

**THE LIVED EXPERIENCE OF BREAST
CANCER SURVIVORSHIP OF SAUDI
ARABIAN WOMEN**

Thesis submitted for the degree of Doctor of Philosophy

by

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Declaration

This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.

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Summary

Background:

There is a debate in the literature about how breast cancer survivors perceive themselves and make sense of their experiences. This conflict has emerged from cancer advocacy communities who attach positive meaning to breast cancer survivorship, and women with breast cancer that do not always share this positive view. Women who have had breast cancer often face difficulties as to how to make sense and understand their breast cancer experiences, and specifically, the ways in which cultural sensitivities impact and shape their perceptions about breast cancer survivorship. In Saudi Arabia, the increased length of survival of breast cancer patients, the younger age at diagnosis, and the unique cultural norms and values all suggest how important is to explore the experience of breast cancer survivorship lived by young Saudi Arabian women.

Methods:

This is a qualitative interpretive phenomenological study. Narrated data includes 18 interviews with Saudi women aged between 30-50 years who had completed their treatment 6-47 months prior to the semi-structured interview. The data that reflect women's experiences begin with diagnosis through treatment and afterwards. The data were then articulated and translated into the English language. The verbatim transcripts were analysed using the Interpretive Phenomenological Analysis (IPA). The lifeworld framework and its fractions (embodiment, social, selfhood, discourse, project and time perspectives) were used to gain a sense of what women encounter during their lived experiences.

Findings:

The analysis produced five superordinate themes. These were: survivorship experience; cancer change me; identity, faith and belief; and health care experience. These themes showed most of the women perceived breast cancer as a deadly disease. Some participants tried to keep their diagnosis hidden from the public and even from their families. Women often had difficulties with psychological adjustment to the physical side effects of breast cancer treatment. Infertility and post-menopausal symptoms were the main reported physical issues. They expressed feelings of fear of recurrence, living with loss, and being lonely; they had concerns for maintaining personal and social relationships. Women faced challenges in carrying out their roles as mothers, wives, and daughters and in keeping the family systems functioning. They constructed their illness experience, restructured their ways of living to accommodate breast cancer's cultural perception, their fear of the devil's eye and their sense of body and self. Their attitudes towards being defined by their illness were varied. Some women embraced being fighters against cancer and the cultural norms. On the other hand, most believed that surviving breast cancer was a result of God's will and viewed their experience as a 'test' and 'wake-up call' to what was important in life. Survival was linked to normality and resuming their activities previous to their breast cancer diagnosis. Some women shared needs concerning health care practice, communication and patient preparation and information. While some participants felt that there was a need for shared decision making in their care, some healthcare providers were obligated to follow cultural norms in involving male relative when breaking bad news and discussing the patient's care plan.

Conclusion:

This study helps to raise the awareness of Saudi women's experience and highlights the need to develop a cultural model of breast cancer survivorship.

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My deepest appreciation belongs to my family for their patience and understanding. I dedicated this dissertation to who I am indebted to for my success in my PhD journey, and who passed away while this thesis was on its way to see the light and being completed. To my beloved sister Haia, who encouraged me and believed in my dreams. Also, to my beloved brother Bader who has always been in my prayers asking God to have mercy on him.

Preface

I began my PhD journey with an interest in the cancer experience and became aware of survivorship through meeting Dr. Samiah Almoudi, the first Saudi woman to speak publicly about her experience with breast cancer, during my BSc nursing studies, and reading newspaper articles about her personal experiences and her key messages to women. Initially, I was interested in studying the quality of life among breast cancer patients in Saudi Arabia. This was a subjective investigation, determined from the patient's view of breast cancer experience from different perspectives, such as physical, social, psychological and spiritual, indicative of treatment outcome. This helped me to gain an extensive background in breast cancer in general. The theme of quality of life was my initial thought for my PhD's scope. However, I did not pursue this theme because it was essential for me to understand the lived experience of breast cancer survivorship and culture's impact on it, uncovering any hidden issues before assessing the impact on the patient's quality of life.

Reading in the context of cancer survivorship alerted me to the fact that the number of people living with and beyond cancer was rising and that they were concluding that the treatment was not the last phase of their journey. Around this time, I read a study by Kaiser (2008), who found that some American women do not want to be identified as survivors. I was surprised to read this because I thought that American women, or Western women in general, embraced the positive feminist image that honoured them for having courage in fighting breast cancer, which is part of the reason why I watch and listen to the media.

Several questions can be posed about the experience of breast cancer survivorship in Saudi women. What is the breast cancer survivorship experience? Why do women either reject or accept being referred to as survivors? Is this associated with culture? Is there something unique about the lived experience of breast cancer survivorship among younger Saudi women? Would the aspects that apply in the Western sphere also be transferable to Eastern culture? All these initial questions led me to think about how women perceive their lived experience after undergoing breast cancer treatment.

Through talking with 18 women about their experiences with breast cancer, I have come to comprehend the cultural impact in the women's life-world. Certainly, breast cancer is about screening, diagnosis, treatment and follow-up, but it is also about how culture defines these matters and makes them practical for women. Although I do not have breast cancer, I have been diagnosed with a long-term health condition and conducting this research triggered my experience, letting me be more involved in these women's worlds. I understand the feelings when your body lets you down, the experience of being vulnerable and dealing with public perceptions of sick women as insufficiently good wives and mothers. These women have been thrown into the context of breast cancer, which involves being obligated to live in/with/beyond it.

I thought that my life-world and those of the participants were different until I experienced hiding the news of my elder brother's medical condition from my mother when I knew how critical it was. My intention was to protect her from pain and I assumed that she would not be able to endure this news given the deaths of my sister and her husband in a car accident on the same day that my brother had his accident. I could not believe that some health care providers showed negative attitudes towards women with breast cancer as they revealed the bad news until I experienced this situation myself when the doctor stated that it would be a miracle if my brother lived. I mentally and physically re-lived this experience during the interviews with the participants, but this mental exercise facilitated a deeper understanding of the women's life-worlds.

Overall, this research project has been an educating, enriching and challenging journey, especially for an international student like me, and I have gained a deeper understanding of my cultural issues. The research has helped me to acknowledge the impact of my personal and professional experiences and to interpret the survivorship experience amongst pre-menopausal Saudi breast cancer survivors. My PhD study presented the opportunity for me, as a Saudi woman, nurse and lecturer, to explore and describe the experience of being a breast cancer survivor.

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Chapter 1 Introduction

1.1 Introduction to the thesis

The aim of this study is to give Saudi Arabian women a ‘voice’ by understanding their experiences of surviving breast cancer. It is important to conduct this study, as most existing studies have been undertaken in Western countries (Kaiser 2008; Sabo and Thibeault 2012; Williams and Jeanetta 2016). Talking with breast cancer patients in Saudi Arabia suggested that the unique cultural and societal perspectives of those women are likely to provide new insights into guiding healthcare practice in terms of informing the potential development of survivorship programmes for breast cancer survivors. At a clinical level, the study focused on the healthcare context and the strategies that have been used in the healthcare provision in order to support the experiences of women who survived breast cancer.

This study determines whether women’s experiences resonate with the Western concept of survivorship or whether any unique aspects to Saudi Arabian women are identified and present in their experiences. It seeks to understand the experience of women who have survived breast cancer. The theoretical perspective employed was based on interpretative phenomenology to enable a richer and deeper understanding of the experience of breast cancer survivorship and accomplish an exploration of a relatively new area of research in Saudi Arabia. Also, underpinning this investigation are two main philosophical frameworks. The first is the Interpretive Phenomenological Analysis (IPA) (Smith et al. 2009), used as a methodological approach to understand the lived experience and interpretation of the women’s language and the influence thereof on ‘meaning making’. The second is the life-world (Ashworth 2003) that locates the experiences lived by Saudi women with breast cancer according to fractions, considering embodiment, sociality, selfhood, discourse, project, and temporality.

1.2 Research problem

Breast cancer is a significant problem in Saudi Arabia even though this country has some modern healthcare facilities. Although both governmental and private institutions exist to diagnose and treat the condition, the global score of the quality of life of Saudi women with breast cancer is 31.15 (Al-Mutairi et al. 2016), which is the lowest mean

score of the group of Arab countries examined in a study by Rahou et al. (2016). Based on using a validated Arabic version of the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life C-30 (Aaronson et al. 1993), the mean scores of the quality of life were varied from 74.6, 72.5, 63.9, 63.7 and 45.3 on a scale of 100 in the case of the United Arab of Emirates, Tunisia, Bahrain, Jordan and Kuwait, respectively (Rahou et al. 2016).

The absence of programmes addressing survivorship concerns and needs in Saudi Arabia, as well as the limited opportunities for women to talk with other survivors, may contribute to the poor adjustment. This deficit in healthcare services was first highlighted by the Institute of Medicine, which emphasised that the transition from active treatment to rehabilitation is crucial and should receive special attention in the care of survivors (Reuben 2003-2004).

The Saudi healthcare literature is replete with studies that have looked at the attitude, knowledge, and protective practices among breast cancer and its screening (Al-Amoudi and Abduljabbar 2012; Alam 2005; Alsaif 2004; Amin et al. 2009; Sait et al. 2010). While the current literature appears to be less focused on capturing women's breast cancer identity (Kaiser 2008), exploring women's perception of breast cancer survivorship and the impact of culture on defining their experience and understanding of survivorship is now taking a central role. Despite the growing efforts in defining cancer survivorship, the thoughts and perceptions of breast cancer survivors remain unclear.

There is a growing need for a response to the needs of breast cancer survivors once the significance of survivorship is understood. Even though the concept of cancer survivorship has existed since the mid-1980s, there is continuing confusion and debate in the healthcare literature about the manner in which cancer survivors identify themselves (Park et al. 2009). This conflict in the perception of cancer survivorship from both the perspective of advocate cancer communities and of women with breast cancer should be clarified, especially when this confusion is derived from the different definitions of cancer survivorship used by researchers in order to fit their own area of interest in cancer research (Kelly et al. 2011). Although the identity of the survivor is

not universally accepted, understanding how women with breast cancer perceive themselves is important since the Saudi culture sends a clear message to women with breast cancer to mask their feelings and live in the shadow of their disease.

Social trends towards self-care, empowerment, and consumer activism have improved the access to information, whereas the expansion of the mutual aid networks is challenging the myths and misconceptions about medical care and the notion of cancer as a death sentence (Leigh 1992). The increased survival of breast cancer patients, the younger diagnosis age, and the unique set of cultural norms and values all suggest that the information on survivorship in this region may be specific and therefore important to both healthcare providers and patients.

1.3 Significance of the study

In view of the growing and aging population of Saudi Arabia, breast cancer rates are projected to increase considerably, which will in turn add a burden to the healthcare utilisation costs (Ibrahim et al. 2008). As breast cancer survival rates have improved, the discourse surrounding the disease has become more complex. With respect to the Western cultural understandings of breast cancer, the discourse of survivorship may replace the beliefs and fears of cancer as a deadly disease. The shift in cancer representation using traditional metaphors, such as ‘cancer victim’ or ‘cancer patient’, indicates that the latter is being replaced in many cases by the term ‘cancer survivor’. In the US, this label is now applied not only to those who have lived for an extended period of time after treatment, but also includes those who have been newly diagnosed with cancer, those who are in treatment, and those who have completed treatment and are in remission (Hewitt et al., 2006). Intuitively, it seems likely that these messages about cancer survivorship might influence the process of making sense of cancer. However, the phenomenological literature on breast cancer often describes the formation of personal and life events without referencing the role of culture and the way that women interpret their life-world.

Saudi Arabian women share a unique set of cultural norms and beliefs. Therefore, the issue of cultural differences might propel healthcare providers and policy-makers to re-examine the current notion of breast cancer survivorship, which is very sensitive to specific cultures, such as Saudi Arabia. The current study seeks to add to the body of

literature in terms of how women with breast cancer identify themselves in relation to surviving cancer within the context of culture. Extensive research has been conducted exploring the issue of breast cancer survivorship, yet it is highly important to understand how transferable findings will be applied across different cultures. Because of the Saudi cultural considerations, there are hidden thoughts, experiences, and socialised meanings which need to be uncovered.

1.4 Research aim:

To explore the experience of breast cancer survivorship lived by the Saudi Arabian women who are younger than 50 years.

1.5 Research questions:

Personal reflection and an extensive reading of the literature allowed me to gradually formulate the following focused research questions.

- What are the unique lived experiences of breast cancer survivorship of pre-menopausal Saudi Arabian women?
- To what extent does the Saudi culture impact on the experiences of pre-menopausal Saudi Arabian women who have survived breast cancer?

1.6 Research objectives:

- To identify how Saudi Arabian women perceive their survivorship from breast cancer.
- To understand their experience e.g., challenges, identities, feelings, benefits and relationships of being breast cancer survivors in Saudi Arabia.
- To identify the role of culture in either helping or hindering women's breast cancer survivorship experience.
- To explore what strategies from health care providers may support the breast cancer survivor's experience.

1.7 Theoretical consideration

The theoretical and methodological perspectives which have influenced this study are a combination of social constructivism, interpretive phenomenology, and IPA. According

to the social constructivism paradigm the ‘reality is socially constructed’ (Mertens 2005), which means that the reality as meaning and value are subjective and experiential; they are created, not discovered. The social constructionism paradigm may enable the thesis to demonstrate a way of understanding and explaining what we know about Saudi Arabian women’s experiences of surviving breast cancer and how these experiences were constructed in light of the potential cultural impact. Interpretative phenomenology was developed by Heidegger (1996), who believes that human experiences are embedded in social, cultural, and political contexts and a person cannot live devoid of interpretation of human experiences. Through gender, culture, ethnicity, religion, relationships, and language the participants are connected in co-creating an understanding and reconstruction of the meanings of their experiences (Van Manen 1990). IPA is informed by the Heideggerian phenomenology, developed by Smith et al. (2009), and it has a flexible set of stages for analysing data which suggest moving from individual to shared experiences and from the descriptive to the interpretive level. These twofold interpretative activities help in uncovering hidden experiences and interpreting meanings difficult to discuss in Saudi women’s cultural world.

The life-world concept is rooted in a phenomenology that was developed by Husserl (1970), based on the natural attitude that calls for complete immersion in one’s experience and being part of its existence. It could be viewed as the meaningful world that is lived and experienced when people encounter their sense of self, body, relationship, time, language and activity (Ashworth 2003). The life-world philosophical framework (Ashworth 2003) has informed the discussion chapter to achieve an understanding of the lived experience of breast cancer and making sense of the data from embodiment, social, selfhood, discourse, project, and time perspectives.

1.8 Research approach

It is important to understand how women make sense of breast cancer and how interaction with others and cultural impact might help in shaping meanings. Therefore, a qualitative approach was used and linked to phenomenology, specifically hermeneutics, which aids understanding of experience. This approach has informed the semi-structured narrative interview style that allowed 18 young women recruited from an oncology outpatient clinic in Jeddah to talk about their experiences in their own words

with a purpose to understand the lived experiences on its own terms. IPA was used as a methodological approach for analysing the data.

1.9 Structure of thesis

The study is organised and presented in 10 chapters. Chapter 1 informs the reader about the thesis's aim, research questions, objectives, and approach. Chapter 2 sets the scene for the study and provides background about the study. Chapter 3 provides a literature review that places the current study in the context of what is already known about the topic and provides justification for the investigation. Chapter 4 highlights the research design and methods, focusing on methodological and theoretical perspectives, like social constructivism, interpretive phenomenology, and IPA. Also, Chapter 4 outlines the research methods, including ethical considerations, sampling, recruitment process, data collection process, semi-structure interviews, testing feasibility, interview process, and practicalities. Chapter 5 presents a detailed description of data management principle and procedures, including transcription, translation issues, and analysis procedure.

Chapter 6 explores and describes the participants' stories and experiences from an individual perspective, while chapter 7 describes their shared experiences. Chapter 8 discusses the findings within the context of the life-world. Chapter 9 provides an evaluation of the study, testing the quality and the validity of IPA together with my reflective experience of the study. Finally, Chapter 10 explores the implications of the study on patients, the public, health care practice, and policy development, and the limitations of the study and direction for future research.

Chapter 2 Background to the study: setting the scene

This chapter presents an introductory view about the current status of breast cancer globally and in Saudi Arabia. It provides information about the diagnostic measurements, treatment options, and survival outcomes in order to fully understand what women with breast cancer are going through, beginning with diagnosis through treatment and afterwards. All this information is presented according to the different organisations' guidelines, such as the World Health Organisation (WHO), the American Cancer Society (ACS), the British Association of Surgical Oncology (BASO), and the European Society for Medical Oncology (ESMO). This chapter discusses the development of cancer survivorship as a concept and the debate concerning its meaning between cancer organisations and women. Also, it describes the Saudi health care system structure, screening limitations and cancer care service. Finally, it offers an overview of Saudi women's life and culture and their attitude towards breast cancer.

2.1 Breast cancer epidemiology

Breast cancer ranks as the most common cancer composing about 27.4% of all female cancers in Saudi Arabia (Kingdom of Saudi Arabia Ministry of Health Saudi Cancer Registry 2014). It is by far the most common cancer in the Eastern Mediterranean countries (Boyle and Levin 2008). In 2012, 1.67 million women were diagnosed with breast cancer and there were 6.3 million women alive who had been diagnosed with breast cancer in the previous five years (Globocan 2012). Breast cancer is also the second most common in the world and the fifth cause of cancer death among women (Globocan 2012).

According to the Saudi Cancer Registry, breast cancer prevalence (1999-2010) has constantly risen from 13.6 to 27.4 per 100,000, respectively (Kingdom of Saudi Arabia Ministry of Health Saudi Cancer Registry 2014). A retrospective descriptive epidemiological review of breast cancer of all diagnosed Saudi female cases from January 1990 to December 2014 was undertaken by Saggi et al. (2015), who used data obtained from the Saudi Cancer Registry. The results showed that the number of breast cancer incidences appear to be increasing. There were 1152 female breast cancer cases in 2008 in comparison with 1308 in 2009, and 1473 in 2010. However, the age-adjusted standardised incidence rates (ASR) of breast cancer in Saudi Arabia were lower than the

other Middle Eastern countries, as shown below in Figure 1. For example, ASR in Bahrain is (54.4), Jordan (52.6), Kuwait (48.0), Qatar (45.6) and United Arab Emirates (25.1) (Kingdom of Saudi Arabia Ministry of Health Saudi Cancer Registry 2014).

