Factors resulting in delayed presentation of female breast cancer patients in Pakistan

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Factors resulting in delayed presentation of breast cancer patients in Pakistani

A thesis submitted in partial fulfilment of the requirement for the degree of Master of Science in Public Health

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List of Abbreviations

BC	Breast Cancer
BHUs	Basic Health Units
BSE	Breast Self-Examination
CBE	Clinical Breast Examination
CDs	Communicable Diseases
CHWs	Community Health Workers
CMWs	community Midwives
DHQHs	District Headquarters Hospitals
DHS	Demographic and Health Survey
EPHS	Essential Package of Health Services
FBSC	Federal Breast Screening Center
GDPC	Gross Domestic Product for Capita
GGGI	Gender Gap Index
GP	General Practitioners
HCDS	Healthcare Delivery System
HIC	High Income Countries
HMIS	Health Management Information System
IARC	International Agency for Research on Cancer
KCR	Karachi Cancer Registry
LHWs	Lady Health Workers
LIMIC	lower in low- and middle-income countries
MNCH	Maternal, Newburn and Child Health
MOP	Ministry of Health
NCDs	Non-Governmental Organizations
NHAs	National Health Accounts
NHIP	National Health Insurance Program
OOP	Out-of-Pocket
PIMS	Pakistan Institute of Medical Sciences
RHCs	Rural Health Centres
THQHs	Tehsil Headquarters Hospitals
WB	World Bank
WHO	World Health Organization

Abstract:

Background: Early detection of breast cancer is key factor contributing to reducing BC mortality among women with the disease. Pakistan has one of the highest prevalence and mortality rate in Asia; many women in Pakistan seek diagnosis and healthcare very late when survival rate is low, and treatment is more sever.

Objective: To identify factors related to knowledge, sociocultural issues, and services accessibility that are affecting delayed presentation of women with BC in Pakistan.

Method: literature review of published research to identify factors resulting in delayed presentation of women with BC in Pakistan.

Findings: this study found that women in Pakistan lack adequate knowledge to recognize BC signs; they also lack awareness of screening and examination methods that enable them to detect the disease. Social, economic, and services accessibility and availability factors were also found to be contributing to delayed presentation. Absences of proper policies for early detection and knowledge enhancement is further contributing to the delayed presentation among women in Pakistan.

Conclusion: Addressing BC burden in Pakistan is urgent, women awareness and knowledge of BC should be enhanced and conveyed to positive health seeking behavior; additionally, more comprehensive intervention and policies should be in place with consideration to available resources to enable women should be able to easily access services that are affordable and culturally accepted in timely manner.

Keywords: breast cancer, delayed presentation, Pakistan, Knowledge, affordability, accessibility, availability.

Word Count: 9,946 words

Introduction

I am a Yemeni female working in public health sector since 2011; even though my background was not in the medical field. I graduated from faculty of information technology, then I immediately joined a local NGO working in reproductive health and directly felt huge interest in public health.

In 2014 and at the age of 26 I was diagnosed with stage II breast cancer; this news was devastating for me and my family. Fortunately, I received timely and proper full treatment and I have survived for eight years now. This significance survival rate was as a result of several factors; I was able to identify my symptoms early, accessibility to quality treatment (outside Yemen) and affordability were available to me, though it was challenges.

I observed many women in my community being diagnosed at late stage, one of my relative sought diagnoses when her symptoms were extremely advanced, she had to go through mastectomy and sever treatment. She and her family struggled to cover cost of treatment; her doctor told her if she had presented earlier her situation would have been less complicated. I observed similar scenarios when I was volunteering to provide social support to female breast cancer patients at a public hospital.

During this master and specifically during social determinants of health course, I was able to fully understand how different factors can influence public health issues and health behaviour; this what draw my attention to think broadly about my situation and my relative's. I asked myself why do women in Yemen seek diagnosis very late when the disease is at late stage? Further in my master study I learned that globally breast cancer is now out ranked lung cancer and is the highest among females. This was motivating enough for me to look for factors influencing late presentation of women with breast cancer, because presenting early is for sure will save thousands of lives.

Unfortunately, Yemen does not have enough quality research in many areas including this public issue. I decided to conduct my thesis looking at Pakistan situation because among Asian countries breast cancer prevalence and mortality are estimated to be the highest in Pakistan. In addition, Pakistan share similar culture and economic level is a bit similar as well.

After finalizing my thesis, I found that Yemeni women share similar challenges I am confident that findings and recommendation from my study can be useful for and possibly applicable in Yemen.

Chapter One: Background

1.1 Geography

Pakistan is situated in the region of South Asia that faces northwest. It borders with China on the north, Iran and Afghanistan on the west, India on the east, and the Arabian Sea on the south. Pakistan is divided into four main provinces: Punjab, Sindh, Baluchistan, and Khyber Pakhtunkhwa (from south to north) (1). Pakistan has a geographic area of about 803,940 square kilometres (2). Figure 1: map of Pakistan.

Figure 1 Map of Pakistan

Source: World Atlas: Pakistan Maps and Facts (3)

1.2 Population

According to the World Bank (WB), population of Pakistan reached to 225 million in 2021 with growth rate of 1.9% (4). Male to female ratio for Pakistan is 106.02 males per 100 females (5) . Majority of the population 63.62% reside in rural areas (6). The total fertility rate in Pakistan is 3.6 births per woman with difference among rural and urban women; women in rural areas have 3.9 birth while women in urban have 2.9 births per woman (2).

1.3 Socioeconomic Characteristics

Pakistan is ranked as lower middle-income country as per WB with 1,537 USD Gross Domestic Product for Capita (GDPC) (4). Approximately a quarter of the Pakistani population (53 million) is living below the national poverty line, whereas fifth of the population (84 million) are classified to fill under some level of poverty (7)

1.4 Cultural and Political Characteristics

Pakistan has multi-ethnic population with majority of them Muslims (97%); other religions include Christianity, Hind, Buddhism, Pars, and Sikh. Additionally, Pakistan has range of diverse cultures including Punjabi, Balochi, Pathan and Sindhi; each have their own customs, values, and languages. The largest ethnic group are Punjabis who are dominantly present in bureaucracy and armed forces fields. Punjabis are greatly inspired by Sufism, therefore; majority of Pakistan literature, music and poetry is influenced by Sufism (8,9).

Pakistan political stability is a historical struggle; since its establishment, Pakistan has been dealing with many political issues such as internal political conflict and hostility. This has significantly hindered the country economic growth regardless of rich natural resources it has. The continuous instability is further causing inconsistency of solid governance, low productivity, increased unemployment, and poverty (10).

