detected it in the first place, their experience with mammography specifically, the type of cancer they had, the medical procedures that they had to pass through, the treatment they used, its side effects and finally the special care that a BC patient should receive.

52 years old participant from Jdaide (GB)

- *"My neighbor had BC 8 years ago, she did the mastectomy and now she is free from it."*

Another social related factor influencing Lebanese women's participation in BC screening activities as found in the KAP survey is their education status. The level of education, as chart 13 shows, affects the respondents' participation in mammography, but it does not constitue a strong predictor to it. It is worth noting that respondents to the KAP survey did not include illiterates as the FGDs did.

Chart 13: Correlation between participation in BC screening and level of education



11.3.6 Physicians and healthcare professionals

Physicians and healthcare professionals constitute one of the main BC awareness sources and facilitators for women for getting the information about the importance and necessity of conducting and repeating BC screening. Given the importance of this factor, its specificity and prevalence, I have included it as a separate section.

Findings from this research show that there are more chances of women seeking screening tests whenever it is requested by their own physician. Participants happen to trust their physician and his recommendations in general and specifically information and advices they give in relation to BC screening. For example, many participants learn how and when to perform a mammography or a the BSE from their physician.

52 years old participant from Dekwane (GB)

- *"When we pray, we pray for our physicians to be trustful and to work humanly"*

Furthermore, if they ever notice any change in their breasts they would immediately contact their physician as 76% of the survey respondents reported. Likewise, when asked about “why do you perform mammography” 19% of the respondents answered “based on my physician’s advice”. In Hallaniye (BHG) one of the participants mentioned that she will never do the mammography unless it is requested by her physician.

Moreover, the founder of the LBCF and oncologist revealed the importance of physicians in informing women about the development of new techniques in therapies for BC. He adds that women feel encouraged and motivated when they learn about the importance of early detection of BC and how it influences the

choices of treatment. Besides, they would feel more confident to get themselves checked when they know that cures for BC are improving and new techniques in mastectomy are being done, such as performing it partially and not necessary totally. Therefore, another motivator for women's participation in BC screening is the knowledge about the improvement in operations methods and reduction in times of recovery after procedures such as the mastectomy.

In Bejje (ML), participants mentioned that knowledge about the importance of early detection to increase the choices of treatment and the possibility of surviving BC act as an essential facilitator to doing the mammography and repeating it regularly. In regards to the influence of healthcare professionals on women's health, one of the BC survivors interviewed recommended that young girls should visit their gynecologists regularly. She added that when each women is monitored by her gynecologist, she would start doing the mammography as soon as possible and it would become a routine exam that she performs on a yearly basis. The BC survivor pointed out the importance of routine check-ups since many BC cases are being discovered at young ages (even under 30 years old).

Finally, another factor influencing on women's decision in repeating the mammography yearly as mentioned by women during FGDs in different locations, is feeling comfortable with the technician performing the test.

11.3.7 Religious factors

As described previously, religious factors have been found to potentially act as barriers to women's participation in BC screening activities. However, this research shows that they can play the role of facilitators as well for BC screening among many women participating to this study.

Results from FGDs show that women who have more faith that God would help them in going through the treatment and in recovering if they are ever diagnosed with BC, would have higher tendency to test themselves. Some women also believe, as they mentioned in the FGD in Mina (NL) for example, that in front of God they have the responsibility to take care of their selves. So their faith in God motivates them to do regular checkups and more precisely to do the mammography.

One of the participants in the FGD in Barbara (ML) believes that "one should do what he has to do then leave life in God's hands". In Arde (NL), participants similarly mentioned that they go check themselves for BC, then they leave the results and their fate in God's hands. Participants in Bejje (ML) also mention that whatever they discover after the results, they will get the power to face it from God.

12 Conclusions

The findings of this research show that there are multiple intertwined factors influencing Lebanese women's decision to seek BC screening, and not only limited to their knowledge of BC as commonly described in available literature and narrative in the country. The level of awareness is not an indicator or a contributing factor on its own to BC screening, but rather is one of the factors and not a strong predictor.

It is therefore worth highlighting that Lebanese women's experience and attitudes towards BC are directly linked to their knowledge, attitudes and experience linked to cancer in general and not only BC itself. The level of awareness and knowledge in itself can act as a barrier when it is inexistent or low, alternatively as a facilitator when a higher level of understanding is available. What I also find in my research is that women have lesser knowledge of various BC's related aspects than what they think they know. The KAP survey results showed that the majority have limited knowledge of the signs of BC, recommended age to initiate mammography and how to conduct BSE even when they thought they knew the right answers.