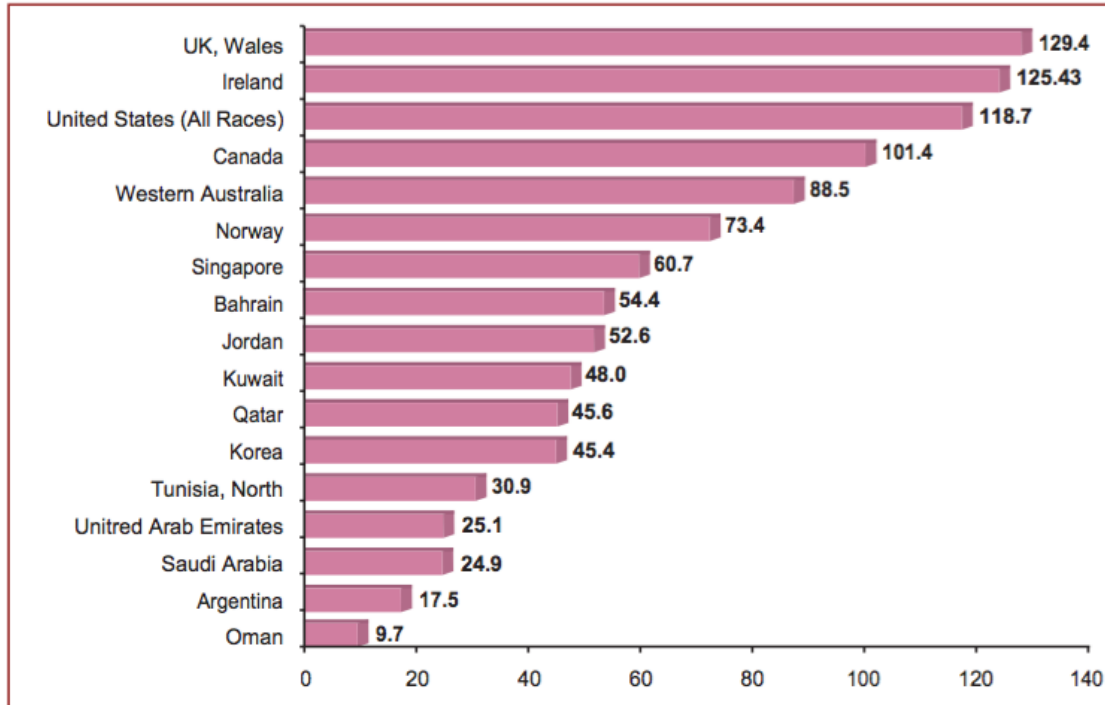


Figure 1: Comparison of ASR for Female Breast Cancer in Selected Countries (Kingdom of Saudi Arabia Ministry of Health Saudi Cancer Registry 2014)

Many variations with respect to age and stage at presentation exist between Saudi Arabia and other countries. Although the incidence rates of breast cancer in Saudi Arabia are low compared to the rest of the world, breast cancer in young Saudi women is a critical problem. In fact, the median age at diagnosis is 49 years (Kingdom of Saudi Arabia Ministry of Health Saudi Cancer Registry 2014), compared to 63 years in developed nations (El Saghir et al. 2007). The younger age at presentation of breast cancer not only affects Saudi women, but Arab populations generally. This is confirmed by a systemic review of 28 studies undertaken in different Arab countries (Najjar and Easson 2010). The results showed that the median age at diagnosis is 48, which means that two-thirds of women with breast cancer are below 50 years. In contrast, in the United Kingdom (UK), 80% of breast cancer cases are above 50 years and 48% aged 65 and over, between 2012 and 2014 (Cancer Research UK 2014). Similarly, in the US the median age at diagnosis is 61 years (National Cancer Institute 2010).

2.2 Breast cancer screening and diagnosis

Because breast cancer tended to be common among younger women, the Saudi Center for Evidence Based Health Care (2014) suggests screening with mammography in women aged 40-49 years every 1 to 2 years and every 2 years for women aged 50-69 years. This is in step with the American Cancer Society (ACS) (2015-2016), that recommends that average-risk women should undergo annual screening mammography beginning at 45 years of age; at age 55 women may transition to biennial screening, or continue with annual screening. Additionally, women 40 to 44 years should have the choice to begin annual screening. The World Health Organization (WHO) (2014c) suggests that women aged between 50 and 69 in both well and limited resources countries to do mammogram screening in intervals of two years. In the UK, the breast cancer screening programme invites all women aged between 50 and 70 for screening every 3 years and beyond 70 at a woman's individual request (National Health Service (NHS)).

According to the best practice diagnostic guidelines for patients presenting with breast symptoms in the UK, the diagnostic tools besides the clinical assessment done by the health care profession are imaging assessment and needle biopsy (Willett et al. 2010). Imaging assessment includes mammography, which is considered to be the gold standard in breast cancer screening all over the world, including Saudi Arabia (Abulhair et al. 2010a). However, it still has a low sensitivity in detecting dense breast tissue that is commonly seen in young women (Halladay et al. 2010). Thus, Benson et al. (2009) claim that 10% of breast cancers could not be detected by mammograms. The second imaging assessment tool is Magnetic Resonance Imaging (MRI). The European Society for Medical Oncology (ESMO) suggest that it is not routinely recommended, but should be considered for screening high-risk patients who are BRCA positive (Senkus et al. 2015). This is because it provides a high spatial resolution and soft-tissue contrast (Kalles et al. 2013). Ultrasound is another measurement tool that is able to measure the size of the tumour and assess the lymph nodes in the axilla (Kelly et al. 2010).

Besides imaging pre-treatment, disease evaluation includes pathological examination of the primary tumour and histology of the axillary nodes by fine needle aspiration/biopsy (Association of Breast Surgery at BASO 2009). It is a highly efficient tool used in Saudi

Arabia showing a definitive breast cancer diagnosis because it has high positive (93.9%) and negative (85.7%) predictive values (Mansoor and Jamal 2002). Other assessments include: complete personal medical history, family history relating to breast/ovarian and other cancers, physical examination, a full blood count, liver and renal function tests, alkaline phosphatase, calcium levels, and menopausal status (Senkus et al. 2015).

Following the assessment, proper staging is essential to determine the treatment plan. In this thesis I used the summary stage system described by the National Cancer Institute (2000), which is shown in Table 1 below.

Table 1: Breast cancer summary stage

Stage 0	Corresponds to in situ stage (Non-invasive; intraepithelial)
Stage I	Corresponds to local stage (Tumour ≤ 2 cm, invasive breast cancer, early stage, invasion limited to breast)
Stage II	Corresponds to local or regional stage depending in lymph involvement 2A - tumour ≤ 2 cm, cancer present in axillary lymph nodes - ≤ 2 cm tumour ≤ 5 cm, no cancer in axillary lymph nodes, no spread to body 2B - ≤ 2 cm tumour ≤ 5 cm, cancer present in lymph nodes, no spread to body -Tumour > 5 cm, no cancer in axillary lymph nodes, no spread to body
Stage III	Corresponds to regional stage 3A - $2\text{cm} \leq \text{tumour} \leq 5$ cm/ tumour > 5 cm, cancer present in axillary and may be in lymph nodes near sternum 3B - any size tumour, cancer present in skin or chest wall, cancer present in axillary lymph nodes or lymph nodes near sternum 3C - any size tumour, cancer spread to lymph nodes near clavicle, cancer present in axillary lymph nodes near sternum
Stage IV	Corresponds to distant stage Spread to body (metastasis)

In Saudi Arabia, the majority of breast cancer cases were presented in the advanced stages as 39.6% and 16.9% were in regional (III) and distant (IV) stages, respectively (Kingdom of Saudi Arabia Ministry of Health Saudi Cancer Registry 2014). That was supported by a Saudi retrospective study carried out by Rudat et al. (2012) who compared data of breast cancer patients in one of the tertiary hospitals in Saudi Arabia

with American publications derived from the Surveillance Epidemiology and End Results (SEER) database between 2004 and 2011. The study revealed that Saudi breast cancer patients who were diagnosed with advanced stage breast cancer composed of 61.2% versus 28.6% of localised stage cancer in the US.

2.3 Breast cancer treatment

- **Surgery**

In the UK, according to the quality assurance guidelines for surgeons in breast cancer screening, patients diagnosed with breast cancer should receive their first treatment within 62 days of an urgent referral (National Health Service Breast Screening Programme 2009). Treatment for breast cancer includes surgery, chemotherapy, radiation, and hormonal therapy (Cianfrocca and Gradishar 2006). According to the Association of Breast Surgery at BASO (2009), breast-conserving surgery (lumpectomy/ partial mastectomy) is recommended for early stage of breast cancer, which provides patients with better cosmetic results because only cancerous tissue and a edge of normal tissue are removed (Jones et al. 2009). However, an Omani study showed that breast-conserving surgery has been performed in a small proportion of patients due to the late stage and the inclination of some surgeons to perform a mastectomy without an effective evaluation (Al-Moundhri et al. 2004). A mastectomy is performed when there is multi-centric invasive cancer, extensive intra-ductal carcinomas, inflammatory carcinoma, and large primary tumours not reduced by neo-adjuvant therapy and patient preference (Benson et al. 2009). In other Arab countries, including Saudi Arabia, modified radical mastectomy remained the most performed surgery for women with breast cancer (El Saghir et al. 2007). In Saudi Arabia, according to a single cross sectional study done in one of health care institution, (44/50), 88% of women receive a mastectomy, which might be explained by the advanced stage at presentation, lack of availability of radiotherapy to shrink the tumour size before surgery, and the lack of awareness of breast cancer screening (Akhtar and Nadrah 2005).

The Association of Breast Surgery at BASO, the British Association of Plastic, Reconstructive and Aesthetic Surgeons, and Breast Cancer Care recommend that those patients with whom mastectomy is a treatment option (or have undergone a

mastectomy) should have the opportunity to receive advice on breast reconstructive surgery (Rainsbury and Willett 2012). Also, they recommend that if this is not available within the breast unit, the breast team should have a recognised line of referral to a breast or plastic surgeon with particular expertise in breast reconstruction. On the other hand, immediate reconstruction after mastectomy is contraindicated in cases like inflammatory breast cancer due to the high risk of recurrence, the aggressive nature of the tumour, and the need for post-mastectomy radiation (National Comprehensive Cancer Network (NCCN) 2014).

- **Other treatment options**

Adjuvant systemic therapy consists of chemotherapy, endocrine therapy, and/or biological target treatment, given after surgery to patients with no evidence of residual cancer outside the breast or the lymph nodes with the purpose of destroying microscopic cancer cells that might remain in the body and cause recurrence of the disease (American Cancer Society (ACS) 2016-2017). Adjuvant chemotherapy is commonly given for a period of 4-5 months at the hospital, followed by hormonal therapy at home for 5 years for hormone-sensitive patients (National Cancer Institute (NCI)). After finishing the curative treatment at the hospital, the patient will be assessed (remission period) to look for specific issues related to treatment side effects and possible recurrence (National Cancer Institute (NCI)). Adjuvant therapy for breast cancer may increase the chance of long-term survival by preventing a recurrence (Early Breast Cancer Trialists' Collaborative Group (EBCTCG) 2005). In Saudi Arabia, adjuvant therapy was used in 24 pre-menopausal (24/38, 63.2%) and 11 post-menopausal (11/12, 91.6%) patients (Akhtar and Nadrah 2005). Similarly, in Oman (Al-Moundhri et al. 2004). While neoadjuvant therapy consist of chemotherapy and/or radiotherapy is often used before surgery in women with large tumours to shrink the tumour possibly enough to make breast-conserving surgery, the early inhibition of the proliferation of micro-metastasis is detected following surgery (Senkus et al. 2015). It is a standard measure in early breast cancer management (Hortobagyi et al. 1988).

Knowing the four molecular subtypes of breast cancer is important to provide health care providers with valuable information that informs adjuvant systemic therapy, like Human Epidermal Growth Factor Receptor 2 (HER2), which is highly endocrine-independent (Oestrogen Receptor ER negative and/or Progesterone Receptor PR

negative), lymph node-positive and poor tumour grade; Luminal A, which is highly endocrine-dependent (PR positive and ER positive) and relatively resistant to chemotherapy; Luminal B, which is also highly endocrine-dependent (PR positive and ER positive), but highly sensitive to chemotherapy (HER2 positive); Basal-like/Triple Negative, which is highly endocrine independent, and highly sensitive to chemotherapy (HER2 negative) (Hayes 2012). Of all the subtypes, Luminal A breast cancer has the best prognosis, especially compared to Luminal B, while HER2 and Basal-like cancers were considered to have aggressive biological behaviour and reduced survival (Cassidy et al. 2015). However, the prognosis of HER2 cancer has improved with the introduction of HER2 directed therapies, such as trastuzumab (Herceptin) (Bonilla et al. 2010).

The existence of ER and/or PR on the breast cancer cell surface makes the cells sensitive to stimulation with oestrogen and progesterone (Cassidy et al. 2015). The stimulation results in cancer cell proliferation and cell growth. Therefore, Tamoxifen (hormonal therapy) is used to block the ER and prevents stimulation (Wilkes and Barton-Burke 2013). A Saudi study carried out by Al Tamimi et al. (2010) aimed to analyse the spectrum of molecular subtypes amongst breast cancer patients. The results of the study showed a 'unique' pattern of prevalence to the Saudi population; out of 231 cases, luminal tumours were 19.9%, and the unclassified group or Triple Negative were 42.8 %, which means that breast cancer cells do not respond to hormonal therapy (such as tamoxifen) or therapies that target HER2 receptors, such as Herceptin. Triple Negative tumours tend to related to the BRCA1 gene and occur more often in younger women and African-American women (Haque et al. 2012). This is in contrast to other countries, such as in Canada where the unclassified group only composed 8% (Cheang et al. 2009), 15.9% in Korea (Kim et al. 2006) and 4.87% in the US (Bhargava et al. 2009).

In regard to cancer diagnosis, treatment, and follow-up, the main cancer care centres are primarily located in major cities: Riyadh, Jeddah, and Dammam. Recently, cancer centres have opened in smaller cities, including Makkah, Al-Madina, and Qaseem, with several more underway. Although these institutions have good resources, the radiation therapy centres in Saudi Arabia are limited (Abulkhair et al. 2010b). Furthermore,

additional specialised centres ought to be established in the southern and northern regions in order to minimise the travel burden on cancer patients (Al-Ahmadi et al. 2013), as shown in Figure 2 below. There is also a deficiency in supportive care systems, social workers, health educators, and plastic surgeons as part of the multidisciplinary team (Abulkhair et al. 2010b).



Figure 2: Map of Saudi Arabia showing the distribution of the main cancer care centres

2.4 Breast cancer survival and surveillance

A variation in breast cancer survival rates has been reported, ranging from more than 80% in North America, Sweden and Japan to around 60% in middle-income countries and below 40% in low-income countries (Coleman et al. 2008). What stands out in Table 2 below, in the UK, 96% of women survive breast cancer for at least one year, with 87% surviving for five years or more (Cancer Research UK 2011).

Table 2: Breast cancer survival, women (Aged 15-99), England and Wales, 2010-2011

		<i>1-Year Survival (%)</i>	<i>5-Year Survival (%)</i>	<i>10-Year Survival (%)</i>
<i>Women</i>	Net Survival	96.0	86.6	78.4
	95% LCL	96.0	86.6	78.3
	95% UCL	96.0	86.6	78.4

The reason for presenting recent data of breast cancer survival rates in the UK, and not in Saudi Arabia, is because I could not find any recent Saudi Arabian data. This is based on an electronic search and contact with an administrative representative of the Ministry of Health (MoH) in Saudi Arabia. Most of the current data about breast cancer in Saudi Arabia concerns epidemiological information and survival rates in particular regions of Saudi Arabia, but not the whole country. According to Kingdom of Saudi Arabia Ministry of Health and Saudi Cancer Registry (2008), the Overall Surviving rate (OS) of breast cancer (1994-2004) for five years was 64.4 %. However, the latter report did not show the survival rate in relation to breast cancer stage.

Different governmental strategies or guidelines have been developed to inform cancer survivorship practice, to meet breast cancer patients' needs and enhance their survival and well-being. In the US, different organisations, such as the National Comprehensive Cancer Network (NCCN), the American Cancer Society (ACS), and the American Society of Clinical Oncology (ASCO), have released publications and guidelines, and events related to cancer survivorship care. The Institute of Medicine (IOM) report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, recommends some main elements of survivorship care, which are prevention, surveillance, health promotion, managing long term effects, and well-planned, coordinated care to help cancer patients progress from the acute treatment phase to life after cancer (Hewitt et al. 2006). Recently, in the UK, the Department of Health established the National Cancer Survivorship Initiative (NCSI), which set out a partnership with Macmillan Cancer Support and NHS England to develop the Living With and Beyond Cancer programme (LWBC) to address patients' needs with and beyond cancer (National Cancer Survivorship Initiative (NCSI) 2015). The following are their top priorities: developing a recovery package that includes access to holistic needs assessment; treatment summaries; cancer care reviews; and patient education and support events. Secondly, they focus on understanding and commissioning of improved management of the

consequences of treatment. Thirdly, the NCSI is engaged in developing stratified pathways of care to support patients in self-management. Fourthly, they promote health and wellbeing, including physical activity (National Cancer Survivorship Initiative (NCSI) 2015).

The ACS and the ASCO updated their guidelines for breast cancer survivorship care, addressing follow-up, prevention, and monitoring (Runowicz et al. 2016). According to their guidelines, it is recommended that the patient should receive a physical examination every 3 to 6 months for the first 3 years, every 6-12 months for the next 2 years, and then annually. Annual mammography is recommended on the intact breast for those who have undergone a mastectomy and on both breasts for who had a lumpectomy (Runowicz et al. 2016). On the other hand, there is no access to Saudi Arabian health care guidelines concerning survivorship care, because the Saudi Arabian cancer care system follows the NCCN's guidelines. However, Abulkhair et al. (2010b) suggest some modifications and implementation of NCCN guidelines in the Middle East and North Africa Region concerning breast cancer. They recommend that a history and physical examination should be performed every 3 months for the first 2 years post-treatment, then every 4 to 6 months for 3 years, and then annually. The justification for this regime is that breast cancer patients tend to have a higher rate of recurrence in the first 2 years (Abulkhair et al. 2010b).

2.5 Development of the concept of cancer survivorship

In the last few decades, the focus of cancer research on diagnosis and treatment has been expanded to include survivorship (Badger et al. 2005). The historical evolution of the concept of survivorship was introduced initially by an American physician, Mullan (1985), who conceptualised his experience with lung cancer as the 'seasons of survival'. He explained the common belief held when a diagnosis of cancer is received and treatment begins. He suggested using the term 'survival' rather than 'cure', as it could apply to both those who were 'cured' and those with cancer. He defined survivors as anyone diagnosed with cancer, since the patients must confront their own mortality following diagnosis and make either immediate or long-term modifications to their lives. Furthermore, Mullan (1985) proposed that cancer survivorship occurred at three stages. These are outlined below and are adapted from the medical surviving model (diagnosis, treatment, and therapy completion):

- The first phase is *the acute stage of survivorship*, which includes the diagnosis and intensive treatment of cancer. In the case of breast cancer, feelings of fear and anxiety about the possibility of death are prominent during this phase; therefore, it requires adaptive abilities and support from family, friends, and the community.
- The second phase is *the extended stage of survivorship*, which follows the completion of the course of treatment. In the case of breast cancer, this period is characterised by fear of recurrence, physical limitations, poor body image, alterations in sexual function, employment problems, and relationship changes.
- The third stage is *the permanent stage of survivorship*, which involves the reduced chance of recurrence and the greater possibility of long-term survival. During this phase, the woman is grateful to be alive, but the worry about cancer recurrence remains.

Feuerstein (2007) claims that Mullan's view aids the introduction of a new method of understanding cancer survivorship as a 'phenomenon' or 'experience'. This includes different phases beyond the biomedical model, with a focus on the 'quality' of cancer survival. Decker et al. (2007) argue that not all cancer survivors experience all three stages since there is no prescriptive timeframe. Furthermore, they noted that Mullan's view did not define treatment types that were supposed to be completed since some breast cancer patients complete their active treatment at the hospital, but continue to take hormonal treatment for a period or receive palliative therapy. It remains unclear from Mullan's (1985) survival categories how women across the spectrum of social differences, such as social class, race, economic stability – and particularly germane here – sexual identity, pass through these phases of survivorship. For instance, how do women with substantial and positive social support experience these phases differently than women who have compromised sources of social support? Does perceived social support moderate phases of survivorship?