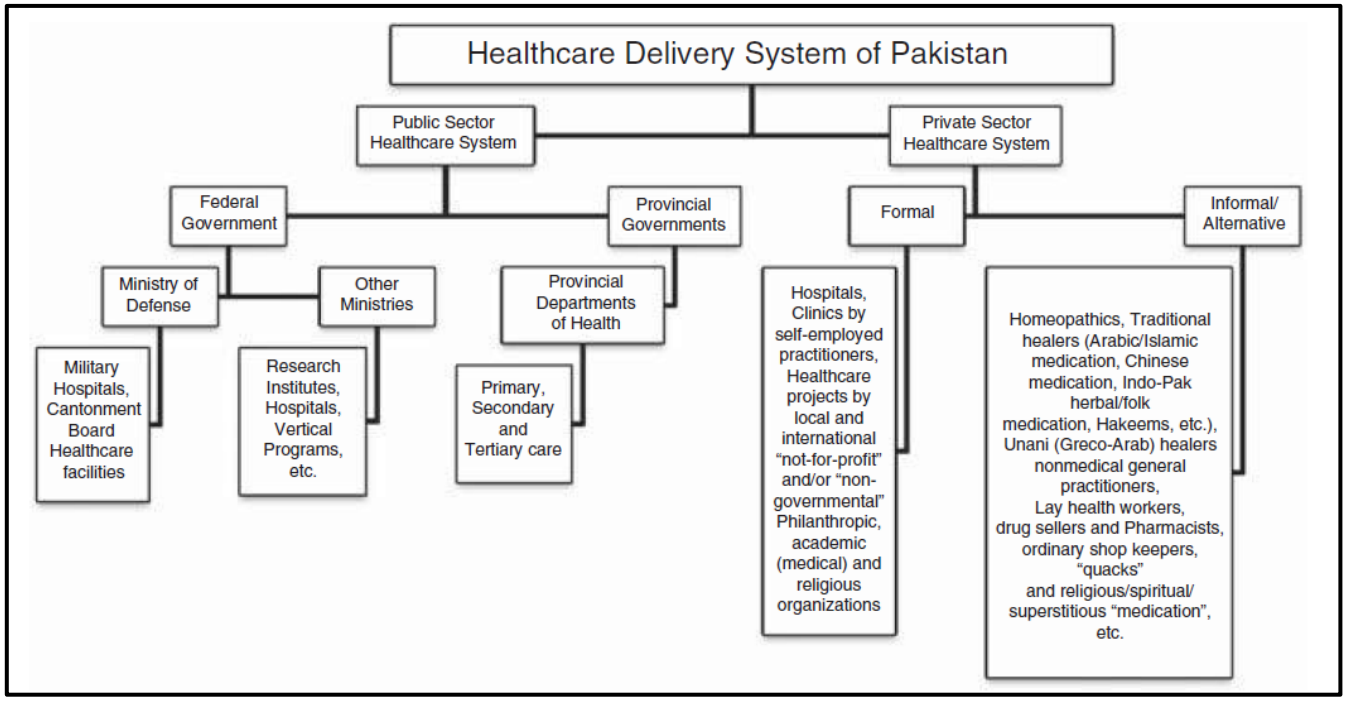
1.5 Sociocultural Characteristics

Gender discrimination is deeply existing in Pakistan as it is male dominated sociality. As per 2020 Global Gender Gap Index (GGGI) statistics, Pakistan is ranked number 151; with closing just 56% of gender gap. Gender disparity continue to deeply exist in economical participation and opportunities. Moreover, Pakistan one of four large countries lagging in closing the gender gap with regards to health and survival, where most Pakistani women are not granted the same ability to access healthcare as men. Spousal violence is high in the country, and one in two Pakistani women who have suffered violence never ask for support or reported it (11).

1.6 Health System

Pakistan mixed health system consist of public and private, Non-Governmental Organizations (NGOs), and civil society and philanthropic contributors(12). Healthcare delivery in Pakistan is provided at three levels: primary, secondary, and tertiary. The primary level consists of Basic Health Units (BHUs) and Rural Health Centres (RHCs). At the secondary level comprises of Tehsil Headquarters Hospitals (THQH) and District Headquarters Hospitals (DHQH); tertiary care hospitals are found at the third level in large cities; these hospitals are also affiliated with teaching institutions (13). Pakistan Healthcare Delivery System (HCDS) provides the population with preventive, promotive, curative, and rehabilitative services through vertical and horizontal HCDS as illustrated in figure 2 below (12).

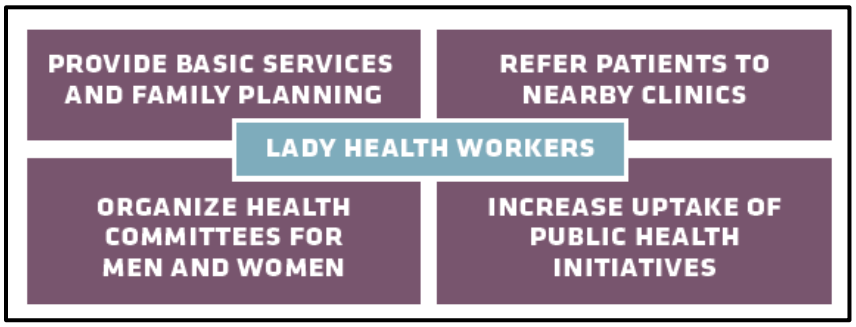
Figure 2 Pakistan Healthcare Delivery System



Source: Analysis of The Health Care Delivery System in Pakistan and Nepal 2021, (13)

Pakistan HCDS established a wide outreach of primary services at community level through Community Midwives (CMWs), by Lady Health Workers (LHWs), Community Health Workers (CHWs). Among these, LHW is the most recognized program which was introduced in 1994 (14). Around 110,000 LHWs work across the country delivering range of primary services at doorstep including: basic Maternal, Newburn and Child Health (MNCH), immunization, referral, and conducting health education; see figure 3 (15). LJWs are provided with 15 months training program of which 12 months includes on job training. They are linked to RHCs or a BHUs for referral (14).

Figure 3 Roles and responsibilities of LHWs



Source: Lady Health Worker in Pakistan, 2014 (14)

However, the deficient infrastructure and inequality of healthcare access between rural and urban areas remain the main challenges faced by Pakistan HCDS. Shortage of health staff is another weakness of the HCDS; doctor to patient ratio is 1:1300 and nurse to population ratio is 1:3568 (13). Moreover, spending on health is another challenge faced by Pakistan; according to the National Health Accounts (NHAs), Pakistan annual government health spending in 2019 is 32%, while the out-of-pocket (OOP) spending is 53.8% (16). Because of these challenges, 70% of Pakistani population access health services from private sector seeking better quality (17).

1.7 Situation and Burden of Disease

Transition of diseases burden has significantly moved from Communicable Diseases (CD) to Non-Communicable Diseases (NCDs) in Pakistan since 2000 (11). Percentage of NCDs related deaths is greatly higher than communicable diseases (58%, 35% respectively). According to World Health Organization (WHO) estimates, approximately four million Pakistani will die of some NCDs conditions between 2010 and 2025 including cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes (18). Nearly 173, 000 new cancer cases and 118,000 cancer related death were detected every year in Pakistan during 2018 (19). In 2016 cancer deaths accounted for 23.3% of NCDs mortality (19). As per statistics from Karachi Cancer Registry (KCR), lung cancer is the most common cancer presented among males, while Breast cancer (BC) is reported to be the most common type of cancer among females. BC has become a major concern of public health due to the high prevalence and increase of cases among young women (less than forty years). Having said that, these data are not necessarily precise due to lack of centralized national registry in the country (20).

In Pakistan, cancer remains primarily a surgical disease facing multiple challenges. The first is absence of national cancer registry system that capture sufficient data of cases across the country. With lack of national screening program an implementation of clear national cancer plan, majority of patients are diagnosed at advance stages at the time of first presentation and lack adequate care. Furthermore, dearth of qualified health providers and scarcity of training opportunities are posing additional challenges to cancer care in Pakistan (21). See figure 4 and 5 for more overview of cancer healthcare capacity.

Figure 4 Pakistan cancer health workforce per 10,000 cancer patients

WORKFORCE

[a] *per 10,000 cancer patients*

Available staff in Ministry of Health who dedicates significant proportion of their time to cancer	2019	yes
# of radiation oncologist[a]	2019	1.8
# of medical physicist[a]	2019	n/a
# of surgeons[a]	2012	128.7
# of radiologist[a]	2019	57.5
# of nuclear medicine physician[a]	2019	14.4
# of medical & pathology lab scientists[a]	2015	n/a

Source: WHO: Cancer Country Profile Pakistan 2020 (19)

Figure 5 Cancer healthcare capacity in Pakistan

# Public cancer centres per 10,000 cancer patients	2019	n/a
Early detection programme/ guidelines for 4 cancers (breast, cervix, colon, childhood)	2019	0 cancer(s)
Pathology services	2019	generally available
Bone marrow transplantation capacity	2019	generally not available
Palliative care availability: community/home-based care	2019	generally not available
Availability of opioids* for pain management	2015-2017	2