There are several identified barriers that simultaneously interfere in the decision making process to seek screening. This research showed that a woman would consciously and unconsciously weigh the different factors, fears and expected outcomes all together, rather than each element separately. Which means that women part of this research upon deciding whether to go for a mammography or not would factor in their knowledge and misconceptions of cancer, BC and signs

of BC, other friends or relatives' experience with BC, her own experience and level of trust in the health care system and institutions, extent of accessibility (including location of residence), religious values and beliefs, as well as her relationship with her family and husband.

All of these elements are also linked with economic factors and affordability extending beyond the mere cost of the test itself, but also the associated expenses with transportation, additional tests, medical visits as well as treatment, drugs and medical interventions potentially required. That is why the availability of health care coverage was not a strong predictor for the test itself, yet it extremely facilitates women's decision making process to go and seek screening services.

In addition there are psycho-social factors influencing her decision such as her self-efficacy and the extent to which she considers her own well-being and external look as a priority, and is influenced by the culture of taboo and shame widespread in the Lebanese community if ever diagnosed.

Mammography is thus only the tip of the iceberg. Lebanese women gets discouraged from the idea of having to do follow-up tests and operations, in addition to how the society would look at her after being diagnosed.

It is also worth mentioning that even when the levels of "ever conducting a mammography test" are relatively high as revealed by the KAP survey, the findings of this research show that this behavior is not maintained but rather conducted intermittently or on one single occasion in a lifetime. This is why it was also important to seek a better understanding of women's actual experience with the

health care system as well as different social and economic factors that influence their decision to integrate screening methods as part of their lifestyle.

There is a need to highlight an important caveat when looking at the results of the KAP survey, as even it was administered in different locations in Lebanon, its findings cannot be generalized given the convenient sampling framework followed, and the relatively small sample size. The findings therefore call for additional national research examining the various identified barriers and facilitators.

My research also identified an extensive list of barriers facing women from accessing and using screening measures. At the same time, it succeeded in deconstructing facilitating factors as well that improve women's decision to opt for screening tests. It is an area that was least studied in Lebanon and the Arab world.

Higher levels of knowledge and awareness of the importance of early detection in addition to the availability of health care coverage and free tests provided by the MoPH during certain months of the year mark better results in terms of screening measures taken. Perceived susceptibility and high self-efficacy significantly acted as facilitators for screening. The results of my survey also reveals that physicians' request had higher adherence to screening measures recommended than the majority of awareness raising campaigns, which signals the importance of having the physicians extending this recommendation consistently.

Overall, there is a significant difference in terms of access, affordability and trust in health care institutions and services between urban and rural locations. My

research also added to the body of knowledge specifying that women in urban areas have better chances of accessing such services.

There was no substantial correlation between women's level of education and obtaining a mammography. However, age was found to be a more valid predicator as the older women get the more they are seeking to take care of their own health.

Religion itself acted as a barrier and facilitator among the different women met during my research. It is worth highlighting that there was no substantial difference between women from different religious affiliations, except for barriers related to commuting and intersex interaction. There were more Muslim and Druze women who depended on the availability of a male chaperon to accompany them to the hospital to obtain any health related service. Additionally, those living in rural areas faced more difficulties in reaching perceived reputable health care facilities. At the same time, women from Druze, Muslim Shiaa, Muslim Sunni and different Christian denominations greatly exhibited a fatalistic belief, which for some acted as a strong push to take care of themselves, and others to lay everything in the hand of God without pursuing preventative actions.

13 Recommendations

The recommendations suggested in my research stem from the identified barriers and facilitators for BC screening and suggestions from women, BC survivor and key informants to improve screening results in the country.

Tailoring Awareness Campaigns

In my research I found that the national and other organized awareness raising campaigns around BC and importance of screening are widely concentrating on knowledge, and targeting women with different characteristics and backgrounds similarly. Therefore, it is important to tailor awareness raising campaigns and messages according to the specificities of women aiming to reach (taking into consideration location, age, socio-economic status and religion).