2.6 The contemporary position of cancer survivorship

Following the publication of Mullan's (1985) article in the *New England Journal of Medicine*, The National Coalition of Cancer Survivorship (NCCS) was founded in response to the increasing number of cancer survivors on a national level in the US

(Doyle 2008). Since then, the concept of survivorship started to take a contemporary position, where the NCCS primarily adapted the term ‘cancer survivor’ in order to improve the delivery of high-quality care for the growing population (Hewitt et al. 2006). The NCCS has defined a cancer survivor from the time of diagnosis, through the balance of his or her life (Hewitt et al. 2006). As a result of the NCCS’s attempts to change the term from ‘victim’ to ‘survivor’ (Morgan 2009), the concept of survivorship in the US was accepted as part of establishing advocate cancer foundations, such as Lance Armstrong and Susan G. Komen for Cure. Generally, the term ‘cancer survivor’ has been used primarily as an advocacy tool, with the positive implications of moving cancer towards the notion of survival.

Due to the growing recognition of cancer survivorship as a diverse phase in cancer development, the implementation of efficient and effective strategies, as well as care plans for the organised transitioning of patients – from receiving active treatment at a specialised cancer centre to post-treatment care in the community – are now being regarded as critical to the overall health and well-being of patients (Hewitt et al. 2006). At a think tank event hosted by Macmillan Cancer Support and the Department of Health (DH) in the UK, more than 100 people affected by cancer (83.3% patients and 16.7% carers) were asked to choose their preferred definition: 42% preferred ‘living with and beyond cancer’ in order to describe this part of the cancer journey; 36% liked the term ‘survivorship’; whilst 13% preferred the option ‘life after cancer’ (Macmillan Cancer Support 2008). Consequently, living with and beyond cancer is the adapted definition by the National Cancer Survivorship Initiative in the UK (National Cancer Survivorship Initiative (NCRI) 2013).

2.7 The debate about the words ‘survivorship’ and ‘survivor’

- **Organisations’ views**

With the multiple options and advances in the treatment of breast cancer, more women are able to survive the disease today than in the past (Globocan 2012). However, the discourse surrounding the concepts of ‘survivorship’ and ‘survivor’ has become more complex. A source of debate is associated with the definition of cancer survivorship, regarding the point at which a person becomes a survivor. Within the framework of this thesis, the participants who completed the curative treatment at the hospital are

classified as survivors because they are living with and beyond cancer, because they are in remission following treatment. Surviving breast cancer following treatment was described as a 'tumultuous experience' in which women try to balance the elation of surviving a life-threatening illness with the demands of persistent physical symptoms (Ferrell and Dow 1995).

Leigh (2007) asserts that survivorship is not about the number of years that cancer patients might live, but about how well they survive and thrive, which was indicative of a more holistic approach. This can be observed in the case of cancer advocacy organisations that attach a positive meaning to breast cancer survivorship and spread hope despite the number of living years. As a result of the substantial advocacy efforts and coordination led by organisations, such as the NCCS, a 'cancer survivor' has been defined from the time of diagnosis, through the balance of his or her life, and recently includes family members, friends and caregivers to be secondary survivors (Hewitt et al. 2006). Meanwhile, the NCCS in the US, states that an individual is considered to be a cancer survivor from the time of diagnosis. Furthermore, the definition provided by the NCCS is extended to include family members, friends, and caregivers affected by the cancer survivorship experience (Hewitt et al. 2006). In the UK, Macmillan Cancer Support (2008) defines cancer survivorship as 'living with or beyond cancer'. This encompasses those who have completed initial cancer management and have no active disease, those living with a progressive (but not terminal) disease who may be receiving treatment for cancer, and those who have had cancer in the past. Therefore, the perception of cancer has evolved gradually from that of an acute disease to a manageable chronic disease (Allen et al. 2009), whereas cancer survivorship is now being regarded as a life-long-journey (Deimling et al. 2007).

There is a lack of consensus in the healthcare literature in terms of when someone may be defined as a 'cancer survivor' (Doyle 2008). Marcus (2004) suggests that survivorship definitions are unclear regarding the inclusion of patients receiving long-term treatments, such as tamoxifen, which decreases the risk of recurrence. From a medical perspective, the term 'survivor' refers to an individual who has had a life-threatening disease, but has remained free of it for a minimum of five years (Marcus 2004). The medical measurements of surviving cancer make it possible to categorise a

specific population of cancer patients who responded well to the treatment (Leigh 2007). Furthermore, labelling a person who lives five years beyond cancer as a survivor is ambiguous, as cancer is considered to be a progressive heterogenetic disease based on the tumour site and stage of diagnosis (Khan et al. 2012).

Women with breast cancer may be labelled as ‘cancer free’ or display ‘no evidence of disease’, but they are seldom told they are cured (Rancour 2008). In view of the complexity of cancer and the risk of recurrence, the word cure is used cautiously in oncology (Miller et al. 2013). According to the report of the Fifth European Conference on Survivorship and Chronic Cancer Patients held in Italy in 2014, a cancer patient can be only referred to as cured when he/she has the same life expectancy as the general population (Tralongo et al. 2015). Surbone et al. (2013) argued that there is no clinical definition of cure that describes the status of being cancer-free in the long-term. Miller et al. (2013) found that most of the oncology clinicians working at the Dana-Farber Cancer Institute in the US claimed that they were hesitant to tell their patients that they were cured. Indeed, uncertainty is strongly correlated with the notion of cure, which healthcare providers should explain to their cancer patients in order to help them understand the expected long-term effects (Surbone et al. 2013).

- **Women’s views**

Upon reviewing the views endorsed by cancer organisations on the notions of survivor and survivorship, this section seeks to explore women’s views and describe how they perceive themselves in terms of their exposure to breast cancer. ‘Cancer survivor’ might be perceived as a chosen identity, thereby demonstrating the possibility for the individual to either reject or accept their new identity as a survivor (Smith et al. 2015). On the basis thereof, this section describes to what extent ‘survivor’ is a preferable identity for the breast cancer population.

Some people adopt the word ‘survivor’ because it is associated with certain events, such as joining a supportive group of women, having been told they had finished the curative treatment, having had the tumour removed from their bodies, or having been told that they are ‘cured’ or ‘free of disease’ by a physician (Documet et al. 2012). The identity of ‘survivor’ can be perceived as a ‘tool’ that women use in order to become a certain kind of person (Swidler 1986). This person could have a sense of control over the side

effects of the treatment and maintain a positive level of functioning, particularly in terms of body image after mastectomy surgery (Wilmoth 2001). In addition, this person may be taking an advanced role in monitoring health and becoming involved in self-help groups (Park et al. 2009). For example, African-American women with breast cancer adopted the survivor identity because they demonstrated resilience and an urgency to help others (Davis et al. 2014).

Although some cancer survivors recover with a renewed sense of life and purpose, what has often been ignored is the toll taken by cancer and its effect on health, functioning, sense of security, and well-being. Some women living with breast cancer experience long-term effects, whereas others suffer permanent and disabling symptoms that impair their quality of life (Aziz and Rowland 2003). For these reasons, women who have suffered from breast cancer may not want to be defined by their illness. Kaiser (2008) suggests that some women with breast cancer believe that the survivor identity conceals the physical and psychological costs of cancer, possibly alienating those in the advanced stages or those who prefer to be defined by their illness. In the UK, some women would not perceive their experience as serious enough to endorse the term ‘cancer survivor’, particularly in the case of those who had been diagnosed with breast and colorectal cancer, due to the higher chances of survival (Khan et al. 2011). Khan’s study is original because of its knowledge contribution to the meaning of cancer survivorship in the UK. It showed the different reasons for rejecting the survivor identity held by the British cancer population who were at least 5 years post diagnosis.

2.8 Linguistic and cultural interpretations of the word ‘survivor’

Societies often link survivorship with special life situations, such as earthquakes, violence, and war (Dow 1990). (Lifton 1980), cited in (Breaden 1997 ,p. 978), studied the survivors of the atomic bomb in Hiroshima, and defined a survivor as someone who ‘has touched, witnessed, encountered, or been immersed in death in a literal or symbolic way and has himself/herself remained alive’. When it comes to chronic illness, people who survived cardiovascular diseases – which represents the leading cause of death worldwide (World Health Organization (WHO) 2014a) – are in a good position to be honoured and earn the ‘survivor’ title. However, the reality appears to be that cancer is receiving a high level of prioritisation in terms of establishing new health institutions, funding, and campaigns compared to other chronic diseases (Maher 2014). So, what

makes the cancer patient 'special' in order for them to be called a survivor? The answer might be related to the cultural stigma attached to the term cancer that was deemed different from any other chronic disease. Breast cancer is often linked to negative metaphors, suggesting death, shame, fear, loss and destruction. It impacts women's lives from different angles, such as self-image, health, relationships, and family dynamics. Astrow (2012) notes that cancer patients viewed cancer cells as 'aliens' that could spread everywhere without a person's control. He added that healthcare providers need to explain to cancer patients during the diagnosis stage that they have a condition which is characterised by variable, rather than fixed chronicity, as in the case of patients with cardiovascular illnesses (Astrow 2012).

On a TEDMED stage, which is a non-profit media organisation that posts online-talks about ideas worth sharing, Dobra talked about her experience with breast cancer and claimed that people got excited about surviving: "*Because they are so afraid of death. It's like, 'you're a survivor'! But the unspoken thought is, 'for now'. Because ultimately, no one survives*" (Jarvis 2014). In fact, the meanings attributed to chronic illnesses are created by patients in order "*to make a wild, disordered natural occurrence into a more or less domesticated, mythologized, ritually controlled, therefore cultural experience*" (Kleinman 1988, p. 48). The US cancer organisations are considered to be among the first to shift the representation of cancer from traditional metaphors such as 'cancer victim' or 'cancer patient', to terms such as 'cancer survivor' and 'fighter'. Positive emotive phrases linked to the notion of survivorship, such as, 'win the battle' or 'conquer', suggest that women were victorious in their battle against cancer, and that in turn gave them a sense of power, cure, and control (Burke et al. 2012). Similar results were reported in the US as well, since the most commonly reported meaning associated to the notion of survivorship was that of 'conquest', as victors against the enemy, a 'new outlook' about life and death, in addition to new values and beliefs (Documet et al. 2012). Consequently, the term survivor gains drive for those affected by cancer and working in a Western society.

The healthcare literature appears less focused on capturing the conflict in the perception of breast cancer survivorship and the language thereof. This emerges from cancer advocacy communities who attach positive meaning to breast cancer survivorship, whereas women with breast cancer do not always share this positive view. The debate

concerning the instance about when a person can be called a ‘cancer survivor’ still exists. Different views prevail in terms of what it means to be a cancer survivor, for both patients and healthcare professionals, who sometimes come from different cultures. It seems that finding a cross-culturally acceptable term that can capture all aspects of breast cancer experience, including gender, age, past experiences, disease progress, specific risks, and follow-up requirements and unique patient needs, is clearly difficult. On the basis of this, the research questions emerged, seeking to understand the experience of breast cancer survivorship and to what extent culture is capable of influencing it.

2.9 Healthcare in Saudi Arabia

This section covers the structure of the health care system in Saudi Arabia, composing of primary, secondary, and tertiary health care. It offers an overview of the difference between the governmental and private sector in accessing health care services. Following that, this section goes on to explore the current cancer care in Saudi Arabia in terms of the breast cancer screening service, professionals’ roles, and cancer centres’ distribution.

2.9.1 The Saudi healthcare system

The healthcare sector in the Kingdom of Saudi Arabia is governed by the Ministry of Health (MoH), which is the major governmental provider of health care services in Saudi Arabia. It was established in 1954, and it is located in the central region of Riyadh city, the capital of Saudi Arabia. The health services are operated on 3 levels: primary, secondary, and tertiary. Primary health care centres supply basic care services, both preventive and curative, referring cases that require more advanced care to public hospitals (the secondary level of care). While patients with chronic diseases, such as cancer – most of whom are referred from public hospitals and require more complex levels of care – are transferred to central or specialised hospitals (the tertiary level of health care).

The Saudi health care system includes the governmental sector, which is regulated by the MoH, with a total of 1,436 primary health care centres, 274 hospitals (41,297), and this constituted 58.8% of the total number of beds in Saudi Arabia (Ministry of Health (MoH) 2015). These hospitals provide basic healthcare services, as well as, in certain cases, specialised facility centres. Besides the MoH health sector, a number of

governmental semi-public organisations were established, such as the King Faisal Specialist Hospital and Research Centre, National Guard, Ministry of Defence and Aviation, Ministry of Interior, the Royal Commission, Ministry of Higher Education hospitals (teaching hospitals), ARAMCO hospitals, and many others, as indicated below in Figure 3. Although the latter hospitals were found to provide free healthcare services via a combination of primary, secondary, and tertiary levels of healthcare for their employees and their dependents, all of them provide health services to all citizens during crises, emergencies, and cancer care. In order to reduce the load on the governmental health service and meet the healthcare demands of the general population, the private sector, which is primarily administered by wealthy individuals and private companies, plays a key role in providing quality healthcare services for a fee.

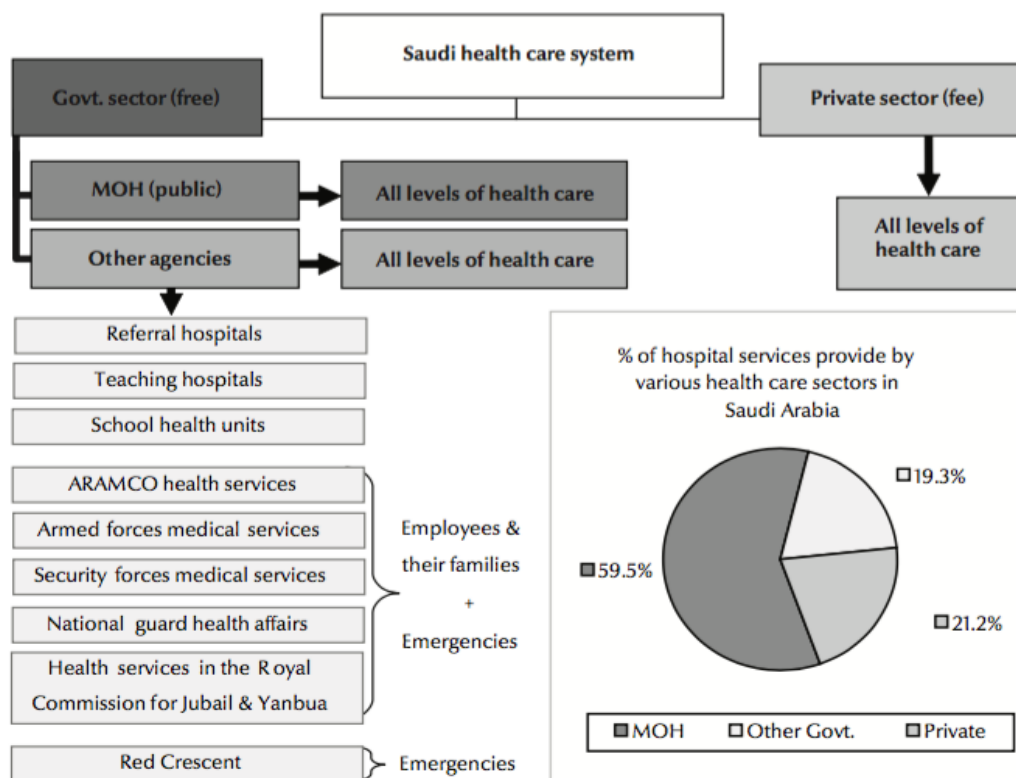


Figure 3: Current structure of the healthcare sectors in Saudi Arabia (MoH, 2009)

A national strategy for the healthcare service has been implemented by the Saudi government with a main focus on the diversification of funding sources, information system development, healthcare monitoring, and incentivisation of the private sector to partake in the provision of healthcare services, prevention, curative, and rehabilitation care (Almalki et al. 2011). A further unique aspect of cancer care in Saudi Arabia is that patients are relieved of a great financial burden faced in other regions of the world, as

Saudi law guarantees that all Saudi patients with cancer receive care free of charge (Ministry of Health (MoH)). Despite the modern medical facilities that contribute to continuous improvements in terms of the early detection of cancer and the reliability of diagnosis and treatment in the countries of the Gulf Cooperation Council (GCC), including Saudi Arabia, a number of challenges still remain. The countries of the GCC face several challenges in relation to cancer care that need to be addressed on the basis of a coordination of services, training, and research (Brown et al. 2012). In Saudi Arabia, the lack of effective coordination and communication channels among the different health sectors results in wasted resources and a duplication of effort (Amir 2012). In terms of the e-healthcare system, gradual developments have been made in Saudi Arabia, yet these information systems located in the private sectors are not connected with the specialised governmental health organisations (Altuwaijri 2008).

2.9.2 Breast cancer screening

In 2007, the Saudi Government intervened in addressing the burden of breast cancer and establishing the first national breast cancer screening centre, known as the Abdul Lateef Cancer Screening Centre (Abulkhair et al. 2010a). It was located in the capital city of Riyadh and thus, the majority of the participants hailed therefrom. Women were examined by a trained female technician, a female family physician, and a female health educator in order to overcome any feelings of shyness or existing cultural barriers. In 2012, the Saudi Ministry of Health, in partnership with the General Electric Company, Saudi Cancer Society, and Susan G. Komen for the Cure, launched the first national screening programme. This deployed three mobile clinics with the aim of offering digital mammography screening to 10,000 women over the course of that year (Ministry of Health (MoH)), with 69 women having been diagnosed with breast cancer and currently undergoing lifesaving treatment (Hewar 2012). The strategy of this programme sought for women to undergo an initial physical examination at a primary health centre, after which they could request a digital mammography at one of the rotating mobile clinics operated near the key primary care centres in Riyadh. The results were subsequently obtained from the King Fahd Medical City in Riyadh. Although establishing mobile screening clinics is an efficient approach, this programme is currently only in its early stages and is only available to women living in Riyadh.

Many other charitable cancer foundations launched screening programmes in the Eastern region, such as the Saudi Cancer Foundation and the Pink Eastern Campaign, which were established in October 2009. In the Western region, the Taibah Cancer Screening Centre in Al-Madina and the Sheikh Mohammed Hussien Al-Moudi Centre of Excellence in Breast Cancer in Jeddah were established. All these foundations sought to prioritise professional education in clinical breast examination and breast self-examination, combined with public education about breast diseases, self-examination, and screening. However, there are no links between the available screening programmes, since they represent individual efforts that lack long-term sustainability and require official sponsorship from the Ministry of Health (Ward 2014). It has also been noted that all the aforementioned programmes are based on self-referred participants because the routine screening service is not available. Therefore, it is not surprising that the World Health Organisation's (WHO) report on Non-Communicable Diseases (NCDs) Country Profiles showed that Saudi Arabia's national response system to NCDs has many limitations. These, in association with a lack of a surveillance and monitoring system of four diseases, including cancer, is indicative of the insufficient and uneven progress (World Health Organization (WHO) 2014b).