**Defined daily doses for statistical purposes (S-DDD) per miliion inhabitants per day*

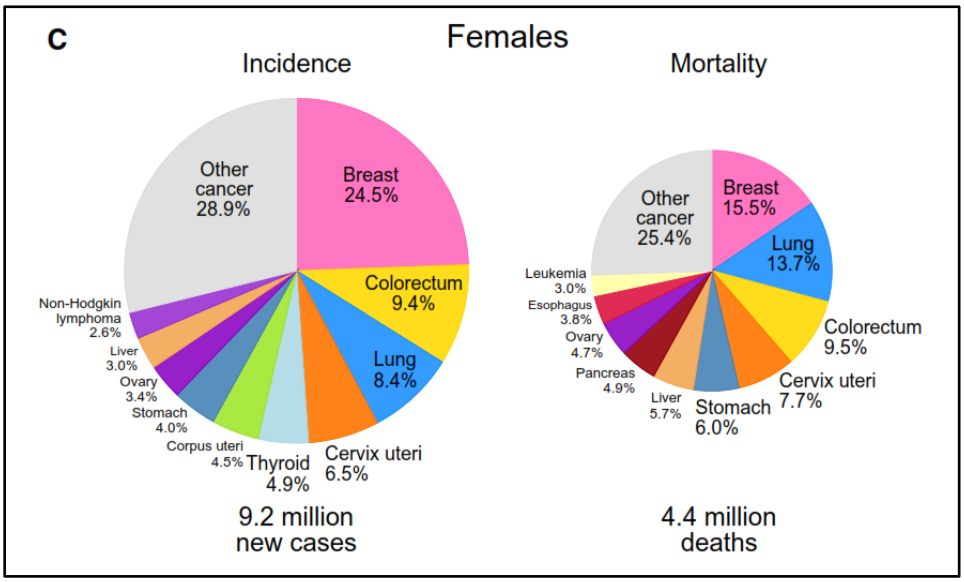
Source: WHO: Cancer Country Profile Pakistan 2020 (19)

Chapter Two: Problem Statement, Justification, and Methodology

2.1 Problem Statement

Overall burden of cancer and related mortality is swiftly increasing globally. According to the International Agency for Research on Cancer (IARC), nearly 19.3 million new cancer cases and 10.0 million cancer related deaths occurred in 2020 (22). The IARC further estimated that in 2040 the global burden of cancer will increase to 28.4 million cases, a 47% rise from 2020. Female BC is the most occurring cancer worldwide: during 2020 around 2.3 million women were diagnosed with BC contributing to 11.7% of all new cancer cases in both genders globally. As illustrated in figure 6, globally BC is the most diagnosed cancer (24.5%) and the first leading death of all cancer (15.5%) among women in 2020 (22).

Figure 6 Distribution of Cases and Deaths for the top 10 most common Cancers in 2020 for women



Source: Global Cancer Statistics 2020 (22)

Although BC incidence rates are lower in low- and middle-income countries (LMIC) than in high income countries (HIC), mortality rates are higher in LMIC (23). The overall five-year survival rate for BC is more than 80% in most HIC (88% in USA); whereas it reached up to 60% in middle-income countries (India 60%) and to 50% in low-income countries (53% in South Africa) (24). The high mortality rate in LMIC is significantly related to lack of knowledge, late diagnosis, and healthcare accessibility barriers (25,26).

Among Asian countries Pakistan has one of the highest mortality rates of BC mainly due to late stage diagnosis of BC at presentation time (27). In 2020 the prevalence of BC was the highest (14.5%) among all male and female cancers in Pakistan, and it accounts of 28.7% of all cancer cases among Pakistani females(28). WHO reported that over 13,500 women died from BC in Pakistan during 2020, and close

to 26,000 women were diagnosed with the disease (29). Incidence of BC is estimated to increase by approximately 23% in 2020 to 60.7% in 2025(30).

The well-known meta-analysis and systematic review results of Richards et al. (1999) revealed that BC patients presenting later than three months of symptoms recognition had a lower survival rate than those who presented earlier than three months. The findings concluded that delay in diagnosis is correlated to larger tumors, advanced disease stages, and worse long-term prognoses (31). Delayed presentation can occur at two levels: 1) patients delay: time interval from recognizing initial symptom by women to presentation at professional medical health services; 2) provider delay: time interval from patient presentation to first treatment (32).

Majority of Pakistani women with BC seek diagnosis of symptoms in a late period (more than three months form the onset of symptoms) and usually present at a late stage of the disease when survival rate is low, and treatment is more complicated (33–36). A study conducted in a cancer hospital in Punjab Province found that 89% of patients delayed presentation for medical consultation for more than three months from noticing symptoms, 59% of all patients presented with late stage of BC (stage III/IV) (33).

2.2 Justification

Over the past ten years, the death rate of breast cancer has decreased by 20% due to greater screening, earlier detection programs, and improved treatment (37). Early screening increases the likelihood that the disease will be successfully treated since it allows for earlier disease detection (38).

Estimates shows that one in nine women in Pakistan suffers from breast cancer (30); sadly, deaths rate associated with BC is also high in the country. Delayed presentation is a significant factor affecting the high mortality rate in Pakistan; presentation early for diagnosis will lead to timely treatment of the disease resulting in higher survival rate of BC patients (30).

Addressing the factors and barriers to health seeking behavior of BC early presentation among the female population of Pakistan would contribute to reducing the burden of the disease. Paucity of literature investigated the reasons of delayed presentation of BC patients presenting specific regions of the country.

This study will present and compare findings from available literature to identify significant factors contributing to delayed presentation of BC patients in Pakistan to give overview of factors across the country. The study will also identify the underling related factors and gap in literature. Moreover, the author will provide recommendations to improve the health seeking behavior to early detection of BC among women in Pakistan.

2.3 Objectives of the Study

2.3.1 General Objective

The objective of this study is to identify factors related to knowledge, sociocultural issues, and services accessibility that are affecting delayed presentation of women with BC in Pakistan.

2.3.2 Specific Objectives:

1. Identify individual knowledge factors influencing timely presentation of female BC patients in Pakistan.
2. Identifying sociocultural and socioeconomic factors contributing to the delayed presentation of BC patients among the Pakistani women.
3. Identifying factors related to services accessibility and availability contributing to the delayed presentation of BC patients among the Pakistani women.

2.4 Methodology

2.4.1 Research Strategy

Study Design: literature review to identify factors resulting in delayed presentation of women with BC in Pakistan.

The data collection method: the author conducted a literature review on the subject using the Vrije University library database, Pub Med, Google Scholar, and ResearchGate. Other reports and grey literature were used from international organizations like WHO and WB. Additional studies conducted in countries with similar context as Pakistan were examined and included in this study. Snowballing was performed thoroughly to identify related literature. The review was in English using the search terms presented in Table 1.

Inclusion criteria: studies published in English between 2010-2022 in Pakistan as well in other countries with similar context.

Studies addressing delayed presentation reasons among female BC patients by three months or more; only two studies included where delay of three month and over was between 39% and 42% the other studies identified that all women presented after three months or later.

Due to the significant association of lack of knowledge and delayed presentation among BC patients, the researcher further explored knowledge among non-BC women in Pakistan to better address the gap of knowledge and its correlation with other factors to provide valuable recommendation. Other studies out of the context of the issue being studied (BC) were exceptionally presented to strengthen argument of evidence.

Exclusion criteria: studies published out of the specified time frame, with exception to the National Action Plan for Prevention and Control of Non-Communicable Diseases and Health Promotion 2004 as there is no update for that. Studies published in languages other than English.

Table 1 Search keywords

#	Objective	Country
1	**Identify individual knowledge factors influencing timely presentation of female BC patients in Pakistan**	**Pakistan**
	"Breast Cancer Delayed presentation" OR "Breast Cancer late Presentation " OR "Breast Cancer Early Presentation" OR "Breast Cancer Late Diagnosis" OR "Breast Cancer"	**OR**
	AND	India, Bangladesh, Asian
	"Knowledge" OR "Awareness" OR "Symptoms "OR "Screening" OR "BSE"	
	And	
	"Factors" OR "Reasons" OR "Causes" OR "Determinants" OR "Barriers" "Patients" "Urban" OR "Educated" OR "Rural" OR "Young"	
2	**Identifying sociocultural and socioeconomic factors contributing to the delayed presentation of BC patients among the Pakistani women.**	**Pakistan**
	"Breast Cancer Delayed presentation" OR "Breast Cancer late Presentation " OR "Breast Cancer Early Presentation" OR "Breast Cancer Late Diagnosis" OR "Breast Cancer"	**OR**
	AND	India, Bangladesh, Asian
	"Income" OR "Socioeconomic" OR "Financial" OR "Autonomy" OR "Employment" OR "Gender" OR "Health Decision" "Education" OR " Residency" OR "Culture"	
	And	
	"Factors" OR "Reasons" OR "Causes" OR "Determinants" OR "Barriers"	
3	**Identifying factors related to services accessibility and availability contributing to the delayed presentation of BC patients among the Pakistani women.**	**Pakistan**