Increasing engagement of family members

Awareness campaigns need to engage direct family members, spouses and other relatives given their major role in the behavioral choices of Lebanese women. This was touched upon in the most recent campaign organized by the MoPH nevertheless, it was only confined to media and communication material. My research specifically recommends that more grass root and individual activities be designed and implemented to achieve a higher level of engagement from direct relatives and family members. This can also include the specific activities that would target husbands, in order to empower them to become more knowledgeable, aware and supportive.

Placing more attention on women in rural areas

Women residing in rural areas according to my research and available literature face greater barriers than their peers in urban areas. This is not only limited to the availability of services, but also to the level of trust in the service provider, cultural barriers as well as financial. Looking at increasing the participation in screening activities in the various rural areas in Lebanon needs to adopt a structural approach addressing the different barriers identified.

Providing psycho-social support for patients and women seeking screening

Although it is not perceived as a direct action to increasing screening, yet BC patients' experience with the disease and the support they receive were found to highly influence their peers' decision to opt for screening measures. My research found that women are greatly affected by what they hear from their relatives and neighbors regarding other's experience with BC and cancer in general as well.

This recommendation would also include action taken to provide psychological support to women attending health care centers for screening in order to feel that there is actual support for them if ever diagnosed.

Increasing personalized communication and messaging with women

The current campaigns adopt a mass population approach and place less attention on direct communication and cues to action. My research suggests that the more women are directly reached the more they tend to take positive actions towards screening. Women could start getting direct phone calls, emails or even messages

from their hospitals or physicians reminding them for follow-up visits, mammography and screening activities, as well as counselling if ever diagnosed. This could also include a suggestion to have a designated hotline run by the MoPH to receive questions and inquiries from women. Peer to peer education built around positive and mouth to ear messaging, could be conveyed through household visits which are widely acceptable among cultural traditions and habits in Lebanon.

Increasing the engagement of community-based organizations

The direct engagement and support of local community-based and grass root organizations especially in rural areas can help in addressing different barriers to screening. Entities such as municipalities and NGOs can help in spreading awareness on BC as well as in mobilization and access to health care institution by providing transportation. Religious representatives and faith-based organizations can also support in tackling beliefs and misconception perceived to be founded in religion. This can also help in emphasizing more on the role of religion as a facilitator rather than a barrier.

Working on prevention in addition to early detection

My research also suggests that framing awareness raising campaigns and efforts to increase screening for BC could be included in a more comprehensive initiative towards prevention and not only detection of BC. Women, and not only those who are at risk, need to know more about preventive measures and changes required. The latter would include more attention to risk factors, environmental determinants, and healthier lifestyle choices.

Encouraging BSE

Campaigns and physicians are also recommended to increase the level of information and attention given for BSE. Findings of my research show that it could be an easy, affordable and acceptable method of primary screening for all women equally regardless of their socio-economic backgrounds and health coverage.

Improving the comfort of mammography experience

It is important that women's experiences of mammography be continuously improved. That would include further and continuous training for health care professionals involved in ensuring comfort, compassion, care and confidentiality throughout the visit. That would guarantee a higher rate of women repeating the test on yearly basis as recommended.

14 Annexes

14.1 Annex 1: Informed consent

Hello everyone, thank you for being part of this meeting, my name is Grace Azar, I am doing a PhD in Psychology, neuroscience and medical statistics at the University of Pavia in Italy. My thesis research project is the following: “Barriers and facilitators to breast cancer screening among Lebanese women”.

As part of my work on my thesis, I am conducting many interviews and focus group discussions to try and understand why do Lebanese women participate or not in breast cancer screening techniques. This is a voluntary discussion, and you have the freedom to end your participation at any time.

Your names will not be mentioned in the study; the findings will remain anonymous.

If you have any questions during the discussion, please feel free to ask.

If you accept, I am going to record our discussion to make sure I’m not missing any of the details. This discussion will take around an hour of time, please feel free to leave or stop at any time you feel the need to.

If you have any further questions, please do not hesitate to reach out to me on my email: grace.azar01@universitadipavia.it

Thank you once again for taking part in this study and for your time. Kindly sign this paper if you want to participate and if you consent to recording the discussion.

14.2 Annex 2: Focus Group Discussion Guide

1- Tell me more about yourselves:

- Demographic characteristics of participants:
    - marital status, family components (number of kids if any)
    - Level of education
    - employment and insurance status

2- How do you usually take care of your health?