2.9.3 Breast cancer care service and its challenges

In other healthcare systems, primary health care physicians are the first to contact the patient and subsequently provide them with a diagnosis (Radi 2013). However, the primary care system in Saudi Arabia is still suffering from a shortage of trained primary care physicians, who require access to an efficient referral system to specialist health care services (Al-Othman et al. 2015). The lack of health care providers in encouraging women to participate in breast cancer screening was another alarming issue. In a Saudi study carried out in order to assess the physicians' perceptions and attitudes towards breast health and examination (Al-Amoudi et al. 2010), the disappointing results showed that breast examinations were not included in their physical examinations, due to complaints received from the patients, embarrassment, lack of time, and fear of the patient's response. Despite this, most of those physicians had admitted to performing breast examinations while they were completing their training outside Saudi Arabia. This shows that there is a lack of awareness among healthcare providers towards the breast cancer concerns in Saudi Arabia. Furthermore, cultural issues are affecting both

the women who might feel shy about asking for a check-up and the male healthcare provider who might feel vulnerable asking the female patient for permission to examine her breast. In Riyadh, Saudi Arabia, a cross-sectional study using self-administered questionnaires was conducted among 180 female General Practitioners (GP) in primary health care centres (Saeedi et al. 2015). The study sought to assess the level of knowledge in relation to breast cancer risk factors, clinical breast examination, and mammography. The results showed that 91.9% of female GPs were aware of family history constituting a risk factor, 96% were aware of the importance of mammography as a screening method in detecting breast cancer, and 84.6% knew that the recommended age for a mammogram screening is 40. However, only 19% acknowledged mammograms as a routine screening tool for women aged 40 years and above. These results suggest that the GPs are not taking an active role with reference to the patients' health education about breast cancer, and it is unknown to what extent the GPs are authorised to interfere in cancer prevention, control, and care. Ibrahim et al. (2008) suggest that family physicians are in a good position to become involved in cancer detection programmes and follow-up checks. Al-Othman et al. (2015) highlights the need to recruit trained GPs who would have access to laboratory and radiological oncology facilities and referral systems to specialised healthcare services. They furthermore call for an effective coordination of cancer care between primary, secondary, and tertiary care services.

Due to the increase of physical inactivity, obesity, and the adoption of Western nutritional habits, Saudi Arabia is required to invest in the training offered to healthcare providers, and to study the cost-effectiveness of cancer prevention programmes against expected future cancer incidence (Ibrahim et al. 2008). The Middle East and North Africa (MENA) breast cancer regional guidelines committee reviewed the 2009 clinical practice guidelines in oncology from the National Comprehensive Cancer Network (NCCN) for breast cancer and suggested modifications suitable for the Arab region (Abulkhair et al. 2010b). The latter suggested that genetic counselling, particularly for high-risk women, is essential. However, in Saudi Arabia there is a major lack of knowledge about the risks associated with breast cancer in terms of heredity and gene testing, of up to 87.8% with a sample size of women (n=599) who were younger than 40 years of age (Amin et al. 2012). Saudi women tend to get married and have children at a young age, with traditional conservative and consanguineous marriage values playing

vital roles. The segmentary structure of the tribes in Saudi Arabia encouraged the custom of endogamy, also referred to as marriage from paternal cousins. Therefore, the need to add the breast cancer genetic test within the pre-marriage listing tests to detect inherent diseases is essential, particularly for women who are at high risk. The pre-marital screening test is conducted for soon-to-be married patients in order to identify any inherent genetic blood diseases, such as sickle-cell anaemia, thalassemia, or infectious diseases, such as hepatitis B and C and the HIV disease.

Al-Othman et al. (2015) recommend working under an umbrella which facilitates the coordination of many fragmented programmes and initiatives, and maximises the benefits of large investments for a better integration of cancer care. An integrated approach is important for the purpose of developing clinical research collaborations and the guidelines thereof (Brown et al. 2012). Enhancing the accessibility of healthcare services requires equity in the distribution of healthcare facilities throughout the kingdom and equity of access to health professionals (Almalki et al. 2011).

2.10 Life of women in Saudi Arabia

Women in Saudi Arabia are less dominant than men due to the existing cultural perspectives, which empower men to take control over the decisions that concern women in relation to work, study, travel, and even access to healthcare (Sex Segregation Keeps Women Out of Public Life 2008). Saudi Arabia is the only Gulf country in which it is prohibited for women to drive cars, which constitute a disadvantage when seeking medical care (El Bcheraoui et al. 2015a). Gender ideologies that can be attributed to traditional and socio-economic values gained legal force in the Saudi society by being associated with Islamic teaching (Hamdan 2005). Although male dominant culture is often linked to the religion of Islam, there is a significant difference between the cultural factors and the Islamic rules and its regulations (Al-Amoudi 2012). In some cases, Islamic and religious texts are being interpreted literally, which in turn enables some conservative religious scholars to silence women's voices in the name of Islam. Religious leaders exert a constant pressure on maintaining the Saudi traditions and values in the form of continuous wearing of veils and sex segregation in public places, as well as the restriction of certain activities for women, such as free mobility and sports in schools (Pharaon 2004). Because women are not allowed to drive in Saudi Arabia, in some societies, without male approval, encouragement, and support to take them to the

hospital, their wives, sisters, daughters, and other female relatives will rarely seek medical advice (Al-Amoudi 2012). Additionally, the attribution of physical inactivity led to an increase in the prevalence of obesity among Saudi women from 14.2% to 26.2% over a period of 10 years (AlQuaiz et al. 2014).

The uniqueness of the situation faced by Saudi women is derived from their involvement in the personal and social domain and yet lack of involvement in the public life, which may be related to social and cultural factors. According to the statistical summary of higher education students (General Authority for Statistics 2015) women in Saudi Arabia have overtaken men in education (female= 85.512, male= 67.709), but women's participation in the work sector is limited to certain industries such as business, health, and teaching. Employment has been a factor related to low physical functional level among Saudi breast cancer patients (Al-Mutairi et al. 2016).

The strong resistance on the part of several religious leaders to changing the role of women could be explained by the underlying fear that women's key role in the family may be overwhelmed by these new roles, thus threatening the stability of the family. As women have an important role in maintaining the family, reproducing successful generations and guaranteeing family continuity (Pharaon 2004). Altorki (1986) argues in her PhD thesis that a good wife's role may be defined in terms of attending to the husband's needs. A wife is expected to give her greatest care to serving food and personally attending to the husband's clothes, even if there are servants employed which could do that. The women in the Altorki's (1986) study acknowledged that failure to perform these tasks could lead their husbands to seek other wives who could do that. Another duty expected from a wife was supervising the house and limiting her expenditures in order to meet the husband's resources. In addition, reluctance to meet the husband's sexual desires provided him with a socially acceptable excuse to look for another wife. The position of women changed from belonging to their tribes to belonging to their husbands, whom they exclusively depend on. Doumato (2000, p. 93) states that "... girls were taught enough to buy into an assigned role, a role in which they were subordinate to men, but not enough to challenge it". On the other hand, women's roles have changed according to their social class and regions. For example, women coming from rural areas benefit from limited opportunities, as opposed to

women in the urban regions, whereas women from the middle and upper class are likely to have more assertiveness and authority in society.

The political, social, cultural, gender, and racial factors intersect in the field of breast cancer and this should be recognised and incorporated into the research surrounding the disease (Eisenstein 2001). The religious/cultural beliefs of Saudi women may affect their attitudes towards understanding breast cancer. Studies have reported that Muslim women's reluctance to attend breast screenings was rooted in their belief that touching the breast, even in private, is not acceptable (Al-Alaboud and Kurashi 2006; Avci 2008; Banning et al. 2010; Kucukkaya 2010). Ide and Sanli (1992) found that Saudi women had little knowledge of the causes of different illnesses or the rationales for preventive measures, as many perceived that disease prevention conflicted with the will of Allah.

Saudis appear to be seeking healthcare only when they are sick, which suggests that the Ministry of Health needs to further investigate the health-care seeking behaviour and the individual characteristics in health-care-seeking practice (El Bcheraoui et al. 2015b). In a Saudi-based study, 189 (24.7%) women justified not going for mammogram screenings because they do not have any health problems and did not think it was important when they answered an internet questionnaire assessing their knowledge and attitude towards breast cancer (Abdallah et al. 2015). In the context of a conservative culture, Saudi women feel shy and do not wish to be examined by a male healthcare provider. Abu-Nasr (2007) reported that:

One Saudi woman ignored her breast cancer because she was afraid of being seen by a male doctor. Another was divorced by her husband simply for thinking she may have the disease. A third was dragged away from the mammogram machine because the technicians were men (Paragraph 1).

Al-Amoudi and Abduljabbar (2012) believe that Saudi Arabian women diagnosed with breast cancer may not be able to function and perform their duties as well as before receiving the diagnosis. Instead they were thought to become more dependent on their husbands who could eventually have them sent away or divorce them. Carol Fleming was an American blogger, married to a Saudi man, who was diagnosed with breast cancer in 2008 and died in 2013. In her blog (Bedu 2010), Fleming explained that breast cancer is a stigmatised problem, especially for a woman who is young and single. She may be classified as unmarriageable because she might be viewed as a defective person.

The most recent studies suggest that the main barrier for seeking health is not only the unstructured screening healthcare plans, but rather the women in the health system, their beliefs, health behaviours, and reluctance to take advantage of the free mammography screening (El Bcheraoui et al. (2015a). Although detecting breast cancer remains an individual reasonability, women need to raise their voices and be empowered. This could not be done without collaboration between the MoH presenters, religious leaders, researchers, and activists, such as Dr. Samiah Almoudi, who was the first Saudi woman to speak in public about her experience with breast cancer.

2.11 Conclusion

This background chapter has described the global prevalence of breast cancer among women, particularly in Saudi Arabia, and the main breast cancer diagnosis, treatment, and surveillance options. It described the development of the concept of cancer survivorship by Mullan (1985) and the main issues surrounding this term. It outlined the debate about the words ‘survivorship’ and ‘survivor’ in terms of definition, usage, and language. Also, this chapter outlined the cancer healthcare system in Saudi Arabia and its challenges. It explored the position and role of women in Saudi Arabia, which may influence attitudes towards breast cancer. The following chapter provides a critical analysis of the existing literature regarding breast cancer survivorship meaning, experiences, and how breast cancer experience is regarded from different Western and Eastern cultural perspectives. This literature review discusses the main existing healthcare strategies that helped women who have finished treatment.

Chapter 3 Literature review

3.1 Introduction

This chapter reviews the literature relating to the perception of breast cancer survivorship. It describes the experience of women post breast cancer treatment, identifying the main psychological, social, physical, and spiritual issues and highlighting the challenges that breast cancer survivors might face after finishing their treatment. The chapter also identifies the lived experience with breast cancer across Western and Eastern cultures. It reviews the current supportive healthcare strategies that can help breast cancer survivors to adjust to life beyond active treatment.

This review was guided by the following research questions:

- What is currently known about the experience of breast cancer survivorship lived by young (30-50 years), pre-menopausal women following curative treatment?
- Are there cultural variations that have an impact on the experience of women with breast cancer?
- What are the challenges that impact on life beyond curative treatment?
- What health care strategies exist to support women following curative treatment?

3.2 Search strategy

For this literature review, an electronic search was conducted in August 2013 to February 2014, prior to the development and submission of the research proposal. The searches were repeated in November 2015, and updated in October 2017. Zetoc alerts were set up following the initial search process using identified themes, to ensure that the researcher would be informed about new studies. The scope of the literature is to explore the perception of breast cancer survivorship among women, specifically in Saudi Arabia. However, due to the lack of specific literature informing the Saudi Arabian perspective, the literature review presents a global view from Arabic and Islamic countries that have some cultural commonalities with Saudi Arabia. The following keywords and their synonyms were used to facilitate the search: Breast cancer, survivor*, perception, experience, post-treatment, culture, challenges, follow-

up, strategies (see Appendix A). The following databases were searched: CINAHL, MEDLINE (Ovid), and PsychINFO. In addition, references were identified manually by searching the references of the retrieved papers for relevant papers (e.g., tracing citation through the reference lists and key journals), for example, the Journal of Cancer Survivorship, the Cancer Nursing Journal and the European Journal of Oncology Nursing, besides performing an extensive search of 'grey' literature, such as dissertations and theses. To ensure transparency, while searching for the related literature I explored the available literature about the lived experience of breast cancer through Google Scholar (general browser) to gain a general view of what is known about the topic. Then, I reviewed the articles by title and abstract to identify the key journals, the type of literature searches, and to find the keywords that were used in those references. These include survivorship, survivor identity, breast cancer experience, quality of life, the unmet needs or challenges of breast cancer patients, the impact of culture on the experience of the survivor, the hidden thought life of the survivor, coping and adjustment, needs, follow-up care, patients' preference, and survivorship service. The large amount of literature available initially appeared overwhelming, but 'Endnote' enabled the identification and removal of duplicate references.

3.3 Inclusion and exclusion criteria

The focus of the literature search was identifying evidence that answers the literature review questions, relating to:

- Cancer survivorship perception of pre-menopausal women in the early stages of breast cancer.
- Experience/life after curative breast cancer treatment.
- Challenges of post breast cancer treatment.
- Strategies used by health workers to support breast cancer survivors.
- Studies with adult female breast cancer patients.
- There was a requirement for research studies to be primary, and to use quantitative and/or qualitative methods.
- Published in English or Arabic between 2000 and 2017 to have abroad recent overview of the literature. Studies published before the 1980s were not included in the literature search because the concept of cancer survivorship was only developed by Mullan (1985), who

started writing his personal diary with cancer. In 1996, the Office of Cancer Survivorship was founded to focus on cancer survivorship issues (for more information, see the development of the survivorship concept in the previous chapter). Most of the studies found between 1985 and 2000 were related to quality of life.

All commentaries, editorials, conferences, and posters were excluded from this review. Furthermore, studies were omitted if they only focussed on 1) breast cancer screening; 2) breast cancer diagnosis and treatment experience; 3) physical exercises, diet, and yoga; 4) medical treatment experiments; 5) duplicate studies; 6) or were not English or Arabic language.

3.4 Quality assessment of the studies

Thirty-eight articles met the inclusion criteria. Abstracts for each of these articles were considered for relevance to my research aim and objectives (Figure 4 shows a flow diagram of the papers selection process). The core studies that address the review questions above were extracted and presented in a table at the end of this chapter. The main purpose of this table is to summarise the content of each core paper according to its developing themes and to identify strengths, limitations, and compare the similarities and differences between papers.

The identified qualitative studies were appraised using the Cardiff University modified online version of the Critical Appraisal Skills Programme (CASP) (Critical Appraisal Checklists), and for the quantitative studies the researcher used Checklist for Analytical Cross Sectional Studies (The Joanna Briggs Institute (JBI) 2017) (see Appendix B). Critical Appraisal Skills Programme (CASP) (2014) was originally developed at the Public Health Research Unit at the University of Oxford. CASP has designed specific critical appraisal checklists to be suitable for each research designs, such as qualitative studies. Each identified paper was read many times and considered according to the CASP tool questions and their additional details. The CASP tool was chosen to make sense of the scientific evidence, to determine each paper's strengths and limitations, and therefore the importance each should have in this literature review. Demonstration of CASP can be seen in the (Grid Table. 4) at the end of this chapter, in the last column, where the strengths and limitations of each paper are described.

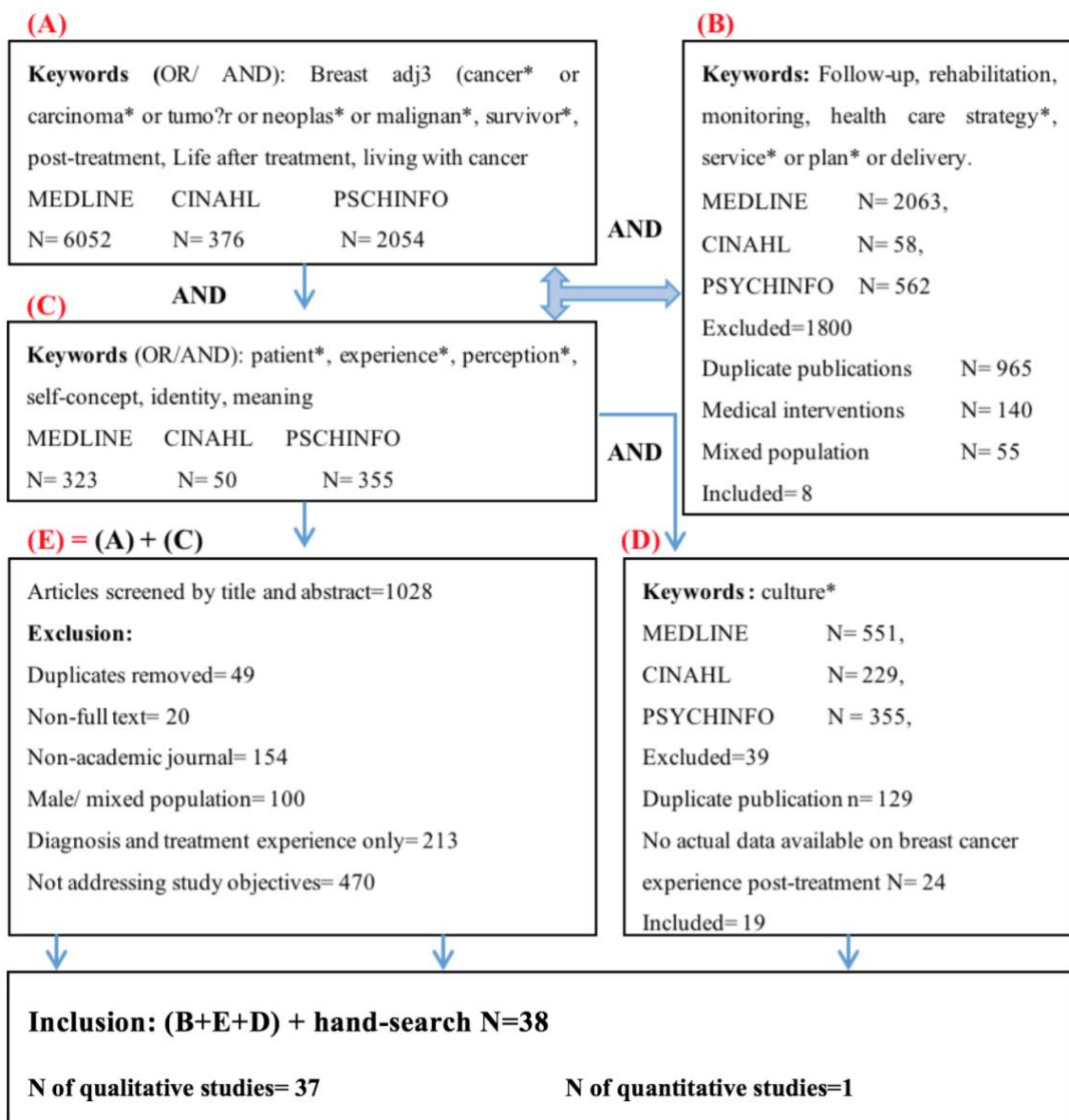


Figure 4: Flow diagram of papers selection process

3.5 Study characteristics

The number of the core studies is thirty-seven qualitative studies and one quantitative study, from across the world, which are all listed in Grid Table. 4 at the end of this chapter. In terms of the location of the core studies, six of the qualitative studies were conducted in Middle-Eastern countries, such as Saudi Arabia, Bahrain, Iran, Jordan, Israel and Lebanon. Three qualitative studies were undertaken in Asian countries, such as Pakistan and Thailand. From Europe, four studies were carried out in the UK, one in Ireland and one in the Netherlands. Finally, seventeen studies were conducted in the

US, two in Canada, one in Brazil and three in Australia. It can be seen that most of the literature relating to breast cancer survivorship experience and survivor identity is found in the US, where the concept of survivorship was discovered.