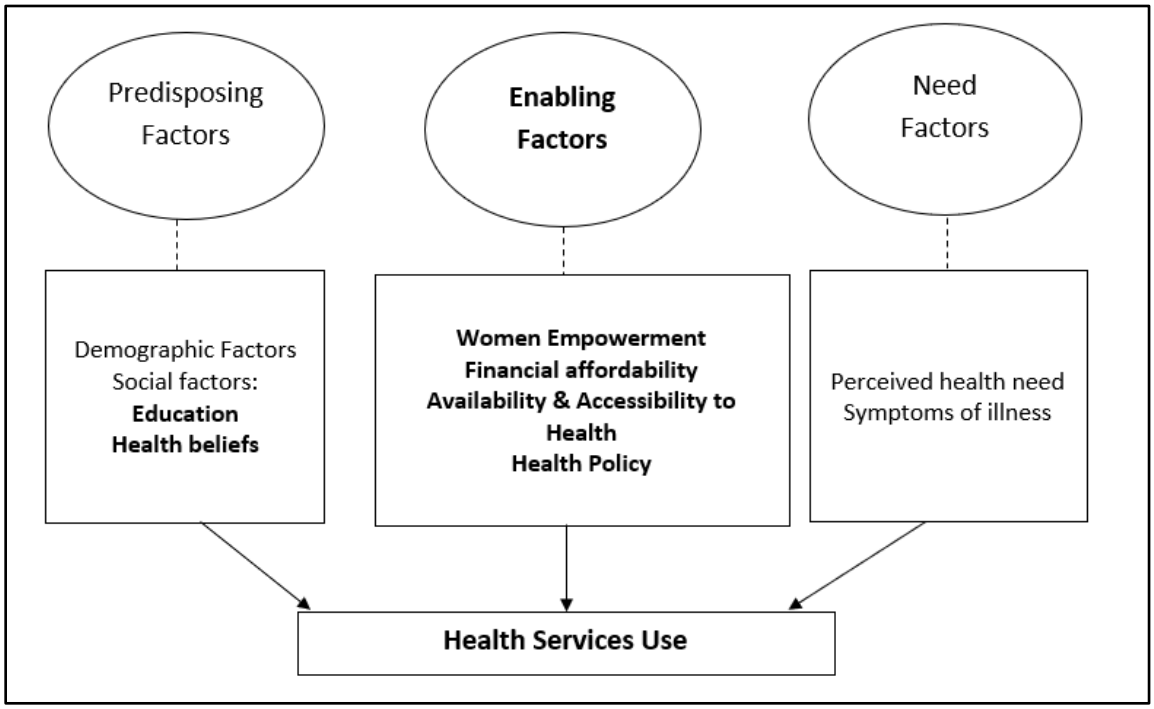
	"Breast Cancer Delayed presentation" OR "Breast Cancer late Presentation " OR "Breast Cancer Early Presentation" OR "Breast Cancer Late Diagnosis" OR "Breast Cancer"		**OR**
	AND		India, Bangladesh, Asian
	"Accessibility" OR "Availability" OR "Health services" "Residency" OR "screening services" OR "CBE"		
	And		
	"Factors" OR "Reasons" OR "Causes" OR "Determinants" OR "Barriers" "Cancer care"		
4	Gray literature	National NCD health plan, Cancer national policy, Essential health package, National health policy	Pakistan

2.5 Conceptual Framework

At first, the author selected Levesque et al. (2013) framework (39), but it was excluded as it addresses accessibility in wide approach; the factors of interest in this study are found in different levels in this framework which can make analysis less coherent. This study focuses mostly on enabling factors that affect women to seek healthcare including contextual and sociocultural factors as well as factors related to health system. The author decided to use Andersen's Behavioral Model of Health Services Use 1995 (40) : this framework puts enabling factors in one dimension, which will help the author present results in more coherent and organized analysis.

The Andersen's Behavioral Model was developed to define the reasons and measures of accessibility to healthcare services. The model focuses on three main factors including predisposing, enabling, and need factors. **The predisposing factors** include the demographic features like sex and age, social factors such as occupation, education, ethnicity, and family status. The predisposing factors also include factors related to health beliefs including knowledge about health and health services. **Enabling factors** investigate personal, community, and organizational factors that enable health seeking behavior. The enabling factors study aspects that enable individuals to access the health services like income, source of health expenses, services availability and coverage, reach/ transportation, availability of health worker, and it also includes available health policies. **Need factors** focus on distinguishing between perceived need for health services by individuals and evaluate need of health/medical care by health professionals (41). The framework was modified to show factors included in this study (Figure 7).

Figure 7 Conceptual Framework



Source: Adapted by author from Andersen behavioral model of health service use 1995 (40)

The author will study the following factors:

1. **Education:** education is significant factor influencing health seeking behaviour of many healthcare services.
2. **Health beliefs:** looking at health beliefs (knowledge, attitudes, and values, related to health and health services). Knowledge of BC and screening methods that contribute to delay in presentation of BC patients.
3. **Financial affordability:** level of income and ability to pay for health services is one key factor that enable or hinder people from seeking health care.
4. **Accessibility to care:** this includes barriers associated with health care access such as transportation, availability of skilled health provider, and preferred gender of health provider.
5. **Women Empowerment:** women ability to decide by themselves on their own health is important enabling factor to increase their seeking behaviour.
6. **Health policy:** national polices and plans in place to increase and motivate use of positive, timely, and efficient health service.

2.6 Limitations of the Study

a) Literature found present certain parts of Pakistan rather than the whole population.
b) Study was limited to English language, studies published with local language were excluded.
c) Timeframe further limited number of literatures reviewed.
d) Research bias is possibility; due to researcher personal influence, she might accidently neglected research with contracted results or did not look deeply to search for any.

Chapter Three: Findings

This chapter will present findings from reviewed literature regarding factors influencing timely presentation of BC female patients in Pakistan.

3.1 Education

Majority of studies investigating reasons of late presentation among women with BC in Pakistan reported strong association of women level of education and length of delayed presentation. Women with low or no education showed more delay of presentation while women with higher education showed shorter delay (33,34,42–46). Multivariate analysis performed in two studies in Punjab and Lahore among women with delayed presentation of more than three months showed strong association between education and late presentation (33,34). Education was also related to delayed presentation among women in Bangladesh (47).

3.2 Health Belief

Knowledge of the BC signs and symptoms as well as screening methods is important factor to early presentation of BC patients. For a woman to be able to identify signs of BC and seek early diagnosis, she should have accurate and adequate health information about BC symptoms. Women who lack knowledge of the disease and its symptoms are more likely to delay diagnosis (48–50).

Knowledge of BC

Lack of knowledge of BC including risk factors, symptoms, screening, and detection method was found to be the lead factor of delay among BC patient in Pakistan.

Studies performed in various parts of Pakistan (Punjab, Islamabad, Karachi, Lahore, and Rawalpindi) investigating reasons of patients' delayed presentation concluded that poor knowledge of the significance of the disease symptoms was the lead factors of late presentation (more than three months) (33,34,42,44,45,51–53). Gulzar et al. (2019) reported that 96% of the patient presented late due to ignorance of symptoms including painless lump (33); similarly, Khan et al. (2018) found that 89% of the patients neglected their symptoms because of the absence of pain, while 75% believed it was harmless (45). Several other studies showed comparable results where at least half of the patients presented with delay due to insufficient knowledge of BC symptoms particularly when they felt no physical pain leading to late reach for medical consultation (34,42–44,52–54). Findings from a quantitative study conducted among 372 female BC patients at a tertiary hospital in Lahore reported that women with initial sign of painless lump showed the longest delay with median delay of nine months (34). Consequently, women tend to seek professional examination when their symptoms are painful and severe such as increase lump size (34,42). A study among female patients in Karachi, of which 70% living in urban areas, reported that 70% of the patients with poor knowledge delayed presentation for ten months from symptoms appearance (53).

Overall observation from these studies show that majority of patients (50% to 96%) included in these studies identified having a lump as initial sign, which they perceived to be harmless and didn't feel the urgent need to seek medical consultation (33,34,42–44,52). Even though these studies were conducted in different areas in Pakistan with sampling size ranging between 49 to 499 of women with BC who delayed medical consultation for more than three months from noticing their symptoms, but their findings concluded that knowledge of the disease was the main factor influencing their health seeking behaviour for early presentation.