- What procedures/actions do you do on regular basis as part of taking care of your health?
- If any, why do you do it? Is it something recommended to you? By whom?
- If none, why do not you do it? Is it recommended for you and you do not do it?

3- What is the first thing that comes to your mind when you hear the term Breast Cancer?

- What do you know about it?
- How do you know about it? From where do you get this information?

4- In your opinion, do you think we can we prevent Breast cancer?

- How?
- From where do you get this information?

5- In your opinion, what do you think are the factors that help women conduct

breast cancer screening?

- Can you provide any examples?

6- What is your perception of possible barriers for breast cancer screening?

7- What are your possible recommendations to increase the number of women of your age to participate in breast cancer screening? And to make this a regular habit?

14.3 Annex 3: Key informants interview guide

1- Please tell me more about your experience working with issues related to breast cancer (awareness, research, treatment…)

- What was it about?
- What were you trying to achieve/ find?
- What was the rationale/ urge/need behind it?

  *If in direct contact with women's needs: How did you find their reaction?

2- In your opinion, what are the factors that influence women's decision to seek BC screening?

- What are possible barriers?
- What are possible facilitators? (parents, peers, fear, family…)
- Why? Can you provide any examples?
  - ➢ <u>If fear:</u>
    - From what? Where does it come from? From where it originates?
    - Why?
    - From the treatment itself?
    - From pain?
    - From how she would be perceived by the society if she was positively diagnosed?
    - How would that affect her life?
  - ➢ <u>If knowledge:</u>

- In your opinion, from where do they mostly get their information about BC?
- How do you think this influences their decision to seek BC screening or not?

➢ <u>If accessibility: (Health care/medical coverage)</u>

- Does their healthcare coverage influence/ affect their providers or family decision to seek BC screening?
- In your opinion, does this still stand when prices are low/close to being free during the months of October and till the end of the awareness campaign?
- From your experience, did that influence their demand over BC screening? How? Why?

➢ <u>Attitudes:</u>

- What is their usual reaction? Do they face it with denial? Why?
- What contributes to that?
- Does shyness or availability of female physicians affect their demand for such services?

3- Questions for physicians/health care professionals:

- From your experience, what is the level of Lebanese women who conduct self-examination of BC?
    - Do they act upon it in case they discover anything?

- Why? / Why not?

4- What are possible recommendations to increase the level of BC screening among Lebanese women?

- Who needs to be involved? And to do what?

5- Missing lines of research still needed to be explored?

14.4 Annex 4: KAP Survey

Survey number:

Hello, my name is Grace Azar and I am a PhD candidate in "Psychology, neuroscience and medical statistics" at the university of Pavia in Italy. I am organizing this survey as part of my research project on: "Barriers and Facilitators to Breast cancer screening among Lebanese women". The objective is to identify and explore both barriers and facilitators of breast cancer screening among Lebanese women.

The survey looks at the current knowledge, attitudes and practices of a sample of potential women participants, aged 40 years old and above. You were selected randomly and your participation is completely voluntary. All your answers will remain anonymous, as I am interested in analyzing the cumulative of the findings that will inform the implementation of my thesis. You have the right to stop the interview at any time, or to skip any questions that you do not want to answer. There are no right or wrong answers. It will take us approximately about 10 minutes to complete the survey.

Thank you for your participation.

If you need any help, you can reach me on my number 03-576070 or contact me by email: grace.azar01@universitadipavia.it

GENERAL INFORMATION Kindly place a mark on your relevant answer			
Governorate:	1. ☐ Greater Beirut 2. ☐ Mount Lebanon 3. ☐ North 4. ☐ Bekaa 5. ☐ Baalback & Hermel 6. ☐ Akkar 7. ☐ Nabatiye 8. ☐ South	**Caza:**	
Age:	1. ☐ 40-47 2. ☐ 48-55 3. ☐ 56-63 4. ☐ 64 & above	**Marital Status:**	1. ☐ Single 2. ☐ Married 3. ☐ Separated/Divorced 4. ☐ Widowed
Children:	1. ☐ Yes 2. ☐ No	**Highest Level of Education**	1. ☐ Primary 2. ☐ Secondary 3. ☐ University 4. ☐ Graduate/Post -graduate 5. ☐ Vocational 6. ☐ Other: _____