The focus of the core studies was varied, with twenty-six qualitative studies exploring the lived experience of breast cancer survivorship. Six qualitative studies (Documet et al. 2012; Dyer 2015; Kaiser 2008; Khan et al. 2011; Smith et al. 2015; Williams and Jeanetta 2016) and one quantitative study (Park et al. 2009) purely investigated the perception of survivorship and survivor identity. Additionally, some studies presented a focus on the transition experience from being a patient to being a survivor (Allen et al. 2009; Kantsiper et al. 2009; Mollica and Nemeth 2014). The remainder of the qualitative studies were about the experience of breast cancer following treatment, exploring many physical, psychosocial, financial and spiritual issues. However, most of the core studies did not fully address how culture shapes women's experiences. Therefore, this thesis extends the work carried out by Kaiser (2008) and Banning et al. (2009) who had raised the subject of the impact of culture on women's lived experiences.

Among the twenty-eight studies that focus on the breast cancer survivorship experience, none of them address the healthcare strategies used by the healthcare providers to support women. In other words, none of the selected studies that explored the breast cancer survivorship experience addressed the topic of healthcare support following treatment. Therefore, a healthcare search was conducted separately to gain a more in-depth understanding of the topic and ten qualitative studies were used (Beaver et al. 2010; Brandzel et al. 2017; Brennan et al. 2011; Kwast et al. 2013; Lawler et al. 2011; Meade et al. 2017; Roundtree et al. 2011; Royak-Schaler et al. 2008; Tompkins et al. 2016; Wiljer et al. 2013). In the previous studies, there was an emphasis on cancer care models, survivorship care plans and the importance of self-management.

3.6 Study methodologies

The core studies exploring the lived experience of breast cancer had relied largely on purely phenomenological methodology, but none of them considered using IPA. A few of them used interpretive phenomenological studies (Alqaissi and Dickerson 2010; da Costa Vargens and Berterö 2007; Doumit et al. 2010). Three were grounded theoretical

studies (Mollica and Nemeth 2014; Roundtree et al. 2011; Saati 2013) and there were two ethnographic studies, by Burke et al. (2012) and Dyer (2015). The only narrative study was conducted in Bahrain (Jassim and Whitford 2014). However, the rest of studies did not mention the methodology used.

The theoretical framework was not mentioned in the most of selected studies, except in that by Kaiser (2008), who used two theoretical frameworks: the cultural tool (Swidler 1986) and the craftwork tool (Frank 2003) to conceptualise women's views on survivorship. Saati (2013) used a symbolic interactionism framework to explore the cultural framework of the lived experience of breast cancer diagnosis and treatment among Saudi women. In addition, Liamputtong & Suwankhong (2015) used a feminist approach to give a voice to Thai women living with breast cancer.

The only quantitative study was cross-sectional and aimed to examine to what extent the following cancer identities are adapted by the cancer population: patient, person who has had cancer, victim and survivor. The authors used a questionnaire to assess correlations between background variables such as age, marital status, length of time since diagnosis and treatment ended, identity, coping and cancer related activities (Park et al. 2009). The statistical analysis tests were biserial, using Pearson correlations between variables and a linear regression model.

3.7 Study methods

In terms of the research methods, the extant literature on cancer survivorship showed that some studies, especially those conducted in the Middle Eastern countries, did not fully describe the recruitment process, ethical considerations and interview settings. Others recruited participants from support groups or private clinics (Documet et al. 2012; Joulaee et al. 2012) and this reflected positive adaptation with the survivor identity and was more connected to the healthcare system. In addition, this is not necessarily transferable to other settings and populations. Most of the core studies used purposive sampling; however, others used snowballing sampling because of the potential difficulty in recruiting a hidden population, such as Thai and Puerto Rican women with breast cancer (Dyer 2015; Liamputtong and Suwankhong 2015).

The exclusion criteria for most of the studies were not fully discussed, which might limit the understanding of breast cancer survivorship. Participant demographics varied with the majority of articles. The subjects' ages varied between 26 and 87 years of age, with the mean age falling between 50-60 years in all of the studies. Although breast cancer survivors of different ages might experience common treatment side effects, there are differences in the quality of life between younger and older women (Bantema-Joppe et al. 2015; Champion et al. 2014), including psychological distress, sexual functioning, body image concerns and relationship problems.

The timeframes in some studies varied from immediately after diagnosis to more than five years after diagnosis (da Costa Vargens and Berterö 2007; Davis et al. 2014; Kantsiper et al. 2009). For example, in the study by Documet et al. (2010), the participants' lengths of experience with breast cancer ranged from four months to nine years. This heterogeneous sample might reflect a lack of understanding of breast cancer survivorship, difficulty in addressing the difference between short and long-term issues and the challenges that are associated with my younger age target group. Some studies included breast cancer survivors with different cancer stages (I, II, III) (Goldblat et al. 2013; Al-qaiSSI & Dickerson 2010; Brandzel et al. 2017). Additionally, some of the studies that explored the concepts of survivorship and survivor were not undertaken with breast cancer patients only, as some participants were recruited with a mixed type of cancer (Dyer 2015; Khan et al. 2011; Park et al. 2009). This fails to reflect on the breast cancer population or show the essence of each personal experience.

Due to the sensitivity of breast cancer, most of the core studies used face to face in-depth interviews to collect their data, while some used focus groups (Kantsiper et al. 2009; Roundtree et al. 2011; Royak-Schaler et al. 2008; Brandzel et al. 2017; Ashing-giwa et al. 2004). Two used a mixed approach, e.g., observations, focus groups and interviews (Burke et al. 2012; Banning et al. 2009), although they had not fully explained the focus group's role in terms of the interaction between participants and the other healthcare teams.

The sample size numbers were varied and some were large for qualitative studies (n= 216,112,115,102) (Allen et al. 2009, Documet et al. 2012, Davia et al. 2014, Ashing-

giwa et al. 2004). The interview guidance and analysis framework were not explained fully for most of the studies conducted in the Middle East countries. Most of the studies used thematic analysis, with one using content analysis (Dyer 2015) and two using grounded theory analysis (Wiljer et al. 2013; Roundtree et al. 2011). Interpretive phenomenology was used by Alqaissi and Dickerson (2010) and da Costa Vargens and Berterö (2007). IPA was only employed by Patel-Kerai et al. (2015); however, it did not show the linguistic interpretation, which is an important element in IPA, and the approach used for the methodology was based on epistemology phenomenology, which might not necessarily fit with the nature ontology of IPA.

Several studies were conducted among a breast cancer population who were not from the study's country of origin, for example, participants from Latin-America, the Philippines and Puerto Rico who were living in the US and Indians living in the UK (Ashing-Giwa et al. 2008; Burke et al. 2012; da Costa Vargens and Berterö 2007; Dyer 2015; Liamputtong and Suwankhong 2015; Patel-Kerai et al. 2015). Thus, a number of issues regarding discrimination, health insurance, immigration and language barriers emerged that could not be applied to all cancer populations (Ashing-Giwa et al. 2008; Mollica and Nemeth 2014). Back translation was not discussed for some of the above the foreign studies, including the Middle-Eastern ones, as some meanings might be lost during the translation process.

Each of the core studies demonstrated key issues, as shown below in Table. 3. Strengths and limitations were all discussed throughout the literature, as well as being presented in the grid table at the end of this chapter.

Table 3: Key points of the literature review

Key points:	
Breast cancer survivorship meaning	Definition of the perception
	Identity
Breast cancer survivorship experience	Physical
	Psychological
	Social
	Financial
	Spiritual
Breast cancer and culture	Health promotion behaviour
	Beliefs about the causes of breast cancer
	Reframing breast cancer survivorship
	Being a breast cancer survivor

	Women's role, communication, supportive services
	Follow-up models
Health care provision	Surveillance
	Survivorship care plans
	Self-management

3.8 Perception of breast cancer survivorship

In this section, the perception of breast cancer survivorship as introduced in the previous background chapter is explored in depth in terms of the way that women perceive survivorship. Several definitions were reported by the cancer population in order to define the concept of survivorship. These include factual definitions which suggest that one is no longer dealing with the cancer, the passage of time since the treatment was over – that cancer has been beaten, as well as the functionally related to the quality of life and performing their activities in a habitual manner. All these results were obtained from a phenomenological qualitative study, aimed to explore the salience of cancer in people's self-concept (Smith et al. 2015). However, the latter study did not significantly represent the perspectives of women with breast cancer only, as 53 individuals with different types of cancer, including breast cancer, were recruited. Another qualitative study undertaken by Documet et al. (2012) sought to explore how and when women diagnosed with breast cancer perceive themselves as survivors. They conducted telephone interviews with 112 women, for whom the lapse of time since the breast cancer diagnosis ranged between 1 and 29 years. The most commonly reported survivorship meaning entailed returning to a normal life, the completion of treatment, and receiving confirmation from someone else. The defining moment was associated with what they were told by healthcare providers or family members, the lapse of five years following the post-diagnosis milestone, joining a support group, and removing the cancer from their bodies; however, no one employed the term 'since diagnosis'. The latter study has several limitations. Firstly, the participants were recruited from the Susan G. Koman for the Cure Organisation, which may reflect a positive influence on participants' experiences. Secondly, variations in the time since the diagnosis may affect the recall capacity of participants. Overall, the authors highlight the importance of cancer survivorship, which could facilitate the psychological adjustment following treatment.

3.9 Survivor identity

While the notion of survivorship represents recovery and moving beyond cancer, as well as changing the perception of cancer as a killer as per the definition of the NCCS, women with breast cancer do not always share this positive view. This is proved by a qualitative study undertaken by Kaiser (2008) examined whether women who had been treated for breast cancer embraced their survivorship. Data were collected from interviews conducted with 39 women who completed treatment 3 to 18 months beforehand. The results showed that some women did not perceive survivorship as ‘winning a war’, since the war against breast cancer was still prevalent. Even after completing treatment, the risk of cancer recurrence was possible, and women felt “*not close enough to death to be a ‘survivor’*” (Kaiser 2008). Similar results were obtained from a qualitative study conducted in the UK by Khan et al. (2011), which sought to explore the interpretations of the notion of ‘cancer survivor’ among those who had lived past a cancer diagnosis. In-depth interviews were conducted with a mixed population of cancer patients (n=40), including those diagnosed with breast cancer. The results showed that the reasons for rejection of the term survivor were because it implied the meaning of a ‘fought battle’, whereas survival was only the result of receiving a curative treatment and of the body responding well thereto and it indicated an advocacy role that they did not want to assume. Other reasons for rejecting the term ‘survivor’ were due to the fact that their experience was described as highly personal and only family and close friends were aware of what had occurred (Smith et al. 2015). Furthermore, from the latter study, individuals with cancer took a complicated position towards survivor identity by claiming that they would accept the survivor identity for themselves personally but not wear such a label in public, based on what this was seen to entail in relation to the expectations towards a survivorship collective. Using a metaphor like ‘winning a battle against cancer’ was not appropriate, especially for those who did not recover due to their advanced cancer stages, and the term erroneously indicated that those people were weak and had lost the battle (Khan et al. 2011). However, the above studies discussed the cancer population’s views on the concept of survivorship, survivors and the meaning-making process, but failed to describe the characteristics or factors that led women to either accept or reject the survivor identity, for example, breast cancer stage, personality, education, age, health care and social support.

Despite the apparent positive influence derived from using the terms ‘survivor’ and ‘survivorship’, there is a lack of functional definitions that adequately describe the cancer experience (Khan et al. 2011). In some bodies of literature, controversy was noted in the contexts in which the terms ‘survivor’ and ‘patient’ were used. For example, the word ‘patient’ is used synonymously with the word ‘survivor’, suggesting that a person who is in the post-treatment stages and may even be cancer-free remains a patient (Twombly 2004). In the article titled ‘Categorization of Cancer Survivors: Why We Need It’, the authors used ‘patients/survivors’ rather than using each term individually in the text, explaining that cancer is characterised by fluidity rather than being perceived as flat (Surbone and Tralongo 2016). The label ‘patient’ is commonly used during active treatment, but using it at a later stage may indicate passivity and the adoption of the ‘sick role’ (Harwood and Sparks 2003). Not choosing the ‘patient’ identity was evident in the quantitative cross-sectional study conducted by Park et al. (2009) with cancer patients (n=167), including breast cancer who completed treatment. The results showed that only 58% of the cancer population agreed to be referred to as ‘patients’. 81% preferred to be referred to as ‘someone who has had cancer’ which indicated a minimal change in terms of self-identity and suggested that cancer was a significant yet temporary issue, which had occurred in the past and that people seek to forget. On the other hand, Park’s study has many limitations as the study used participants with mixed types of cancer, including breast cancer, and the response rate was low in the first phase of the study, with 250 out of 600 questionnaires, which could be due to sending questionnaires by mail with only one reminder.

Women use ‘craftwork’ which means that women work and create their own linguistic and conceptual interpretations that best reflect their experiences with breast cancer (Frank 2003). Dyer (2015) explored the complexity of the linguistic differences related to the meaning of ‘survivorship’ when the term was translated from English into Spanish as part of her qualitative ethnographical study undertaken with 23 young participants suffering from various types of cancer, including breast cancer. The participants claimed that the alternative linguistic meanings of survivorship in English were limited and only reflected the status of survival, thus overshadowing the implication of ‘thriving’. Others noted that the meaning of survivorship in English

entailed limitations and was not the same as living, because the latter was interpreted as living a life full of joy and benefitting from being alive. Thus, they preferred the term ‘the one who lives’, because it included the meaning of being alive. Brazilian women perceived themselves as ‘the same women who always were in the past’ who could live normally, but who suffered the loss of a breast (da Costa Vargens and Berterö 2007). Across culturally diverse cancer survivors (11 Greek, 14 Chinese and 14 Mandarin) a grounded theoretical qualitative study aimed to understand the concept of survivor. However, back translation was not discussed in the latter studies, as some words might lose their meanings through the translation process. Most women did not describe themselves as survivors, because it reminded them of the disease. Thus, they used alternative terms such as ‘saved’, ‘escaped from death’, ‘normal’, ‘not dead’, and ‘alive’ (O’Callaghan et al. 2016). However, it appears that further research related to the linguistic interpretations of ‘survivor’ is needed because some studies, such as the study conducted by Park et al. (2009), sought to provide a list of terms, and thus participants responded to the term that best suited them and failed to show their individual preference in creating their own terms by their own languages.

In conclusion, the perception of breast cancer survivorship and the lack of universality associated with the language used to describe the survivor identity is a debated topic in the current body of reviewed literature, since women perceive their breast cancer experience from diagnosis to follow-up consultations in a different manner. On the basis of the aforementioned literature, it appears that most of the studies related to adopting the survivor identity were conducted in the US, where the concept of survivorship was developed. Some women were recruited from cancer societies, where they were widely acknowledged as being breast cancer survivors by the public thanks to their active engagement in support activities. Therefore, women were more likely to refer to themselves as survivors because they embraced the power of the term and its positive metaphorical meaning. Although different socio-demographical and treatment factors enhanced the development of the survivor identity, the cultural factors were not fully investigated. Different studies criticise the use of the term ‘survivor’ because of its failure to capture the uncertainty associated with an actual cancer experience. This variation in meaning could constitute a challenge to healthcare providers and policy-makers in terms of developing an operational definition that reflects patients’ needs and

beliefs. It can be suggested that it is important to have a better understanding of the terms ‘survivorship’ and ‘survivor’ because words are important in our lives, but yet they are often insufficient to capture the reality. Women with breast cancer would like to be identified with a term that they feel best describes their experience, regardless of whether this term is ‘survivor’ or ‘fighter’ or whether there is no label at all associated thereto. On the basis thereof, the research question emerged, seeking to understand the perception of breast cancer survivorship and to what extent culture exerts an impact on that meaning.

3.10 Women’s experiences following curative breast cancer treatment

Breast cancer is often described as a transitional process, in which the woman transitioned from a state of well-being to being a person diagnosed with breast cancer who subsequently received treatment in different phases, and then concluded it in order to continue living beyond cancer (Lally and Underhill 2012). The transitional survivorship ‘re-entry’ phase could be a challenging event for breast cancer survivors, because they no longer required treatment, but at the same time they were no longer exposed to the safety net of healthcare (Allen et al. 2009). McCann et al. (2010) claimed that concluding the curative treatment does not mean the end of suffering, but instead signifies another challenging beginning. On the other hand, Tomkins et al. (2006) found in their phenomenological study that Black African women expressed feelings of relief after finishing from frequent treatment appointments that often overlapped with their social activities. However, this assumption was based on a qualitative study, so it might not be transferred to all breast cancer populations.

The literature shows that women experienced long-term consequences as a result of receiving different types of cancer treatment (chemotherapy, surgery, radiation and hormones). The long-term effects include alterations in the physical functioning, mental health, social life, and relationships (Ganz et al. 2004; Hall et al. 2014; Yanez et al. 2011). The most frequent and common symptoms that were found to be particularly relevant to breast cancer survivors are discussed here. These are evident immediately upon concluding the treatment and may or may not be resolved over time. Therefore, one of the objectives of cancer care is to improve the quality of life (Perry et al. 2007).

3.9.1 Physical experience

Physical functioning is a very global concept that simply refers to the freedom with which women are able to be independently mobile and active, which is integral to a good physical quality of life and ability to actively meet expectations across various life domains (Ganz et al. 2004). Following treatment, there are several physical symptoms that exert an impact on women's life and their ability to return to their previous levels of activity, including breast symptoms, pain, physical functioning, fatigue, menopausal symptoms, muscular atrophy, osteoporosis, upper limb dysfunction, and lymphoedema (Ahmed et al. 2008; Bulley et al. 2014; Meade et al. 2017). These symptoms may be interrelated, and women may experience more than one at the same time (Ganz et al. 1998).

Fatigue has been noted as the most commonly reported physical symptom upon concluding the curative treatment in the literature (Bower et al. 2005; Romito et al. 2012). Cancer-related fatigue has been defined as a persistent, subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning (American Cancer Society 2014). It has been correlated with other symptoms, such as cardiovascular problems and the presence of depressive symptoms and sleep problems (Bower et al. 2006). In order to reduce the levels of fatigue, early physical exercise is encouraged (McNeely et al. 2006). However, this can be difficult to apply in Saudi Arabia, where the lifestyle is characterised by low levels of activity and a diet high in fat (Al-Othaimen et al. 2004).

Many young Pakistani women reported their inability to work and exercise their roles as mothers at home because of the physical weakness, which was perceived as a reminder of the disease (Banning et al. 2009). Levkovich et al. (2017) reported similar results, differentiating between women's views about the physical experience post-breast cancer treatment, based on age, by explaining that younger participants viewed themselves as '*being imprisoned in the body of an 80-year-old*' and experienced difficulty in taking caring of their children and families, while the older women mentioned perceiving themselves as a burden on their families. Both the latter studies were qualitative phenomenological studies and their results were drawn from participants who varied in age, ranging between 20 and 60 and 34 to 67 years old, respectively (Banning et al. 2009; Levkovich et al. 2017). However, Banning's study did not show if age had an

impact on the fatigue level and, demographically, most of their participants were mothers, which might have an impact on the transferability of the results.