Correlation between education and residency with patients' knowledge was observed in two studies; Majeed et al. (2021) reported that less educated women had more difficulties to identify their symptoms, their results also showed that rural women presented with more delay and had lower level of knowledge of the disease (34). The second study by Ayaz et al. (2016) didn't find significant relation between lack of knowledge and education or residency (52). Variance in results could be due to the different design of the studies, Ayaz et al. (2016) study had smaller sample (100); of which 69% live in rural areas; the study was conducted over one month only in Rawalpindi and Islamabad. In contrast to Majeed et al. (2021) quantitative study, the sample size was higher (372), and study was conducted over two years in Lahore, however; no data were presented to show place of residence demographics of the sample.

Generally, knowledge of BC signs and symptoms is weak among majority of women in Pakistan; high percentage of females had little to no knowledge about signs and symptoms of BC (48,55). In Peshawar, a study was conducted among 400 women: 62% of them were rural and 72% were housewives. The study found that majority of women lack adequate awareness regarding BC signs and risk factors, and only 2.5% performed BSE at least once a month (55)

Most of Pakistani women were able to recognize breast lump but other signs like bloody discharge from nipple and ulcer on breast are rarely known to them (56). Two studies investigating BC knowledge attitude and practices among women in Karachi and Rawalpindi, where majority of study participants are urban, concluded that knowledge among these women was inadequate in general but found that women with **higher education and income** levels were **more aware** and had better knowledge of BC including symptoms as well as detecting methods of BC (56,57). Furthermore, the study in Rawalpindi confirmed that women living in **urban areas had better knowledge** than those in rural areas; the study showed that relatives, friends, and neighbours were the main sources of information regarding BC (56).

Furthermore, a systematic review of 26 different quantitative, cross-sectional, and observational studies conducted in Asian developing countries, mostly India and Malaysia, examining factors related **to delayed presentation**, found that individual knowledge of BC symptoms and examination was the most common factor recognised for delayed presentation. Similarly to the finding in Pakistan, majority of the studies in the review found that women perceive symptoms to be harmless particularly when

pain does not exist. The study concluded that sufficient knowledge and health literacy regarding BC and its symptoms was associated with less delayed presentation (58).

Knowledge and Practice of BC screening methods

Knowledge of BC detection and screening methods is essential to enable all women to discover any related symptoms early and reach for early medical advice. There are three common screening techniques used for BC diagnosis including: Breast Self-Examination (BSE), Clinical Breast Examination (CBE), and mammography (38). Both BSE and CBE are inexpensive and effective methods that assist in detecting BC early which can be used in countries with limited resources (59). Mammography is advance screening technique and is the most effective and precise method to detect BC in very early stages (38,60)

Knowledge of BC detection and screening methods is important to early presentation. A study investigated factors influencing delayed presentation of **BC patients** in Rawalpindi, Pakistan found that 41.6% of patients had no knowledge of BSE or any screening methods (54). Results from another study exploring knowledge and practice of BSE among women diagnosed with BC found that even though 66.5% of them thought that BSE is a means to detect BC early, only 34.6 % had proper knowledge of it and 53.9% of them irregularly perform it; the study results showed that the lead reason for not performing BSE was lack of knowledge (61). The study further identified **strong relationship** between knowledge and practice of BSE and women **education**, **residency, and socioeconomic status**. Clear disparity among urban and rural residents was observed in this study; findings showed that **patients** with good knowledge and higher practice rate of BSE were coming from urban areas, and the same observed among patients with high education and socioeconomic level compared to those with low education and socioeconomic status.

Several studies studying awareness and knowledge of BC and screening methods among the Pakistani women (non-BC patients) found that majority of the women (60%-85%) believe that early detection of BC is associated with higher survival rate (49,56,62,63). However, findings from these studies and others indicate that majority of women have inadequate knowledge of screening methods used to detect BC.

Two studies in Lahore with good sampling number (1,184- 2,000) of which majority had low education level (**illiterate or primary education**), reported that high percentage of women **don't possess adequate information** of screening methods (48,62). The first study reported that 70% of women didn't hear about mammography and some women (48%) thought that mammography is painful (62). **Practice** of BC screening (Mammography, BSE and CBE) among women was **very poor**: 99% 88% and 93% had never done mammography, BSE, and CBE respectively. Results from the second study was similar; 84% had no knowledge about breast cancer screening methods including mammography, and 96% of

women had inadequate knowledge regarding BSE (48). Similar findings were reported in the study performed in Rawalpindi where only 5% of women were able to identify mammography as BC screening method and 72% of the participants had no knowledge on how to perform BSE (56). **Knowledge** of **screening programs** and **practice of BSE** were also very **poor among female students at University** in Bahawalpur and female hospital attendees in Peshawar; majority of women in these two studies came from **rural areas** (77% and 62% respectively) (55,64). Knowledge of BC risk factors, signs and symptoms were also assessed among participants in these two studied and found to be insufficient.

Studies looking specifically at **urban** women had similar results with slight variance. Two studies investigating knowledge of BC among females, one in Lahore and the other in Karachi, found that majority of women have not heard of mammography and BSE (57,65). The first study was conducted at **educational institute in Lahore** among 1,115 women, majority of them were less than 30 years old and 84% of them **had education between 10-14 years**. The study results showed that 60% of the respondents have **no idea** about mammography, practice of BSE and CBC was also poor among the respondents (65). The second study was performed in **urban areas of Karachi** among 373 women; 57% of them are graduates; only 35% of the participants were aware of mammography and only 21% had mammography done at some point. Of all participants, nearly 49% ever heard of BSE, 38% knew how to do it, but around 26% frequently performed BSE (57).

Analysis in these studies showed that **education was strongly associated with knowledge**, women with higher education had better knowledge of screening methods. In the study conducted among urban women in Karachi, **income** was also associated with **better knowledge**. In both studies, television was the most common sources of information but was associated with poor knowledge in Lahore study (65), while women in the urban Karachi believed that media campaign of BC awareness should be improved and more culturally sensitive (57). On the other hand, a study conducted at University of Lahore found that **68%** of the participants had **moderate knowledge** of BC symptoms and screening methods including mammography, BSE, and CBE (66). The variance of level of knowledge in this study compared to the previous ones could be justified that the Lahore study was performed among students of high education and professionals working in the university all studying and working in medical related field (radiology, pharmacy, laboratory, nutrition).

Even when information is presented among women, practicing BSE requires prior knowledge of how to perform it; a study among one thousand students in Karachi revealed that 71% of the women heard that BSE and realize its importance to discover BC early; however, 67% had never performed it due to lack of knowledge on how to do it (67). Additional study that took place in several parts of Karachi found similar findings; 91% of women didn't have mammography screening, 84% had never had CBE, 75% of women lacked knowledge on how to perform BSE; moreover only 25% of women aged 40 and above ever had mammography (68).

3.3 Financial affordability

Poverty is a major obstacle to receiving healthcare; direct cost of pricey diagnostic tests and treatments in addition to the indirect cost of transportation and opportunity cost of losing jobs or being absent is a major barrier to healthcare seeking (69).

In Pakistan, the cost of any cancer treatment is borne by the patients and their close families, with no or limited funding from the state or insurance policies, especially among those with low income (70). Reliable BC screening programs including mammography are mainly available in large cities in both public and private hospitals but at a cost to patients: only few hospitals provide free diagnostic services to eligible patients (poor), and majority of these hospitals are funded by charity (54,71–73). In addition to the availability of the few free screening services at the tertiary level in large cities, most women lack knowledge about their availability and accessibility; thus, additional time for referral and access causes more delay (74).

Strong association of over three months delayed presentation and socioeconomic status of BC patients was found in two studies in Lahore and Karachi. Both studies reported that patients with low socioeconomic status showed longer delay in presentation (34,44). Two other studies performed in Punjab and Karachi reported that 81% and 55% of patients respectively presented late for diagnosis due to limited financial resources (33,51); two additional studies, one in Islamabad and the other in northern areas including Khyber Pakhtunkhwa and Kashmir, found that financial barrier was a factor of late presentation among 25% and 33% of women respectively (45,46). The variance of percentage might be due to the difference in studies location. Fear of financial burden was also reported among BC patients as reason of late presentation where women believe that BC treatment is expensive and unaffordable (46,75). Fear of the cost of treatment is realistic given the fact that majority of the population are poor; estimation of average monthly cost of most cancer treatment between 1,093 USD and 946 (76).