Employment Status:	1. ☐ Unemployed 2. ☐ Employed on a full-time basis 3. ☐ Employed on a part-time basis 4. ☐ Business owner 5. ☐ Freelance 6. ☐ Other: _____	**Monthly income range**	1. ☐ Less than 700 000 LBP 2. ☐ 700 000LBP-1 million LBP 3. ☐ 1-2 million LBP 4. ☐ > 2 million LBP 5. ☐ Other: _____ 6. ☐ NA
Insurance status/Health coverage	1. ☐ Available 2. ☐ Not available	**Type of insurance:**	1. ☐ Private Insurance 2. ☐ NSSF 3. ☐ ISF 4. ☐ صندوق التعاضد 5. ☐ Other: _____

KNOWLEDGE Kindly place a mark on your relevant answer	
1. From where do you get your information about health in general? (you can choose more than one answer)	1. ☐ TV shows 2. ☐ NGOs 3. ☐ Friend(s)/Neighbors 4. ☐ Brochures/Magazines/Newspapers 5. ☐ Radio 6. ☐ Online / Websites 7. ☐ Physician 8. ☐ Social Media 9. ☐ Through my participation in conferences and awareness sessions 10. ☐ Other: _____
2. From where do you get your information about breast cancer? (you can choose more than one answer)	1. ☐ TV shows/ Radio 2. ☐ NGOs 3. ☐ Friend(s)/Neighbors 4. ☐ Brochures/Magazines/Newspapers 5. ☐ Online / Websites 6. ☐ Physician 7. ☐ Social Media 8. ☐ Through my participation in conferences and awareness sessions 9. ☐ Other: _____
3. Are you aware of the warning signs of Breast cancer? (if answered 2 (No) or 3(Not sure) skip to Q.5)	1. ☐ Yes 2. ☐ No 3. ☐ Not sure
4. If yes, what are they? (The respondent can choose more than one option)	1. ☐ Change in the Breast skin, dimpling, pitting or redness 2. ☐ Change in the size of the breast 3. ☐ Change in the shape of the breast

	4. ☐ Lump or thickening in the breast 5. ☐ Breast or armpit pain 6. ☐ Discharge or bleeding from the nipple 7. ☐ Nipple rash 8. ☐ Change in the position or shape of the nipple 9. ☐ Other: _____
5. In general, at what age do you think a woman should start having routine mammograms?	1. ☐ <20 2. ☐ 20-29 3. ☐ 30-39 4. ☐ 40-49 5. ☐ >50
6. In your opinion, when is a mammography needed?	1. ☐ Every year 2. ☐ Every 6 months 3. ☐ Every 2 years 4. ☐ More than 2 years 5. ☐ Never
7. Are you aware of the Breast cancer awareness campaign organised by the Lebanese MoPH? (reduced price of BC screening test during the months of October, November and December)	1. ☐ Yes 2. ☐ No 3. ☐ Not sure
8. Have you ever benefited from the offers on BC screening tests during the MoPH awareness campaign? ? (if answered 2 (No) or 3(Not sure) skip to Q.10)	1. ☐ Yes 2. ☐ No 3. ☐ Not sure
9. If yes, then how do you describe your experience/satisfaction of the service?	1. ☐ Very Bad 2. ☐ Bad 3. ☐ Average 4. ☐ Good 5. ☐ Very Good
10. Has anyone of your family or relatives been diagnosed with Breast cancer?	1. ☐ Yes 2. ☐ No 3. ☐ Prefer not to Answer

ATTITUDES					
Kindly place a mark on your relevant answer	**Strongly Agree**	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
11. Early detection of BC can increase the possibility of recovery/ effectiveness of the treatment					
12. A woman only needs a breast ultrasound/mammogram when she experiences breast pain					
13. A woman only needs a breast ultrasound/mammogram when she notices changes in her breast					

(shape, size, discharge from nipple…)					
14. I prefer not to know if I have breast cancer					
15. At my age, I do not need to worry about breast cancer					
16. I would be afraid to tell my family members (husband, children, brother, sister…) that I have BC					
17. I would be afraid to know that I have BC, so I avoid doing the necessary exams					
18. My family's health is more important than my health					