Weight gain is another reported symptom associated with hormonal therapy, e.g., Tamoxifen and steroids as part of chemotherapy regimens (American Cancer Society). Befort et al. (2011) sought to describe weight status and the methods used for weight control in rural breast cancer survivors (n=918). Their results showed that 68% of the survivors were overweight or obese; 37% were obese, and 25% reported a weight gain exceeding 5 kg since receiving the diagnosis. Their results suggest that weight control programmes should be part of the survivorship plan. On the other hand, the study did not show the levels of physical activity, metabolism and hormonal changes. In addition, the study was conducted among breast cancer survivors from different races who lived in rural areas, where weight control resources might be limited.

Women treated for breast cancer with hormone therapy and/or chemotherapy reported problems with sexual interest and sexual functions (Carpenter et al. 2002; Ganz et al. 2004), because of menopausal related symptoms, such as hot flushes and vaginal dryness. Although menopausal symptoms are part of the ageing process, young women experienced difficulties in dealing with these symptoms (Fang et al. 2015). Saudi women with breast cancer reported lower levels of functional activity, especially in relation to sexual satisfaction (Al-Mutairi et al. 2016). Both Euro-Americans and Latin-Americans reported having a 'damaged womanhood', resulting in a decreased sexual desire and activity following breast cancer treatment (Ashing-Giwa et al. 2004). Although the latter study showed an in-depth understanding of breast cancer experiences among different types of ethnic groups, the sample size (n=102) is considered to be large for a qualitative study. In addition, it included participants with different breast cancer stages.

In terms of fertility concerns, some women felt that they received the relevant fertility-related information too late, and did not have time to make informed decisions in terms of treatment and fertility protection, such as banking embryos, alternative chemotherapy regimens that would be less likely to negatively impact on their fertility, and ovarian suppression (Gorman et al. 2011). Similar results were reported in Ireland, where

women reported that healthcare providers were not fully open in discussing all of the treatment side effects and in providing them with a survivorship care plan (Meade et al. 2017). Interestingly, Meade's two-phase study used focus group interviews and nominal group technique that let women list and prioritise their top needs related to survivorship care.

3.9.2 Psychological experience

As indicated in the previous section, various areas of physical health are affected by breast cancer treatment in the course of time; these are often associated with psychological distress (Banning & Tanzeen 2014; Jssim & Whitford 2014; Davis et al. 2014). The prevalence of physical symptoms was surprising to some women who thought that when the treatment was over the side effects would disappear as well (Mollica and Nemeth 2014). This might have had an impact on their relationships with others and subsequently triggered feelings of insecurity (da Costa Vargens and Berterö 2007). Women expressed feelings of uncertainty and anxiety, but fear of recurrence was the most frequently reported form of distress in breast cancer survivors.

Women feared the possibility of breast cancer recurrence, either in the breast in which the cancer was originally diagnosed, or in the opposing breast (Thewes et al. 2013). Several quantitative studies found that fear of cancer recurrence is particularly common among younger breast cancer survivors (Starreveld et al. 2017; Hall et al. 2014; Bantema-Joppe et al. 2015; Champion et al. 2014). Different methodological measurements were used to assess the predictors of fear of recurrence among breast cancer survivors, such as age, demographical data, type of surgery and treatment, time since surgery, optimism (Starreveld et al. 2017), fatigue and insomnia (Hall et al. 2014). Starreveld et al. (2017) used a longitudinal approach to test the fear of cancer recurrence among (n=267) breast cancer patients and followed them for 18 months after surgery. The results showed that fear of cancer recurrence was higher among less optimistic survivors and younger women who were at 1.5 years after breast surgery than among older survivors, who showed stable levels during the first 6 months. Another quantitative study found that higher levels of fear of recurrence were noted among younger women who were 2 to 4 years post treatment and was associated with self-reported psycho-physiological symptoms, such as fatigue and insomnia (Hall et al.

2014). Both the latter studies aimed to assess the level of fear of cancer recurrence by using different measurements; however, Starreveld's study was significant because it used the longitudinal approach in different time frames after breast surgery, unlike Hull's study, which used a cross-sectional design.

Several explanations for the increasing level of cancer recurrence among young women, it may be attributed to the multiple and varying demands in younger women's lives, such as employment, family, and raising children. Younger women report greater difficulty in coping with the original diagnosis and thus logically may have a greater fear of facing a second diagnosis (Saati 2013). Compared to older women with breast cancer, younger women were more vulnerable to the physical and psychological consequences of breast cancer and its treatment (Bantema-Joppe et al. 2015; Champion et al. 2014). In Saudi Arabia, breast cancer was generally more aggressive among younger women and they may statistically be more likely to actually experience a recurrence (Elkum et al. 2007). Therefore, Astrow (2012) suggests that oncologists might help their patients by enabling them to face their future with hope tempered by awareness and realistic expectations. There is strong evidence to suggest that information provision can facilitate the adjustment to cancer by increasing the patients' perceptions of control, reducing the feelings of threat and anxiety, and improving the perceived quality of life (Davies et al. 2008).

Because women were often seen less regularly by healthcare providers by the end of the treatment compared to the intensive care during the diagnosis and treatment periods, they developed the need to seek health information and self-management of the condition (Hewitt et al. 2006). Some women complained about a lack of attention and being left with unanswered questions, because they felt confused about whether their newly developed health problems were related to cancer or not (Roundtree et al. 2011). Furthermore, less frequent follow-up visits post-treatment, less communication and less information related to managing treatment side effects had generated feelings of uncertainty and fear of cancer recurrence (Meade et al. 2017).

A phenomenological study was conducted among 13 Iranian women to explore the meaning of living with breast cancer (Joulaei et al. 2012). Women reported a feeling of

loss related not only to health and femininity, but also peace of mind. They lived with confused emotions about their new bodies, people's compassionate attitudes towards them, fear of recurrence, and lack of confidence in their ability to prevent the recurrence of cancer. On the other hand, some Australian women used their fear of cancer recurrence to make changes in their lives and to be close to their families (Elmir et al. 2010). The data from both the latter studies were drawn from participants who were not fully representative, as women were only recruited from a private cancer clinic in Tehran (Joulaei et al. 2012), while the other study was conducted among 4 participants with middle to high socioeconomic status in Australia (Elmir et al. 2010).

3.9.3 Social experience

Life beyond breast cancer often involves reflection on the social experience. As the transition is made from being a patient to becoming a survivor, new identities, roles, and relationships are developed. All these could be viewed as challenges for women following curative treatment. Body image is viewed as an important element in the context of breast cancer experience (Fang et al. 2015). It is suggested that physical self-perception is formed through a multifaceted psychological discourse and complex social interactions (Zebrack 2000). As a consequence of the various physical changes, women felt ashamed, undignified, and embarrassed by the changes in their bodies, and had difficulty looking at themselves (Holmberg et al. 2001).

Cancer survivorship is linked with cure and normality; therefore, endless gratitude is expected by other individuals (Little et al. 2002). Breast cancer survivors faced challenges in carrying out their roles as mothers, wives, friends, and employees; and obtained benefits from overcoming the disease (Zebrack 2000). Women with breast cancer experienced difficulties returning to a normal life once others had labelled them with a death sentence (da Costa Vargens and Berterö 2007). Women attempted to conceal the physical effects, because appearing sick would alter the intimate relationship (Kendrick 2008). In relation to the changes in their role as wives, Bahraini women claimed that despite their lack of sexual desire, most felt obligated to meet their husbands' needs (Jassim and Whitford 2014). On the other hand, this issue cannot be generalised, as it represents certain cultural views on women's roles and gender issues.

Women with breast cancer struggle with their new role change, Fisher and O'Connor (2012) aimed to explore the impact of breast cancer on the identities of young women as mothers. The results showed that some young breast cancer patients claimed they were no longer perceived as mothers, but rather they were now objectified and labelled by others as 'breast cancer patients'. Nevertheless, these women reported a lack of information and support in terms of how to tell their children about their illness, treatment, and hospital stay, and the consequences for the family. Filipino women with breast cancer living in the US had difficulty in adapting to their role's change from care giver to care receiver. They perceived the role of caregiver as being always available to help and even sacrifice their own health to support others. This cultural perception of caregiving exerted pressure and guilt on breast cancer survivors, especially on those working as caregivers, because their illness affected their ability to support their family (Burke et al. 2012). However, this study did not show the interactional role of the focus groups. In addition, the sample represents immigrant women who suffer from socioeconomic issues that might affect women's roles in keeping their family systems functioning.

Breast cancer survivors struggle with a reversal of their normal roles and the need to manage the expectations of those around them. Survivors were aware of the importance of giving back to others by continuing their hospitality towards family and friends, and, for some, to carry out God's will in their lives. The consequences of breast cancer treatment, such as fatigue and pain, are debilitating for African-American breast cancer survivors, yet they chose to consistently perform their tasks of caring for others (Gallia and Pines 2009). Brazilian women were viewed by the people around them as women with certain needs and limitations, and in order to prove the opposite, they chose to work hard and carry heavy things (da Costa Vargens and Berterö 2007).

3.9.4 Financial experience

Breast cancer patients with limited incomes shared their concerns regarding the cost of treatment, which could lead to disparities in the quality of life (Alqaissi and Dickerson 2010). In Pakistan, some women felt guilty because they had to spend their savings on treatment and its expenses, rather than on meeting the needs of their family (Banning et al. 2009). While other women reported that the fear of financial distress associated with a potential job loss prevented them from undergoing treatment (Ashing-Giwa et al.

2008). In order to address these financial burdens, Pisu et al. (2014) asked 23 (14 African-American and 9 white) breast cancer survivors '*what could help women deal with the financial burden that cancer brings to them and their families?*'. The majority called for affordable medical insurance, information on treatment costs, and public agencies that help them with issues, such as transportation. Financial challenges are complex issues associated with a country's economic status, its healthcare system, and health insurance, but this was only reported for specific ethnic populations and cannot be generalised to all breast cancer patients.

60% of women diagnosed with breast cancer were of working age (Cancer Research UK, 2015), returning to work after treatment constituted a challenging issue (Cancer Research UK 2015). In France, 82.1% (n=379) of women who had worked before their diagnosis returned to work after a median sick leave of 10.8 months (Fantoni et al. 2010). Ashing-Giwa et al. (2008) found that several Hispanic breast cancer survivors changed jobs in order to avoid discussing their illness with their employers. They added that the fear of financial distress associated with potential job loss prevented them from attending treatment. Kennedy et al. (2007) claimed that breast cancer survivors were concerned about returning to work due to worries about their physical fitness and work capacity after treatment. Brazilian women claimed that people perceived them as women with certain needs and limited work capacity (da Costa Vargens and Berterö 2007). In the UK, women felt anxious when they returned to work and the situation was described as being similar to 'childhood experiences at school' (Banning and Griffiths 2014). Furthermore, they expressed concerns about their physical appearance at work, in particular in cases of those who have undergone mastectomy. Another qualitative study sought to understand breast cancer survivors' views on the supporting practices of their supervisors at work (Caron et al. 2017). To do that, they carried out semi-structured interviews with 10 Canadian women who returned to work 18 months after their treatment's end. The interviews found that supervisors could support survivors if they maintained communication with them during the return to work process and offered them flexible schedules that met their needs. The above studies showed that fear of work related failure is a common issue that faces women who return to work after breast cancer, but none of them showed employers' views of it. Although each country has certain legislations and resources to facilitate cancer survivors returning to work, it

is important to assess the level of information that employers hold about breast cancer, its treatment side effects and survivors' abilities to work post-treatment.

3.9.5 Spiritual experience

In order to adjust to all of the aforementioned physical, psychological, social, and financial issues, spirituality and religious beliefs were used by some women in order to cope with breast cancer. Women of different ethnicities, such as Mexican, Asian, and Black-American, who suffered from breast cancer, reported feelings of comfort, well-being, and protection through spiritual practices, such as praying and attending church (Schreiber and Brockopp 2012; Thuné-Boyle et al. 2013; Visser et al. 2010). Muslim women's experience with breast cancer demonstrated a high degree of coping behaviour, accepting God's will, and perceiving their disease as a challenge to be confronted, which indicated strength and growth (Joulaee et al. 2012; Obeidat et al. 2012; Saati 2013). Satti (2013) aimed to explore the experience of Saudi women during breast cancer treatment. The findings revealed that women accept their disease and cope with it through their faith, religious beliefs, and help from their families. Moreover, Bahraini women claimed that their breast cancer experience brought them closer to God by encouraging them to be thankful for God's blessings (Jassim and Whitford 2014). On the other hand, negative religious coping behaviour such as the reappraisals of God's power, expressing anger at God, and feeling abandoned or punished by God were experienced by people with cancer who reported problems in terms of psychological adjustment (Hebert et al. 2009).

Many breast cancer patients report benefits after their experience. Sherman et al. (2012) found that 15 women, ranging from 18 to 69 years of age, who had completed breast cancer treatment over a period of 1 to 20 years, perceived survivorship as a 'journey', during which the women's lives progressed, while being physically, emotionally, socially, and spiritually affected. They explained that being diagnosed with breast cancer, following its recognition and acceptance as a part of life, was a stimulus for change, thereby leading to the necessity of learning to live with breast cancer and, finally, moving ahead with a new life and developing a new way of contributing to the world on one's own terms. In addition, Albaugh (2003) found that some women viewed breast cancer as a wake-up call to discover what is truly important in their lives. Others realised that life was too short, and began to view the world differently by appreciating

their health and family, and by being grateful to be alive (da Costa Vargens and Berterö 2007).

3.11 Cultural perspectives on living with and beyond breast cancer

Culture is defined as socially transmitted behaviours, values, beliefs, languages, religions, and customs that are shared by particular people (Moore and Spiegel 2004). It is recognised as an essential element of the subjective experience of illness by describing the ways of life for a group of people (Kagawa-Singer and Blackhall 2001). Cancer survivor experience may be defined as a complex interaction between the self, the body, and society (Astrow 2012). The meaning of illness, the usefulness of treatment, and the health behaviour towards disease prevention and control were all influenced to a certain extent by the cultural model of the disease (Coreil et al. 2004). The cultural variation in breast cancer experience between the Western and Eastern cultures appears to encourage women to respond differently, especially in relation to health promotion behaviours, treatment options, causes of breast cancer and its meaning, woman's role, being a breast cancer survivor, communication, and support services.

3.11.1 Health promotion behaviours

In Western countries, there is a high level of breast cancer awareness; the uptake in preventive and screening measures results in an increased number of survivors (Torre et al. 2016). In the US, women claim that their prior knowledge of breast cancer, its risks, and the benefit of screening has helped them to identify the symptoms and detection of breast cancer at an early stage (Williams and Jeanetta 2016). On the other hand, Middle Eastern women suffer from a lack of knowledge about breast cancer and the relevant screening measures. 89% out of a total of 10,735 Saudi women over the age of 50 reported not having a clinical breast examination, and 92% never requested a mammogram, which is a widely available and free-of-charge procedure (El Bcheraoui et al. 2015a).

In terms of knowing the biomedical causes of breast cancer, it seems that Western women are interested in having mastectomies as a preventive measure, especially in the case of those who are at high risk of developing breast cancer, such as the American actress Angelina Jolie, who had a double mastectomy (Parry 2015). A qualitative study

conducted in the US showed that some women decided to have more surgeries because of their fear of cancer recurrence (Williams and Jeanetta 2016). This is in contrast with Korean-American breast cancer survivors, who showed a degree of hesitation towards undergoing a mastectomy surgery because of their image as mothers and wives (Lim et al. 2012). It seems that for some women the attractive feminine image in their husband's eyes is important for the stability of their relationship, as a woman may express concerns about whether her partner will still find her attractive and about whether she would still be able to enjoy sexual stimulation in the affected breast. On the other hand, a higher level of education appeared to have an impact on women's decisions about having breast surgery (Fallbjork et al. 2010) and this was not mentioned in the latter two studies.

3.11.2 Beliefs about the causes of breast cancer

In Western culture, it seems that the cultural meaning of breast cancer emphasises individual responsibility for the disease, both in terms of the detection of the disease and identifying its risk factors. Women's experiences with breast cancer are primarily shaped by notions of individual factors, such as age, genetics, obesity, smoking, alcohol, and environmental risk factors, such as radiation (Williams and Jeanetta 2016). In the Eastern cultures, and in particular in Muslim culture, illness causations are primarily classified into four categories: supernatural causes (God, devil), social causes (evil eye, stress), natural causes (cold, dirty environment), and hereditary causes (Kulwicki 1991).

There are several myths and beliefs associated with the causes of breast cancer. For example, a qualitative study was conducted among 12 Bahraini women in order to explore their experience with breast cancer. Based on the semi-structured interview results, women blamed their stressful lives as the cause of breast cancer, and some wondered what wrong they had committed that would lead to such punishment, while others commented on experiencing envy from their peers (the evil eye) as the likely cause of the disease (Jassim and Whitford 2014). This belief system has been reported in Saudi Arabia, where 27.9% (n= 376) of female school teachers believed that the evil eye may cause breast cancer, when they were asked to fill in a survey about the risk factors of breast cancer (Dandash and Al-Mohaimed 2007). In the case of Muslim countries, such as Saudi Arabia, Bahrain, and many others, the belief of the evil eye, or

‘*Ayn al-hasad*’ in Arabic, is commonly accepted. The phenomenon of the evil eye refers to a gaze associated with envy, jealousy, and extreme admiration from one person to another that may cause suffering as well as physical or mental problems (Khalifa et al. 2011).

In Eastern culture, it seems that women’s role in the process of overcoming breast cancer extended from the responsibility for the detection of breast cancer to the responsibility for the conditions under which breast cancer develops. In Thailand, a qualitative study used a feminist approach in order to explore the experiences with breast cancer of 20 Thai women (Liamputtong and Suwankhong 2015). Thai women perceived their illness as ‘karma’ based on the bad deeds they had committed in the past that had now led to negative consequences. Interestingly, some of the beliefs associated with karma were about abortions that some women had undergone in the past: they believed that abortion was considered to be a bad deed in Thai culture and that explained the subsequent occurrence of breast cancer. Furthermore, in the latter study, women were asked to express their feelings and views about breast cancer by drawing, alongside interviews. Although women might not have the drawing skills that reflect their experiences, Liamputtong and Suwankhong’s study is significant because they used art to help those who live hidden and could not express their experiences in words.

3.11.3 Reframing the perception of cancer

Hope is a central element adapted by occidental cancer organisations who are trying to send a reassuring clear message informing the public that breast cancer is a long-term chronic disease that could be managed like any other chronic conditions by means of medical, psychosocial, and educational support (American Cancer Society). According to Plotkin (1996), the emphasis on early detection, particularly on mammograms, and the media’s tendency to trumpet each new research finding as a ‘breakthrough’, has resulted in women being both too fearful of the disease and too hopeful about the scientific ability and support system to treat breast cancer. In the UK, ‘I wish I had breast cancer’ was the title used by the Charity of Pancreatic Cancer Action campaign in order to highlight the poor survival rates of pancreatic cancer compared to other types of cancers, such as breast cancer (Pancreatic Cancer Action 2014). The public has criticised the campaign’s message, calling it ‘insensitive’, especially towards those who suffered from breast cancer. However, the charity’s founder explained that many

pancreatic patients preferred to have another type of cancer with a better prognosis, such as breast cancer or prostate cancer. Despite the competitive nature of the latter campaign regarding the most preferable type of cancer, it seems that breast cancer is less frightening. A qualitative study was conducted among 67 British people in order to ask them about their perception of cancer (Robb et al. 2014). The results showed that the first response identified fear and death, but in the following statement some participants showed a hopeful view, especially with the increased survival rates as a result of advanced treatment options. Nevertheless, the latter study did not show the type of cancer feared by the British public. In general, fear still exists in association with cancer, but people are trying to maintain positive thoughts about it.