Financial capacity is an important element to enable women to seek BC screening: a study found that majority of women coming for mammography at Shaukat Khanum Memorial Cancer Hospital in Lahore were able to fully pay for the screening test (77); another study conducted in Punjab among small sample of 45 female BC patients with low economic status concluded that lack of financial resources is a main barrier to seeking proper timely screening (78). The hospital also provides free screening to poor women with high risk of BC, this is a further indicator that majority of women don’t know about the free services.

Indirect cost such as transportation and accommodation can be also a barrier to present early even when diagnosis and treatment are cost-free; a study conducted at Fauji Foundation Hospital in Rawalpindi Pakistan, which provide free BC diagnosis and treatment for eligible patients coming from

low-income households and rural areas, found that patients presented late due to inability to pay travel expenses and accommodation (54).

Association between late presentation (more than three months) and low socio-economic status was found to be positive in other countries with similar context to Pakistan like India and Bangladesh (47,79). A study conducted in Indonesia reported that financial hardship was a barrier among BC women to seek early BC screening and lead them to seek alternative medicine (80). On the other hand, women coming from both low and high income household in Northeast of Thailand were reported to present with longer delay (81).

A systematic review of studies conducted in developing countries to address barriers leading to delayed presentation of BC patients including personal, sociocultural, and economic barriers concluded that clear evidence supported that poverty is a strong barrier to early presentation of BC patients which also related to low education, rural residency, and lack of healthcare accessibility (32).

3.4 Women Empowerment

Gender inequity in Pakistan is largely found at all levels; women face many constraints in education, employment and even healthcare due to gender discrimination (82). Statistics from the late Demographic and Health Survey (DHS) of Pakistan published in 2019 showed that only 10% of women can fully make their own decision regarding their health (83). The ability to make independent decision related to health was also observed to be a factor to late presentation among Pakistani women with BC; 50% of women participating in a survey studying factors influencing use of mammography perceived the need of husband permission as a barrier to seeking mammography screening (84). Due to the social norms male approval is a requirement for women to seek heath consultation among majority of the Pakistani women (85). Moreover, women not only need permission but must be accompanied by other family member to access healthcare facility; Habibullah et al. (2016) reported that 13% of women delayed seeking early diagnosis of their symptoms due to time constraints of family member to accompany them to the health facility (43). The need of male permission and accompanying is found to be major barriers to women accessibility to basic health services including maternal and reproductive health especially when female workers are not available (86,87). Women accessibility to health services is further limited when they need to travel long distance to seek the required health services especially when traveling from rural areas; they can't travel without being accompanied by a male relative (88). Empowered women have better autonomy; education and employment enormously contribute to women empowerment and autonomy: employed women with BC showed less presentation delay (34). Education was obviously associated with the length of delay in presentation for medical consultation which was already presented above. A study among one hundred women - 53% of them illiterate, and 93% are housewife - remarkably reported that all hundred women presented late in three months or later of noticing their symptoms (52). Evidence showed that Pakistani women

who are employed have stronger autonomy to make decisions related to their health including use of contraceptives (89).

3.5 Availability and Accessibility to care

BC Screening services are limited in Pakistan especially in rural areas where 64% of the population live (75). Pakistan has limited screening facilities: breast screening available in health facilities accounts for 9.5% and 4.8% of urban and rural population respectively (56). Limited mammography screening is available in the public sector, and mostly provided by private or semi-private hospitals at the cost of patient (90).

Non-availability of a health service was identified as a factor of late presentation among 33% of BC patients (54); in another study it was identified by 28% of patients (45). Majeed et al. (2021) reported that delay in presentation among rural women was found to be higher than those residing in the urban areas because of barriers to services availability and accessibility including indirect access to healthcare and long travel time (34). They also found that rural women have the longer delay of all type of delay: patient, physician, and system delay (34). Khan et al. (2018) study further showed that rural women are more likely to present late (45). Facilities in rural areas lack diagnostic equipment like mammogram and skilful health workers, which are mainly available at tertiary hospitals in larger cities; this puts additional burden of time and cost of travel to seek the services (91,92). Transportation availability and affordability has been identified as a barrier to reach health services for BC detection (54,84). Yet, binary regression from Gulzar et al. (2019) study showed insignificant association between delay and place of residency (33). Variation in results of these three studies (Majeed et al. (2021), Khan et al. (2018), Gulzar et al. (2019)) might be due to difference in sampling size and area (Sample size: 372, 48, 125 respectively) (Lahore, Kashmir, Punjab respectively)(33,34,45).

Longer delay was also found to be associated with unavailability of services or poor services as well as distances needed to reach health facilities among women belonging to rural residency in India and China (93,94). A systematic review of 13 studies performed in LIMC investigating cause of late presentation of BC patients found moderate link of patient delay with rural residency and accessibility to healthcare services (32).

Several studies reported that considerable number of women access informal health services through seeking traditional/alternative therapy and spiritual healing which pose more delay to early presentation of BC patients; this is an important accessibility factor to consider. Only few studies reported low percentage of women (9%-12%) with delayed presentation due to use of alternative/traditional therapy (42,44,54), in contrast to majority of studies reporting higher percentage (41%-71%) of women seeking alternative and traditional medicine which resulted in later presentation (33,34,45,46). Furthermore, Gulzar et al. (2019) study results showed that 61% of women

went to spiritual healers to the disease (33). However, these studies didn't look at underlying causes of using alternative/traditional medicine prior to seeking professional health services. An analytical study done in Lahore to identify pathways and time interval associated with referral to diagnostic of BC patients reported that women approaching traditional healers has the longest delay; lack of awareness was the most identified reason to seeking traditional therapy; fear of surgery and believing in spiritual treatment were also presented (75). A qualitative study performed in India found that, among other factors, lack of awareness, belief in alternative therapy, and financial barriers were factors correlated to women with BC seeking alternative/traditional therapy which resulted in more delay (95).

Findings from two studies investigating delayed presentation among women in Malaysia and Bangladesh found that use of alternative therapy was a cause of delay among 43% and 46% of the participants respectively (96,97). Additional studies from other LMIC found that using alternative medicine and spiritual healing is associated with BC patients delay (98,99).

Availability of female doctor is important for Pakistani women: embarrassment to be treated by a male doctor was found a cause of late presentation among 73% of BC patients in Gulzar et al. (2019) study (33); whereas in Ayaz et al. (2016) and Khan et al. (2015) 13% and 10% of BC patients respectively delayed presentation for professional consultations due to unavailability of female doctor (46,52). In a study investigating perceived barriers of mammography among women in two tertiary care hospitals of Rawalpindi and Islamabad, 53% of the women identified examination by male doctor as barriers (84); similar study showed that 90% of the women considered non-availability of female doctor a barrier to seek early consultation (100). Interestingly, a study performed in Karachi that investigated BC screening attitudes among General Practitioners (GPs) found that 98% of Female GPs performed CBE compared to only 24% of male GPs. Women shyness and embarrassment to be examined and show such sensitive part of their bodies particularly when female doctor is not available is also associated factor to delayed presentation among women BC in other countries with similar conservative culture such as India and Saudi Arabia (101–103).

At primary level, women can access awareness campaign regarding BC through LHWs who provide reproductive health services (104). However, a study conducted in one district in Pakistan among 105 LHWs reported that majority of the LHWs had inadequate knowledge of BC including its symptoms and the importance of early detection due to lack of refresher trainings. The results showed that 35% of the LHWs had good knowledge of early symptoms and 16% knew of warning features, 56% thought that screening is beneficial for early identification of BC; but only 25% said that early detection of BC is helpful in increasing patients' survival, and 16% knew that early diagnosis can enhance treatment outcome. Screening knowledge among the LHWs was poor as well; of all LHWs participating in the study 62%, 65%, 56% had heard of mammography, BSE, CBE respectively; 50% knew how to perform BSE while only 36% practice it periodically (105).

Generally, cancer care in Pakistan needs more improvements; beside the few cancer centres available, public hospitals lack the required resources of oncologists and specialized nurses as well as equipment such as mammography (106). A study assessing elements of Punjab's healthcare system for cancer identified gap in healthcare professional awareness, infrastructure including diagnostic test and drug access, radiotherapy, and education and research programs (107).

3.6 Health Policy

As per WHO cancer control guideline, early detection is an essential part of a comprehensive cancer control program through patients' awareness of early signs and symptoms and national or regional screening for asymptomatic and at-risk individuals (108).