PRACTICES Kindly place a mark on your relevant answer	
19. How often do you go for check-ups or visit your doctor?	1. ☐More than Twice a year 2. ☐ Twice a year 3. ☐ Once a year 4. ☐ Only if there is a need or I am feeling something 5. ☐ Intermittently and not on regular basis
20. If you found a change in your breasts, would you visit your doctor? (if answered 2 (No) or 3(Not sure) skip to Q.22)	1. ☐ Yes 2. ☐ No 3. ☐ Not sure
21. If yes, how soon would you visit your doctor?	1. ☐ Immediately 2. ☐ After a week 3. ☐ After a month 4. ☐ When I have the time for it 5. ☐ When the doctor is available for an appointment 6. ☐ Other: _____
22. If no, then why?	1. ☐ Cost of visit is high 2. ☐ Too embarrassed to go 3. ☐ Too scared to go 4. ☐ Too busy to make time to go 5. ☐ Too many other things to worry about 6. ☐ Worrying about what the physician might find 7. ☐ Other: _____
23. Have you ever visited a doctor concerning a change you have noticed in one of your breasts?	1. ☐ Yes 2. ☐ No 3. ☐ Never noticed a change in my breast 4. ☐ I do not remember 5. ☐ Other: _____

24. Have you ever done a mammography test? (if answered 2 (No) or 3(I do not remember) or 4 (Prefer not to answer) skip to Q.29)	1. ☐ yes 2. ☐ no 3. ☐ I do not remember 4. ☐ Prefer not to Answer
25. Why do you perform the mammography?	1. ☐ For prevention purposes 2. ☐ Out of fear of getting the cancer 3. ☐ Based on my physician's advise 4. ☐ Based on my friend or parent's advise 5. ☐It has become a routine 6. ☐ Other: _____
26. When was the last time you performed a mammography?	1. ☐ Within the last year 2. ☐ 2-3 years ago 3. ☐ More than 3 years 4. ☐ I do not remember
27. How would you rate your overall experience of having mammograms?	1. ☐ Extremely comfortable 2. ☐ Very comfortable 3. ☐ uncomfortable 4. ☐ very uncomfortable 5. ☐ Extremely uncomfortable
28. How often do you get a mammogram? (Kindly proceed to Q.30 after answering)	1. ☐ Once a year 2. ☐ Twice a year 3. ☐ Once every 2 years 4. ☐ Intermittently and not on regular basis 5. ☐ Other: _____
29. Why do not you consider performing a mammography? (you can choose more than one answer)	1. ☐ Fear of cancer being diagnosed 2. ☐I do not know how to do it 3. ☐ I do not know where and when to do it 4. ☐ I usually perform tests only if requested by my physician and till now he did not 5. ☐ It hurts 6. ☐ I do not think it is useful 7. ☐ I never thought of it 8. ☐ I do not think I need it 9. ☐ For its high cost 10. ☐ Other: _____
30. Have you ever done the breast self-exam before? (if answered 2 (No) or 3 (Prefer not to answer) skip to Q.32)	1. ☐ Yes 2. ☐ No 3. ☐ Prefer not to answer
31. I perform the BSE:	1. ☐ Once a year 2. ☐ 2-4 times a year 3. ☐ Once a month 4. ☐ Twice a month 5. ☐ Once a week 6. ☐ Once a day or more 7. ☐ Irregularly 8. ☐ Occasionally
32. If no, why? (you can choose more than one answer)	1. ☐ I do not know how to do it 2. ☐ do not think it is important 3. ☐ I forget 4. ☐ It is time consuming 5. ☐ I am afraid of finding a mass

	6. ☐ I know I can never have cancer 7. ☐ I do not have any breast cancer symptoms 8. ☐ Other _____

COMMENTS	
33. Do you have any comments or additional information that you would like to add?	

I would like to thank you very much for helping me and I appreciate the time that you have taken.

15 List of Abbreviations

BC: Breast Cancer

BSE: Breast self-examination

BCE: Breast clinical examination

NSSF: National Social Security Fund

UAE: United Arab Emirates

MoPH: Ministry of Public Health

GB: Greater Beirut

ML: Mount Lebanon

SL: South Lebanon

NL: North Lebanon

BG: Beqaa governorate

NG: Nabatiye governorate

BHG: Baalback El Hirmel governerate

NCR: National Cancer Registry

SES: Socio-economic status

LBCF: Lebanese Breast Cancer Foundation

AUB: American University of Beirut

AUBMC: American University of Beirut Medical Center

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19 Bibliography

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