The image of breast cancer in the Eastern cultures is associated with death, pain, and helplessness (Daher 2012). This was true among 21 Pakistani women who participated in a qualitative study, who claimed that they were shocked upon receiving the breast cancer diagnosis, and believed that the disease was caused by God and it could mean the end of their lives (Banning and Tanzeen 2014). Gujarati Indian women found it difficult to make sense of their experiences, because they lacked knowledge about breast cancer and did not expect it to occur. Furthermore, this unexpected diagnosis encouraged them to search for explanations, such as God's will (Patel-Kerai et al. 2015). For Pakistani women, not accepting their breast cancer diagnosis led to many women refusing to undergo treatment for a period of time, which subsequently resulted in a deterioration of their condition in the later stages (Banning et al. 2009). However, the latter study fails to describe which stage of breast cancer the participants were diagnosed with, and thus it is not possible to fully interpret their experience.

In Saudi Arabia, women hesitated to get screened on a regular basis because they feared the treatment more than the disease itself (Ravichandran et al. 2011). 410 cancer patients (90.5%) in Saudi Arabia used some type of Complementary and Alternative Medicine (CAM) remedies. Non-dietary supplement (DS) remedies were used by 399 patients (88%) and were mainly of a religious nature, including reciting the Quran (74.8%), prayer (16%), supplication (13%), and others (3.7%). However, 386 patients (85.2%) used DS remedies, including: *Zamzam* holy water (59.8%), honey (54.3%), black seeds (35.1%), water with the *Quran* (the holy book) being recited over it

(29.8%), and other remedies. The majority of patients (90%) used CAM as a cancer treatment method and the rest used it for various reasons, such as symptom control or supportive treatment. Only 18% of the patients discussed the use of CAM with their physicians, compared to 68% who chose to discuss it with religious clergy people (*Sheikhs*) (Jazieh et al. 2012). On the other hand, healthcare providers showed their concerns about the use of herbal treatments in Middle Eastern countries that might entail several potentially negative effects, including toxicity and negative interactions with anticancer medications (Ben-Arye et al. 2016).

3.11.4 Being a breast cancer survivor

According to Swidler (2001), culture provides clear guidelines for what it means to be a survivor, as well as opportunities to practice being a survivor. This is evident in Western culture where the cultural shift in breast cancer survivor stories represents some degree of acceptance in adopting the ‘survivor’ identity, disseminating hope to others, and taking an activist approach to cancer (Documet et al. 2012). However, the dominant Western societal view, that one should speak freely about being a breast cancer survivor, may not resonate in some populations in South America. An interpretive phenomenological qualitative study (da Costa Vargens and Berterö 2007) was conducted among 11 Brazilian women who underwent breast cancer treatment. They claimed that previous family experience of cancer had a negative impact on their experience, stating that they were ‘living side by side with the phantom of death’. Because of their feelings of loss and necessity to construct a new body image, they established a new way of communicating with the world. This was determined by hiding their illness, firstly in order to protect themselves from the glances of others, and secondly in order to protect their loved ones from pain (da Costa Vargens and Berterö 2007). Latin-American breast cancer patients felt uncomfortable discussing their symptoms and concerns with healthcare providers due to feelings of shame (Lopez-Class et al. 2012). Martinez-Ramos et al. (2013) further explained that Latin-American breast cancers survivors feared they would be stigmatised and treated differently if they talked about their breast cancer experience. It was found that some cancer survivors claimed that their survivorship was a result of luck more than of any other elements within one’s control (Smith et al. 2015).

In terms of advocacy and foundation creation, not all breast cancer survivors were fervent about creating foundations in their names, as they preferred acting ‘quietly’ rather than attracting public attention (Williams and Jeanetta 2016). Similarly, many women in Eastern cultures felt that they were not represented by the Western public portrayal of survivorship as publicised through media and the stories of survivors. This was simply because the individual’s sense of the self was based on the perceptions of society, whereby cancer is an issue ‘shrouded in social silence’ (Little et al. 2002). In order to avoid stigmatisation, the frequent reactions to breast cancer involved remaining silent about the disease and living in isolation (Daher 2012). In Lebanon, women did not express their feelings to others because of fears of being pitied and causing their loved ones to worry, and also because of feelings of guilt that their possible genetic susceptibility might negatively affect their daughters’ marital prospects (Doumit et al. 2010a). In Pakistan, a qualitative study conducted among 30 women with breast cancer revealed that because of the local perception of breast cancer as a deadly disease, Pakistani women sought to hide their disease, even from their immediate family, considering that the breast cancer stigma reduced the chances of unmarried women to get married, as it was believed that breast cancer could be a contagious disease (Banning et al. 2009).

In a male-dominated society, women with breast cancer were often concerned that their relationship with their husbands would be affected due to their disease, especially in the case of Muslim countries where women largely depend on their husbands (Doumit et al. 2010b). Women not only showed their fear of cancer, but also their fear of being separated from their loved ones (Doumit et al. 2010a). In Jordan, women diagnosed with breast cancer depend on their husbands financially and any change in their relationship could constitute a risk to the woman’s security (Alqaissi and Dickerson 2010). Women viewed themselves differently after being diagnosed with breast cancer; they felt inadequate in their role as a woman or partner and less comfortable with their bodies (Jassim and Whitford 2014). Malaysian women were fearful of being rejected by their partners and losing their husbands to other women, especially because by Muslim law, Malaysian men can legally have four wives (Gopal et al. 2005). Similarly, a phenomenological study seeking to explore the experience of living with breast cancer among Iranian women found that the physical changes experienced by women could

negatively affect the marriage stability between the woman and her spouse, leading to divorce (Joulaee et al. 2012).

Beyond the impact on the personal relationship with a partner or husband, some Haitian immigrant women claimed that their friends did not want to get physically close to them for fear of catching the disease or because of the belief that cancer survivors were poisonous as a result of receiving chemotherapy (Kobetz et al. 2011). African-American and Latina breast cancer survivors reported that they feared that other female relatives might have a chance of being diagnosed with the disease because of genetic susceptibility (Ashing-Giwa et al. 2004). Some Brazilian women reported discrimination due to their breast cancer diagnosis, because there was a fear that they could have a negative impact on those who live or work nearby, as if the illness was contagious (da Costa Vargens and Berterö 2007). This negative view led women to be less social and uncomfortable being surrounded by people who reminded them of their disease (Banning et al. 2009). Arab women living in Israel became less social because of an insecure feeling as a result of the physical changes from hormonal therapy (Goldblatt et al. 2013).

3.11.5 Women's role

When it comes to diagnosis and treatment plans, expanding a patient's autonomy by maintaining his/her right to make informed decisions about their own care without undue influence or manipulation from others is highly essential in healthcare (Beauchamp and Childress 2001). Western women with breast cancer are involved in the decision-making process concerning their healthcare plans starting with the diagnosis, which facilitates the establishment of a trustful relationship between them and their physicians (Martinez et al. 2015). Furthermore, they showed an interest in terms of participation and engagement in treatment decisions, as well as searching for information in order to support them to deal with breast cancer (Van Hezewijk et al. 2011). With adequate knowledge, women are able to make informed decisions regarding their care and benefit from an increased quality of life, which is an essential concept within healthcare in order to evaluate different treatments and interventions (Manning-Walsh 2005).

By contrast, cancer diagnosis disclosure to the patient is not yet prominent in some Middle Eastern countries (Khalil 2013). The Middle Eastern social structure is based on maintaining strong family bonds, as well as helping and protecting family members. Therefore, family members find themselves obligated by their cultural and religious values to take over some of the patient's decisions (Mohieldin et al. 2016). For example, Lebanese families hesitate to inform the patient about the breast cancer diagnosis in order to protect her and spare her from pain (Doumit et al. 2010a). Controlling patient health information is not only restricted to family, but also extended to include some healthcare providers in Jordan who hold information regarding breast cancer patients with the intent to protect and maintain hope (Alqaissi and Dickerson 2010). An Iranian qualitative study showed that the word cancer is rarely used in communication between patients, families, and healthcare providers because of its negative connotations (Zamanzadeh et al. 2013). The pattern of cancer diagnosis disclosure could be challenging for healthcare providers in terms of what term they should use in order to define the diagnosis, either to the patient or their family and who should be involved in the decision-making process.

3.11.6 Communication

The language barrier between cancer patients and healthcare providers is considered to negatively impact the provision of support. Among White British breast cancer survivors, communication challenges were reported as a result of their higher expectations from health care providers (Tompkins et al. 2016). On the other hand, Gujarati women with breast cancer who live in the UK reported a limited understanding of breast cancer care because of the language barriers (Patel-Kerai et al. 2015). Furthermore, their dependence on family members who sometimes took time off from work in order to facilitate the communication with healthcare providers during medical appointments caused them to feel like a burden. Saudi breast cancer patients find it difficult to communicate with non-Arabic healthcare providers, especially nurses. They trusted doctors when they were Arabic and spoke the same language (Saati 2013). Nurses participating in the latter study reported during the focus groups that good communication between patients and healthcare providers could be enhanced if the patient had a reasonable level of education. Saati's study is the only Saudi study that explores the experience of breast cancer patients and highlights the gap between the perspectives of both healthcare providers and patients. However, during the data

analysis, the author did not capture the entire experience nor the differences between women who were in the early, mid, and final stages of treatment and follow-up consultations; rather, she only focused on interpretation themes, such as communication, acceptance of the disease, and the positive cultural dimensions.

3.11.7 Support services

In order to cope well with the breast cancer experience, Western women used different support resources offered by the government and private sectors (Hewitt et al. 2006). Furthermore, family, friends, the public, and cancer societies are all available to support the patient (Cappiello et al. 2007). This support system aims to help women with breast cancer to be independent in self-care and have a sense of control (Kaiser 2008). As a result, some women develop a ‘fighting spirit’, characterised by a willingness to recover and a positive outlook about the future (Bower et al. 2005). Spirituality is a coping mechanism commonly used by specific ethnic groups, such as African-Americans and Mexican Americans (Tam Ashing et al. 2003). On the other hand, joining the support group was not a key to surviving for all women, as Williams and Jeanetta (2016) found in their qualitative study. Several American breast cancer survivors perceived that support groups might work for certain people, whereas these may be less effective in the case of those who received preferred support from family and friends.

In Eastern cultures, especially in the case of Muslim countries, women believed in God’s will and perceived the disease as a test that they should accept in order to be rewarded by God (Goldblatt et al. 2013). The concept of fatalism, which is the notion that life is out of a person’s control, has been reported in the literature exploring the coping strategies for breast cancer. It is a belief that an individual’s health outcome is controlled by fate or God (Cebeci et al. 2012). Gonzalez et al. (2016) suggest that fatalism could be a barrier to requesting breast cancer screening and treatment.

The lack of community-based support programmes was a key concern for many women, especially in the case of developing countries such as Lebanon, where breast cancer survivors highlight their need to have the opportunity to talk with people in similar situations in order to share their experiences of living with the illness (Doumit et al. 2010a). However, not all Eastern women share the same need to talk with others. For example, Pakistani women perceive the breast as a ‘private organ’, and thus, they were

reluctant to talk to others about their concerns (Banning et al. 2009). For Arab breast cancer patients living in Israel, listening to breast cancer survivor stories was a source of distress, especially if the stories were negative. Therefore, they limited their social network to include only close family members (Goldblatt et al. 2013). Alqaissi and Dickerson (2010) explain that in the Middle-Eastern culture, it is expected that family members will have a desire to help each other, which suggests that their support is enough to help the patient to cope with the disease. Laffrey et al. (1989) discuss the Arab American tendency to rely on others for advice and guidance. Their close unity and increased need for affiliation results in Arab Americans anticipating each other's needs without verbalising them. In Saudi Arabia, women are not only expecting support from the family, but also from the healthcare provider, who is often unaware of the patients' needs without them being previously verbalised. Saudi patients are only dependent on physicians as a source of information because it is the only available support pathway (Saati 2013). As a result, they frequently expect healthcare providers to automatically know what they need and provide the best for them.

As discussed earlier, the cultural differences in terms of breast cancer prevention, screening, treatment, and support might be considered as challenges for health care providers. Cancer care teams should acknowledge the impact of culture and its complexity on patients' health values and behaviours (Moore and Spiegel 2004). Several cultural variations in beliefs and values between patients, families, and healthcare teams may become understood by applying concepts like 'cultural sensitivity' and 'cultural competence' into the healthcare context (Surbone 2008). Cultural sensitivity is related to health care professionals' attitudes and ways of being sensitive to their patients' health care values and their differences from their own (Goicoechea-Balbona 1997). Cultural competence is referred to as a set of knowledge and practical skills to assess cancer patients and families coming from different cultures (Surbone 2009). It involved information and checklist on different cultural elements like environment, economy, technology, religion, language, social structure, beliefs, and values. Further, Kagawa-Singer et al. (2010) suggest that health care providers should assess each cultural element by asking the cancer patients a number of questions. To assess the environment, health care providers are recommended to ask their patients about the available assistance community service in the neighbourhood and if she or he

know others who faced the same health condition. To assess the economic status, health care providers are recommended to ask questions concerning the type of work, income, and if any other family member is working. In terms of the technology, questions concerning the degree of technology involved in employment, safety, and environmental exposure are considered. Religious questions include the type of religion and the degree of faith, and belief about Western medical care and traditional treatment. In terms of language, the health care team or trained medical translator should be aware of the patient's spoken language. Also, questioning the patient's position, role, and to what extent the support system is helpful or harmful should be considered. Finally, questions should be posed about beliefs and values related to cancer.

To conclude, the experiences of being diagnosed with and surviving breast cancer are discussed in the reviewed literature, yet few studies explore the experience of cancer survivorship, specifically within the context of breast cancer and culture (Kaiser 2008). As Ashing-Giwa et al. (2004) claim, the research on breast cancer survival from diverse ethnic and socioeconomic backgrounds is limited. Acculturation is defined as a psychological adaption of persons from their own cultures to a new cultural environment (Berry 2005). In relation to breast cancer survivorship, it is clear that Eastern women may find it difficult to adapt to the Western breast cancer survivorship model. Although medical breast cancer treatment could be the same for women from both cultures, each culture has a unique view and belief system which shapes women's living experience.

3.12 Healthcare provision

Completing treatment is a changing process, whereby breast cancer patients no longer receive active treatment in the hospital and a new phase of their journey has started. This phase is that of the follow-up care, designed in order to address patient needs, surveillance, improve quality of life, and detect any future complications (Hewitt et al. 2006). Different approaches were implemented in Western countries concerning the delivery of survivorship care. They were designed to shift the concept of care from 'one-size fits all' in the traditional follow-up of clinical monitoring of cancer recurrence to more personalised self-care (Jefford et al. 2013). This type of care underpinning the use of self-management and summary care aim to improve quality of life (National Cancer Survivorship Initiative (NCSI) 2009). Also, the delivery of survivorship care

involves new professionals, like the primary care providers (PCPs), breast physicians, breast cancer nurses, and GPs. All of this information is discussed in the following sections.

3.12.1 Follow-up models

Due to an increasing number of breast cancer survivors and the demand on oncology services, different alternative follow-up models in terms of care delivery were established in order to meet patients' needs. These include progressing the cancer follow-up care from secondary to primary care, such as following up with PCPs, breast physicians, breast cancer nurses, and GPs (Davies and Batehup 2011). According to the recommendation from the Institute of Medicine's report 'From cancer patient to cancer survivor lost in transition', the involvement of primary care in follow-up is essential (Hewitt et al. 2006). The involvement of PCPs and their roles in follow-up care contributed to more than cancer prevention and early detection (Nekhlyudov et al. 2017). However, in Saudi Arabia, survivorship care is only restricted to oncologists; thus, continuous investment in primary care physicians is strongly required in order to improve the efficiency of healthcare provision (Al-Othman et al. 2015).

Primary care providers play an important role in caring for cancer survivors. A randomized controlled trial study allocated 968 patients with early-stage breast cancer, who had completed adjuvant treatment to follow-up care with either oncologists or family physicians, considering the rate of cancer recurrence detection and health-related quality of life (Grunfeld et al. 2006). The results showed similar rates of recurrence detection and of the health-related quality of life. On the other hand, some barriers were reported that challenged the incorporation of PCPs into the cancer survivorship care. Some of these barriers were related to patients' preference, as some breast cancer survivors preferred to be followed up by their oncologist and were less likely to trust PCPs in their ability to deliver follow-up care (Brennan et al. 2011). Other barriers were related to PCPs' inadequate training in managing breast cancer survivorship issues, such as lymphoedema (Smith et al. 2011). They provided lesser cancer-specific surveillance care than oncologists, especially if they were young and taking care of a small number of cancer patients (Klabunde et al. 2009). Women across different ethnic groups reported that follow-up appointments were brief, which contributed feelings of worry about not being fully examined and unable to ask questions, especially in their first

appointment (Tompkins et al. 2016). Therefore, some studies suggested ‘the shared care model’ to facilitate coordination between the oncologist and PCPs (Brennan et al. 2011; Oeffinger and McCabe 2006). For example, PCPs-led-survivorship care focused on meeting survivors’ physical and emotional needs (Nekhlyudov et al. 2017). Also, referring patients with specific problems and who were at moderate and high risk of cancer recurrence to oncologists (Oeffinger and McCabe 2006).

Another model of follow-up is the introduction of a breast cancer nurse (BCN) or a clinical nurse specialist in breast health, who cares for patients with long-term conditions, including cancer (Royal College of Nursing (RCN) 2007). The potential benefits of breast care nurses include having more time to spend with women who are more accessible and easier to talk to about psychological and sexuality related issues (Brennan et al. 2011). Furthermore, BCNs undertake a telephone-based type of care to breast cancer survivors. To understand more, Beaver et al. (2009) conducted a randomised controlled trial in order to examine the efficacy of this service, when compared to a face-to-face follow-up, among 374 women treated for breast cancer who were exposed to low to moderate risk of recurrence. The study found equivalent results with respect to patient anxiety, time to the detection of recurrence, and the number of clinical investigations. Patients in the telephone group reported greater satisfaction with the information received and deemed appointments to be more helpful in meeting their needs. Other positive views on telephone-based care were reported in a complementary qualitative study by the same authors conducted among 28 breast cancer survivors and nurse specialists. Breast cancer survivors claimed that telephone follow-up consultations promoted care continuity, because a trusting relationship was developed, as they were contacted by the same breast cancer nurse during each consultation. Furthermore, they perceived it as a more ‘normal’ activity than attending hospital outpatient clinics, yet they missed having contact with other patients. While from the nurse specialists’ perspective about telephone follow-up consultations, they claimed that this was a convenient and relaxing alternative for patients, saving time in terms of transportation and waiting; however, the process requires knowledge and communication skills (Beaver et al. 2010).