Until now Pakistan has no national screening program for cancer (74). In 2004, the Ministry of Health (MoH) of Pakistani jointly with WHO launched a National Action Plan for Prevention and Control of Non-Communicable Diseases and Health Promotion in Pakistan which included cancer prevention activities. The plan suggested that mass population mammography of women over 40 years old is not feasible in Pakistan due to limited resources including financial, human, and equipment. However, the action plan focused on the enhancing prevention activities of cancers and early detection through comprehensive behavioral communication strategy for NCDs and increasing awareness of BSE (109). However, majority of implemented health education programs on NCDs are usually focused on the prevention and control of NCDs through addressing health lifestyle changes and mainly pre-and post-natal healthcare of women (110). This was reflected in the Essential Package of Health Services (EPHS); mostly health promotion and education including BSE are provided at community level via LHWs and CHWs. Beside these services at community level, BHUs and RHCs provide general clinical examination with referral of treatment and laboratory to tertiary level (111). Advanced diagnostic tests and technologies such as mammography and treatment for cancer are included in National Health Insurance Program (NHIP) which is voluntary and limited coverage (112).

Given the above, many campaigns have been launched by the MoH and working organization like Shaukat Khanum Cancer Hospital and Pink Ribbon Campaign to increase awareness of BC among the population. In addition to awareness campaigns, both Shaukat Khanum Cancer Hospital and Pink Ribbon provide free screening in several part of the country; the Pink Ribbon Campaign provides mobile breast cancer screening as well (71). Evidence on the effectiveness of BC promotional campaign in Pakistan is limited, however available evidence showed that media campaigns contribute to enhancing knowledge of BC but deliver insufficient knowledge of the significant impact of screening practices among women (113). In a quantitative study investigating effectiveness of media public health awareness campaigns of different diseases including BC in various parts of Pakistan found that BC awareness campaign are not sufficient to drive positive change behavior among females (114).

3.7 Available Intervention

A study conducted to strengthen mammography screening in Islamabad through comprehensive pilot program for BC screening (115). This pilot program was designed using WHO six building blocks of health system strengthening in Islamabad and implemented in three phases as illustrated in **Table 2**.

Table 2 Program phases

Phase	Objective	Methodology
Phase 1 (2013–15)	Breast Cancer Screening Interventions Using 6 Tiers of Health System Strengthening in ICT	A well-equipped center for the diagnosis of breast cancer was developed bearing in mind the six basic tiers of health system strengthening. The center was equipped with two mammography screening facilities and one ultrasound machine. The center became functional, and a referral system was created.
Phase 2 (2016–2018)	Community Based Medical Education.	To bring awareness among the female population of the capital territory, rural areas, and female educational institutions including higher schools, colleges, and universities were targeted. Female health workers were also trained.
Phase 3 (2015–2020)	Impact of Screening Mammography	Mammography screening started and the records were maintained and analyzed after five years of performance.

Source: Strengthening Breast Cancer Screening Mammography Services in Pakistan Using Islamabad Capital Territory as a Pilot Public Health Intervention, 2022 (115)

The government allocated total of PKR 255 million (equivalent to USD 2.6 million) for the program activities including establishing Federal Breast Screening Center (FBSC) at Pakistan Institute of Medical Sciences (PIMS) and organizing BC awareness campaigns in urban and rural areas of Islamabad. Number of health workers including doctors, nurses and LHWs were provided with comprehensive training to increase knowledge about BC signs and symptoms, clinical examination, referral, and performing public awareness campaigns. LHWs who were trained by health professionals, performed community BC awareness campaign at BHUs and RHCs; the campaigns provided information about risk factors, symptoms, screening, and BSE. Whereas doctors and nurses along with other experts provided same community awareness campaign in urban areas of Islamabad at school and university. Printed and electronic media campaign were launched during 2018 and 2019 with less frequent field community campaigns. The objective of conducting these awareness campaigns was to increase utilization of mammography screening in FBSC. Referral system was created within the three levels BHUs, RHCs, and FBSC; all women above 40 years old were referred and provided with free mammography screening, younger women (30-40 years) were provided with general breast examination, and women between 30-40 with any symptoms were also provided with free mammography screening. It is worth mentioning that screening via mammography was performed by a female technologist.

This program design considered different parts of WHO six building block: services delivery, health workforce, commodities and equipment, information, finance, and governance. It provided free

screening service with advanced screening technologies; results were recorded in Health Management Information System (HMIS), health workers including LHWs, doctors, nurses, cancer professionals were involved and trained, governance was implemented through the District Health Office, and budget was secured from government fund.

The utilization rate of mammography screening increased annually; at the start of the program in 2015 only 39 women presented for mammography screening while in 2019 the number increased to 1,403. The program assessment through the conducted study claims good impact as it found that majority of women had alarming symptoms and were confirmed to have localized disease.

Chapter Four: Discussion

This chapter focuses on the key findings found during the literature review related to factors influencing delayed presentation of BC patients in Pakistan.

4.1 Summary of the main results

This review aimed to identify different factors related to individual knowledge, sociocultural, and services accessibility contributing to delayed presentation of women with BC to seek medical consultation in Pakistan.

Women **knowledge** regarding the disease including risk factors and **symptoms** was the **most significant factor** affecting behavior of most female BC patients in Pakistani to seek early professional consultation or diagnosis. Awareness of cancer symptoms and accessing care is the first step of early diagnosis as per WHO cancer guide for early diagnosis (116). The ability of women to recognize changes or signs in their body is a key element to early detection of BC especially in countries with limited resources and have no national screening program that target high risk group among the population to catch the disease at early stage and increase survival rate.

Findings from the literature reviewed in this study strongly confirm that **inadequate knowledge** of BC signs is the **most common** barrier faced by Pakistani women to present early. In particularly, **lump** is the most common sign initially noticed among all women with BC; however, most of them did not consult a doctor because they were not aware of its significance especially when they feel no pain or when the lump is small.

Because knowledge is the most common cause of delayed presentation, this study further looked at studies conducted among female **population in different part of Pakistan** to explore **general knowledge**. Evidently, most women in Pakistan **lack the proper knowledge** of BC clinical feature and warning signs that enable them to detect the disease early. **Awareness and practice** of **screening methods like BSE, CBE, and mammography** were also **poor** among **BC patients** and general **female population**. This poses more barrier to detect BC at the earliest possible. Knowledge of the disease and how to detect it is the first essential step to improve survival and quality of life followed by proper treatment. Aspects of **information dissemination** used for BC were not well examined in the reviewed literature, only few identified television and word of mouth. It is important to identify source and type of messages delivered to identify the gap in knowledge.

Education was the most significant correlated factor linked to knowledge among both patients and non-patients, the higher level of education the more **knowledgeable** women are of BC and its screening methods. Disparity between **urban and rural** women were evident in term of **knowledge adequacy**, **socioeconomic** was also found to be associated with knowledge in some findings. Clearly, rural women are usually less educated and have lower income of household. Channels and tools used for information dissemination could be another factor, not everyone in rural have television or electricity; their education level hinder them to read flyers or brochures; or language used to convey the message might be appropriate as Pakistan is a multi-ethnic country with various local languages. The role of **LHWs** could be enhanced to deliver the correct message and knowledge. LHWs are usually selected from the same community, and they

work with women directly from their own community; the level of **trust** and communication is high; thus, they can close gab and barriers related to **culture and accessibility.**

Education was noticed to affect **timely presentation** of BC patients: the less level of education the longer the delay in presentation. This is mainly because educated women are more **knowledgeable** and have better understanding of the disease including symptoms and their significance, screening methods, and importance of early detection. Yet, **satisfactory level of knowledge** was found among women with **advance level of education** (academic and master) while majority of Pakistani women have little or no education, meaning that majority of Pakistani women still at risk.

Financial affordability is another important enabling factor to seek healthcare; women coming from low-income households are more likely to present with longer delay. **Indirect cost** of **transportation and accommodation** poses extra burden; this is particularly challenging for women living in **rural areas** where professional diagnostic consultation and tests are not available nearby and only found in tertiary level in large cities. Moreover, free diagnostic tests like mammography are limited to few initiatives depending on charity which might not be visible to most women. Women and their families must bear the financial burden of any related cost for diagnosis or treatment. With no financial coverage like insurance and inability of most women to bear the burden associated with high cost of cancer treatment, **women's fear** of diagnosis and treatment cost further hinder them to present early.

This study looked at **women empowerment** and ability to make their own **decisions** related to health and health accessibility; many Pakistani women **lack the ability to make decision** regarding their own health with full independency since they live in **male dominate society**. Many women would require approval of husband or male guardian to access and utilize healthcare; furthermore, being accompanied by them is additional requirement. Consequently, women present with longer delay as they would wait for approval and availability of a relative to accompany them; this is an extra challenge for women living in **rural** areas as they need to travel to another city to **access** the service. **Education** and **employment** support women **empowerment** which relatively enhance their ability to make their own **decision;** both **educated and employed** women were found to be able to present earlier. Clearly, educated women have adequate knowledge and better awareness of BC and screening methods, while employed women are further able to **afford** access to healthcare services. Overall, women empowerment is important factor epically in country where gender disparity highly exists in all levels. More **research on gender barriers** and delayed presentation is important to better understand gender barriers to this specific issue.

Availability to healthcare is another essential dimension to late presentation. Pakistan has **no national program** to perform population wide screening for breast cancer among high-risk group. Few hospitals supported by charity and private initiatives by NGOs promote health education and free mammography screening; majority of cancer screening and treatment is provided in private sector; public cancer care

is generally inadequate and in need for improvement across all components of the health system including services deliver, equipment, workforce, and policies.

Health services for detecting breast cancer are limited in urban and rural parts of the country; however, women living in **rural areas** present with **longer delay**. Majority of the population lives in rural areas facing many obstacles to access essential health services dur to unavailability of proper diagnostic test and professional health provider in addition to time and **financial** resources needed to travel.

Interestingly, seeking **traditional/alternative therapy** was found to be another **substantial factor** to **delayed presentation** at professional medical healthcare. Many women wasted time trying traditional/alternative therapy and even spiritual healing to heal their symptoms. Even though not proven but it is possibly linked to lack of knowledge, financial resources, and availability of healthcare. Accessing traditional and alternative therapy before reaching to medical healthcare was significantly evident, therefore identifying reasons associated with such behavior is essential to effectively address fundamental reasons of delay.

BC is a disease affecting reproductive part of female and examination require exposing and touching the breast. Given the sensitive culture of Pakistan, women feel **embarrassed** to approach healthcare especially when there is no **female doctor**. Barriers of **culture acceptability** are important; women are discouraged to **access** regular or needed screening because they don't prefer to be examined by a male doctor. Cultural barriers additionally hinder male doctors from providing regular clinical examination for women. Limited female health professionals is a health system related factor affecting accessibility to healthcare. Inability of women to **autonomously** seek and access healthcare could be corelated here, families/husbands might not allow women to be examined by male doctor. Cancer is a surgical disease in Pakistan; globally majority of surgeons are male and this probably the case in Pakistan; thus, this is another **gender barrier** to address.

Health policies addressing breast cancer in Pakistan are limited with focus on preventive; health promotion largely emphasized on lifestyle changes and maternal health at the primary level. The national action plan for NCD 2004 clarified that with current financial resources, it is difficult to establish a **national screening** program for BC in Pakistan and recommended establishment of such program when country can secure required financial resources along with other resources. BC intervention included in the NCDs national plan were limited to **awareness campaigns** to raise awareness BC and BSE. However, the proven **poor knowledge** and **low practice** of BC **screening** observed in the studies presented in this review is a strong indicator that current health education program related to BC are ineffective given that majority of BC patients as well as general population of females in Pakistan still require **sufficient knowledge** to reduce delayed presentation and improve survival rate. **Media campaigns** are not achieving their main objective which is increasing knowledge that enable women to seek early diagnosis. **LHWs** working at the primary level, whose role to provide health promotion within

their community and refer cases to clinics in secondary and tertiary levels, can be greatly deployed to deliver the appropriate knowledge. However, they **lack satisfactory knowledge** which makes them incapable of delivering sufficient information.

A pilot program implemented in Islamabad was designed and addressed several barriers that where evident in this review. The program was designed to in small scale trying to improve early detection of BC through increase utilization of mammography screening with efficiency and effectively. The program addressed many barriers identified in this review; it employed the existence of **LHWs** at primary level and equipped them with comprehensive **training** to be able to deliver health **promotion** regarding BC to women in **rural** areas which results in **increased screening** uptake. Awareness campaigns were also conducted among **urban** women in Islamabad. The program provided **free of cost** screening service in the capital city in Islamabad using advanced technologies for screening. **Referral system** to the screening facility was introduced to ensure **accessibility** in timely manner. **Female** health providers were providing awareness and screening to reduce **culture barrier**. Even though no strong evidence can confirm the level of impact of this program, results showed that utilization of screening increased, and many women were able to detect the disease.

4.2 Relevance of the analytical framework

The behavioral model designed by Andersen et al. (1995) and adapted for the purpose of this study has worked well. This review puts major emphasis on enabling factors influencing health seeking behavior of women with BC regarding early presentation for health professional consultation after noticing alarming signs of the diseases. However, there was some ambiguity or overlapping in allocating some factors, such as residency which is mostly found under predisposing factors, but in this review, the author found it is better suited to be under enabling factor within accessibility to health care, residency was also under enabling factor in other studies.

4.3 Limitations and strengths

This review is limited by the dearth of literature found representing the whole population. Pakistan health system is decentralized; research is usually conducted in different areas; it is unfair to claim that this review was able to cover all population. Additionally, association among some factors were not strongly observed in most literature. For example, reasons for using alternative therapy were not observed which can be related to other factor like financial, accessibility, or lack of knowledge.

This review included different types of studies; majority of the studies were cross sectional; quantitative studies were also included with majority conducted over one year and more with fair sample size (40-2,000). This review can confidently claim to be recent; as far as the researcher is aware, this is the first literature review conducted recently including literature from 2010-2021 mostly, addressing factors influencing delayed presentation of BC patients in Pakistan. Even though literature found was limited

in representing the whole population of Pakistan, this review tried to cover the different regions of the country and considering demographic differences (young, urban and rural, education levels).

Chapter Five: Conclusion and Recommendations:

This chapter present research overall conclusions and recommendations achieved by this review.

5.1 Conclusion

This study found that lack of knowledge and failure to recognize significance of BC symptoms is the most common factor impacting delayed presentation of Pakistani women with BC. Besides, Pakistani women face several social and economic barriers which further influence timely presentation; low financial affordability, low education, and low empowerment of women are all factors contributing to delayed presentation. Poor services availability and accessibility particularly in rural areas is additional challenge to timely presentation. Rural women are found to face greater impact of most factors and longer delay. Pakistan health system lack adequate health policy and intervention to enhance early detection and health promotion among women in Pakistan further contribute to the problem.

5.2 Recommendations

Apparently, current fragmented interventions to tackle delayed detection of BC in Pakistan are not effective. A national screening program is the most effective intervention to improve early presentation and detection of BC, but this is not feasible in Pakistan. As per WHO recommendations, LMIC could adapt screening modalities according to their economic capacities; this could involves enhancing practice of BSE and CBS. All in all, awareness and knowledge of BC should be conveyed to positive health seeking behavior; additionally, women should be able to easily access services that are affordable and culturally accepted in timely manner.

It is important that health policy makers take an urgent action to reduce BC burden, starting from the first essential step of early detection which is awareness and accessibility. In general, allocating needed resources and addressing the different parts of the health system components related to this issue is recommended. Even with lack of adequate resources, Pakistan can still achieve considerable impact through small comprehensive interventions; more detailed recommendation can be summarized in the points below:

1. Assessment of current health promotion/education program for BC to identify existing gaps in knowledge, quality and appropriateness of messaging, and channels/tools used for information dissemination given the evidence in this study.
2. Assessing and enhancing health workers knowledge and skills to provide CBE at all levels of health system.
3. Comprehensive training for LHWs to provide well designed educational health campaigns in rural areas and link them with referral system.
4. Introduction of strong referral system.
5. Partnership and alignment with private initiatives providing free screening and integrate them in the referral system.

6. Including informal health services providers of traditional/alternative therapy in awareness training and referral system to enable them to identify BC cancer signs and immediately refer women to the needed and proper services.
7. More research to address underlying factors influencing to delayed presentation including information dissemination tools, use of alternative therapy, and gender related barriers.

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