3.12.2 Survivors' preference for follow-up care providers and long-term care

Despite the introduction of different cancer survivorship follow-up models, it was important to evaluate survivors' preference and their views on the current practice. Breast cancer survivors suggest that the main characteristics of health care providers were a good knowledge of the cancer history, a convenient consultation time, and establishing a long-term relationship through the cancer journey (Brennan et al. 2011). It appears that establishing good relationships with the oncologist from the point of diagnosis meant that some women preferred to be followed up with the same health care team. A qualitative study was conducted in order to explore the preferences and attitudes to alternative models of long-term breast cancer care (Brennan et al. 2011). The authors conducted telephone interviews with 50 women recruited from the Breast Cancer Network Australia (BCNA, the largest consumer support and advocacy group in Australia). The results showed that breast cancer survivors tended to opt for follow-up consultations with their oncologist rather than with their GP or breast care nurses. Also, Kantsiper et al. (2009) found that African-American breast cancer survivors had created strong relationships with their specialists, valuing their reassurance and expertise, while they believed that PCPs lacked the necessary specialist oncology skills in order to provide the required information and guidance. Breast cancer survivors claimed that the primary care providers did not have an active role, since they relied on referrals to the oncologist instead of addressing their needs and providing care, hence the preference for treatment referral to an oncologist rather than PCPs (Roundtree et al. 2011).

Communication between healthcare members and continuity of care with the same health care providers were expected elements in follow-up care by many breast cancer survivors (Brennan et al. 2011; Tompkins et al. 2016). This is evident when some women living in rural Australia felt frustrated with having to see different healthcare providers during their follow-up appointments, because they had to repeat their medical history each time (Lawler et al. 2011). Moreover, lack of coordination between healthcare providers in managing patient records, treatment histories, and medical issues was another reported issue in a qualitative study conducted with 33 women who concluded their breast cancer treatment (Roundtree et al. 2011). On the other hand, other views supported following-up with GPs because there would be less travelling involved, and there is already an established relationship of trust with them (Brennan et

al. 2011). However, the authors assumed that the purposive sample was informed and committed to improving breast cancer services, and was likely to give considered opinions about the survivorship issues raised. Hence, recruiting the participants from a supportive group with background knowledge about survivorship care might affect the results' transferability to other settings or populations. To conclude, it appeared that patients' preference for the follow-up model was important and impacted by the health care system to which they were accustomed to and comfortable with, regardless of the effectiveness of other approaches (de Bock et al. 2004).

There is a debate about the provision of private services and whether patients have better outcomes than those treated in the public sector. The possession of private medical insurance led to variation in the service's uptake (Carney et al. 2013). Women with limited access to private care is a common aspect among those coming from ethnic minorities and socio-economical groups (Ashing-Giwa et al. 2008). The occurrence of breast cancer in these groups tended to be in advanced stages and the survival outcome low compared to private users (Tin et al. 2016). In Northern Ireland, Carney et al. (2013) found that the median interval between diagnosis and treatment is shorter in the private sector (14 days) compared to the public sector (19 days). This suggested that people who held private insurance might opt for private care because of the speed in service (Besley et al. 1999). Furthermore, some American studies reported lower proportions of breast cancer reconstruction surgery among patients who are not insured (Coburn et al. 2008; Roetzheim et al. 2000).

3.12.3 Surveillance

Breast cancer surveillance includes regular assessment of breast cancer recurrence, screening for new primary breast cancer, and physical examination (Runowicz et al. 2016). The frequency of clinical appointments and screening procedures, such as mammography and clinical procedures, are debated topics among breast cancer patients. In terms of the frequency of mammography, Australian women with breast cancer reported that an appointment every 3-6 months was a vital timeframe for a follow-up consultation, especially in the first couple of years following the diagnosis (Lawler et al. 2011). Also, they would like the provision of follow-up care to involve a wider spectrum of healthcare providers, such as dieticians, psychologists, and physiotherapists. In the US, according to the results of qualitative study, the women

showed their satisfaction with the current mammography frequency every 3 or 6 months for 1 to 3 years (Brandzel et al. 2017). In the Netherlands, a qualitative study was conducted among breast cancer patients and healthcare providers (HP) (n= 23,18, respectively) (Kwast et al. 2013). Semi-structured interviews were conducted in order to explore the opinions and preferences concerning breast cancer follow-up care. In terms of the perceptions of the current follow-up, HPs claimed to be following the current national breast cancer guidelines, which are every 3 months for the first year, every 6 months for the second year, then annually for the subsequent 3 years. The annual follow-up continues until the age of 60, while patients above the age of 60 are referred to their GP or to the national screening programme. Subsequently, patients were satisfied with the follow-up coordination and accessibility of their HPs. The main goals of the follow-up examination for HPs were early detection and psychological support, while for patients, these referred to the examination of the breast and reassurance. On the other hand, multi-ethnic breast cancer survivors in England showed their disappointment in breast cancer nurse-led follow up care because the nature of the appointment focused on discussing the physical issues and gave less priority to the psychological problems (Tompkins et al. 2016).

Another important aspect of surveillance experience is the effectiveness of imaging and clinical procedures in reassuring breast cancer survivors. In terms of the laboratory tests, some breast cancer patients requested additional investigations, such as blood tests or a total body scan, because they felt that such tests would provide conclusive results (Kwast et al. 2013). However, the most recent ACS and ASCO guidelines suggested that laboratory tests and other imaging procedures should not be provided as routine care, because they do not show any improvement in the survival outcomes (Runowicz et al. 2016). Brandzel et al. (2017) reported that some breast cancer survivors in the US preferred to have a false positive result with a follow-up procedure, such as a biopsy or MRI. These women experienced anxiety, either during the mammography – because it reminded them of when they were first diagnosed with breast cancer – or after the test, because they disliked having to wait for the results. Most women who reported the issue claimed that their breast cancer was not found in the mammography, and thus they had less trust in it. On the other hand, health care providers suggested that the reassurance was ‘meaningless’, because some patients seemed to think they could not get cancer as

long as they were in the follow-up programme and doing extra screening tests (Kwast et al. 2013). All this suggests that there is a discrepancy between the expectations of the patients and the ability of the health care providers to reassure them as well as build their trust.

3.12.4 The survivorship care plan (SCP)

The survivorship care plan (SCP) is an individualised summary of the on-going care together with the proposed problems and solutions discussed with the cancer patient in detail (American Society of Clinical Oncology). The IOM recommend that the following information plan should include in SCP: complete information about the stage of the disease, treatment received, and risk of recurrence; screening guidelines that target the level of risk; information about long-term symptoms and effects of primary treatment (e.g., lymphedema, depression); and information regarding diet and evidence linking good nutrition to health (Hewitt et al., 2006). SCP was mostly developed at the end of treatment and either delivered by someone involved in the follow-up care, such as an oncologist or PCP, or breast-cancer specialist physicians (Brennan et al. 2014). They are delivered to cancer survivors in different forms, such as booklets, DVDs, and online websites (Ashing-Giwa et al. 2013; Blinder et al. 2013). Brennan et al. (2011) found that women preferred SCP that included a report with complete information about diagnosis, treatment, and follow-up visits as a tool that enhanced communication among the health team members.

From the literature, it appears that there is a gap between setting guidelines regarding SCP and its application in practice in order to meet patients' needs (Ashing-Giwa et al. 2013; Brennan et al. 2014). For example, some group of women were not given full information about surveillance while others had received straightforward information after completing treatment, although they were both recruited from the same health care centre (Brandzel et al. 2017). In terms of accessing healthcare promotion information needs, African-American breast cancer survivors complained about SCP's inadequate information about health history, comorbidity, health promotion, and functioning (Ashing-Giwa et al. 2013). Royak-Schaler et al. (2008) conducted four focus groups with 39 African-American breast cancer survivors in order to explore their communication experiences from diagnosis through to follow-up care. Most participants reported the desire to have a more collaborative role in the medical decision-making

process and more information about their survivorship care plan. Participants had cancer recurrence concerns and expressed confusion about the specific guidelines of preventive intervention. Almost all participants reported a lack of specific recommendations from healthcare providers regarding diet or physical activity.

3.12.5 Self-management

Self-management is defined as self-awareness, the assumption of an active role, and participation by the patient in managing the long-term consequences of treatment and promotion of a state of well-being (National Cancer Survivorship Initiative (NCSI) 2009). This support may take the form of programmes in order to enhance patients' coping skills, manage the physical side effects, and promote healthy life-styles (Davies and Batehup 2011). Additionally, the support could be in the form of accessing information and group discussions, which help the patient to become skilled and knowledgeable about cancer care. In Canada, the Survivorship Consult (SC) is a programme which aims to help breast cancer survivors develop an individualised action plan that best meets their physical, psychosocial, and spiritual needs throughout all phases of their journey (Wiljer et al. 2013). Breast cancer patients were introduced to the Breast Cancer Survivorship Programme (BCSP) through SC, which is a one-hour, self-reflective interview conducted by a supportive care clinician, who could be a social worker, nurse, or psychologist. It involved a review of the survivors' understanding of their experience along with treatment, need, and supportive systems. A total of 26 women with breast cancer were interviewed in person two weeks after seeing the SC. The findings demonstrate that SC has great potential to positively enhance the survivor experience and self-management. The women expressed feelings of being supported, being given attention and time, and being cared for, especially in the case of those who had finished their treatment and felt 'forgotten'. Moreover, some women reported being motivated to take the lead in reflecting on their diagnosis, treatment, and strategies for reaching their aims by increasing their health awareness on the basis of the given information. It gave them a sense of confidence in their ability to take care of themselves and manage their health issues. This study explored a perception of service that positively enhanced the experience of women with breast cancer, and served as a tool to explore and meet their needs. However, it would be better to conduct a randomised controlled trial in order to identify the difference in the experience with SC by using measurement tools, such as quality of life and need assessment scales.

3.13 Gaps in the literature

A considerable amount of breast cancer literature exists on experience (Davis et al. 2014; Willams et al. 2015; Tompkins et al. 2016; Smith et al. 2015), yet little is known about breast cancer patients who faced difficulties in terms of how to make sense and understand their experiences following the administration of treatment. After reviewing and analysing the core studies in this chapter, the reality appears to be that the breast cancer population is still struggling to attach meaning to their experience in order to be defined as survivors. In other words, dealing with the title of ‘survivor’ is not the only problem that they seek to address. Indeed, perspectives from different cultures had influenced many aspects of women’s lives, including family and spousal relationships, religious beliefs, and social image. However, the ways in which cultural sensitivities impact and shape their perceptions about breast cancer survivorship and identity are not extensively discussed or documented by the literature (Documet et al. 2012; Kaiser 2008). Most of the results reported from the Middle Eastern studies did not show an in-depth understanding of how their cultures shape women’s experience (Jassim and Whitford 2014; Joulaee et al. 2012; Saati 2013), although one study explained the cultural impact on women’s experience and compared it with the Western literature in the discussion part (Alqaissi and Dickerson 2010). Some issues reported in the Middle Eastern studies in terms of religious beliefs were similar to the Saudi culture, but they did not explore in depth the role of culture in shaping women’s experience and the sense of living beyond breast cancer. The other used literature came from Eastern and South American cultures that had different belief systems, like karma, which cannot be compared to the Saudi Arabian culture. All these gaps indicate how important it is to address specific cultural dimensions of breast cancer experience among Saudi women and how they actively ‘craft’ illness meanings.

Most of the core studies had varied heterogeneous samples in terms of age, breast cancer stage, and period following treatment, which may reflect a lack of understanding of breast cancer survivorship, difficulty in addressing the difference between short and long-term issues, and challenges that are associated with those below 50 years. Therefore, this thesis sought to be original because it focused on homogeneous younger women with early stages of breast cancer and who finished treatment and explored the cultural role in breast cancer survivorship experience in the first place.

3.14 Conclusion

This chapter shows that confusion prevails in relation to the concept of breast cancer survivorship and how it is differently perceived as life-changing, frightening, stressful, life-threatening, beating cancer, winning the battle, and completing the process. Women may be alienated by the optimistic public nature of breast cancer survivorship, preferring not to engage publicly in their cancer journey. Following breast cancer treatment, women across cultures experienced positive and negative effects, ranging from physical, psychological, social, and spiritual perspectives. Understanding cancer survival requires a consideration of both the personal and the cultural aspects. Different follow-up strategies and models of care were developed in order to support breast cancer patients and enhance their quality of life.

Moving beyond what the literature stipulated about the notion of breast cancer survivorship, the next chapter provides a discussion of the research design and methods used in order to achieve the aim and objectives of this study.

Table 4: Grid table

No	Codes	Author/ Year/ Country	Title of the study	Aim	Study Design/ Method	Study Sample /Size	Findings	Strengths and Limitations
1.	Identity	Khan et al. (2011) UK	Interpretation and acceptance of the term cancer survivor a United Kingdom based	To explore the interpretations of the term 'cancer survivor' amongst British people living past a cancer diagnosis	<ul style="list-style-type: none"> •Qualitative •In depth interview one to one 	<ul style="list-style-type: none"> •N= 40 men and women •Mixed cancer including breast cancer (at least 5 years post diagnosis) 	<ul style="list-style-type: none"> •Accepted because survivorship as a factual definition of having had cancer and survived. •Rejected because implied a high risk of death. •Did not reflect their experience, that it suggested survival from cancer was dependent on personal characteristics, or that it meant they were cured despite the possibility of recurrence. •Respondents felt 'cancer survivor' was a label that did not describe their identity or that it implied. 	<ul style="list-style-type: none"> •Could not be generalised because it is a qualitative study. •It showed different reasons for rejection with good data analysis.
2.	Identity	Park et al. (2009) USA	Self-identity after cancer: "survivor", "victim", "patient", and "person with cancer"	To examine (1) the extent to which four post-cancer identities (patient, person who has had cancer, victim, and survivor) are adopted, (2) relations between each identity and involvement in cancer-related activities and mental and physical well-being, and (3) correlates of these identities.	<ul style="list-style-type: none"> •Quantitative (Cross-sectional) •Qs (Identity- coping-related activates) • 2 phases study 	<ul style="list-style-type: none"> •Mixed cancer N=168 including breast cancer (1-3 years) •N= 108 women and 59 men between age 18-55 years 	<ul style="list-style-type: none"> •83% endorsed survivor identity, 81% identity of "person who has had cancer", 58% "patient", and 18% "victim". •Survivor and person who has had cancer identities correlated with involvement in most cancer-related activities such as wearing cancer-related items and talking about prevention. 	<ul style="list-style-type: none"> •Doing the study within 2 phases affect the response rate. •Similar results to Helgeson (2011) whereas survivor identity linked to whom engaged in cancer activities with better QOL.
3.	Experience, challenges	Ashing-Giwa et al. (2008) USA	Understanding the breast cancer experience of Latina women	To explore the impact of breast cancer on quality of life among latin-survivors within the cultural context.	<ul style="list-style-type: none"> •Qualitative, focus group • Thematic analysis 	<ul style="list-style-type: none"> •N= 26, Latino breast cancer survivors and health care providers N= 6 	<ul style="list-style-type: none"> •Psychological, emotions and financial concern, language barriers, lack of support, role conflict • Need for information positive communication 	<ul style="list-style-type: none"> • Similar to Saudi Arabia in terms of language barriers in study by Satti. 2013. • Give more insight into culture and ethnic health believes and perception of health care providers on survivorship.
4.	Challenges, Transition, Experience	Allen et al., (2009) USA	The transition from breast cancer 'patient' to 'survivor'	To explore women's fears regarding risk of cancer recurrence, sense of loss of medical monitoring, social support from health-care providers as well as the strategies they use to cope with these issues.	<ul style="list-style-type: none"> •Qualitative, interviews •Cognitive and emotional processing 	<ul style="list-style-type: none"> •N=216 breast cancer patients who had completed adjuvant chemotherapy or radiation for new stage I or II breast cancer in the prior 12 months. 	<ul style="list-style-type: none"> •Termination of treatment can shatter the tentative equilibrium that many cancer patients achieve during treatment. •Fear of recurrence is common and persistent. •Emotional and physical stresses are prevalent following the completion of treatment. 	<ul style="list-style-type: none"> •Was not to obtain a representative sample, but rather to hear from women with a variety of experiences. •It is possible that the women who volunteered to participate in this study either had more positive transition experiences or were more connected to the health-care system. • large sample size
5.	Challenges, Support	Kantsiper et al. (2009) USA	Transitioning to breast cancer survivorship: perspectives of patients, cancer specialists, and primary care providers	To explore the needs and priorities of breast cancer survivors, oncology specialists, and PCPs.	<ul style="list-style-type: none"> •Qualitative •Focus groups •A semi-structured interviews 	<ul style="list-style-type: none"> •N= 52 breast cancer survivors, after period of 18 months of completed treatment •Nine focus groups 	<ul style="list-style-type: none"> •Supports prior findings that breast cancer survivors are at risk for developing medical and psychosocial sequelae arising from their cancer and its treatment. •Supports the finding that survivors wish to collaborate with providers in making medical decisions and want to receive care plan information 	<ul style="list-style-type: none"> •Review of the transcripts did not show differences between patients who were active in the breast cancer community. •Providers who participated may

						were held	directly •Specialists reported that they struggle with discharging survivors due to protective relationships. •PCPs were concerned about time and training to provide survivorship care and communication problems with oncologists.	have had a special interest in survivorship care and may not be representative of all medical providers.
6.	Identity, meaning of survivorship	Kaiser K. (2008) USA	The meaning of the survivor identity for women with breast cancer	To examines whether women treated for breast cancer embrace survivorship	•Qualitative •In depth Interview (one to one)	•N=39 breast cancer survivors (3-18-month post- treatment), aged (28 -87 years) •Used 2 framework (cultural too and crafting tool).	•Despite the positive meanings attached to survivorship, many women altered the meaning of survivorship or rejected survivorship. •Survivor discourse alienated women who struggle with the threat of recurrence, who feel their cancer experience was not severe enough to merit this title, or who desire a private disease experience.	•It is an interesting study focus in BC and explore the culture impact. •Did not explain the background of the participants. •Different from what other studies found in terms of accepting the survivor identity.
7.	Breast cancer Perception	Documet et al. (2012) USA	Breast Cancer Survivors' Perception of Survivorship	To explore (a) how women who were diagnosed with breast cancer (BC) defined themselves as survivors and when this occurred, and (b) the types of benefits they derived from their experiences.	•Qualitative, telephone interview •Thematic analysis	•N= 112 Breast cancer survivors	•Survivorship meaning was 'conquering' as they were victories against the enemy (n=36), a 'new outlook' about death, life as well as new values and believes (n=30). The other themes were 'helping others' especially other cancer survivors, 'free of cancer' as being a live, 'beyond one's control' because they believed that surviving from breast cancer was with in God's hand or by luck. •Defining survivorship moment was associated with when they have been told "cured" or were "free of disease" by a physician, joining a supportive group of women and once the tumour was removed from their bodies.	•Women were recruited from Susan G. Komen for the Cure The results are therefore, not necessarily transferable to other settings and populations. •There is no inclusion and exclusion criteria • Large sample size
8.	Experience Culture (Communication family support and religion) barriers Saudi Arabia	Saati (2013) Saudi Arabia	Saudi Arabian women's experiences of breast cancer treatment	To explore the cultural framework of Saudi Arabian women's experiences of breast cancer diagnosis and treatment	•Qualitative study (Grounded theory) and symbolic interactionism framework •Semi structured interview with patients and focus group with nurses	•N=60 with breast cancer patients who are in early, mid and final treatment and follow up. • N=8 nurses	•Five themes: communication, acceptance, knowledge and understanding, limitations imposed by culture and positive dimensions of culture.	•Did not mention how and where patients were recruited from the named hospital and when the data reach the saturation •The themes did not fully capture the meaning of the data e.g., acceptance, understanding and Positive dimensions of culture Women's faith in God had similar data. •Variation on treatment period was only addressed in terms of offering information by health care needs declined during the late phases of treatment. •Did not write about study limitation

9.	Culture, Survivorship Meaning, Challenges, change	Burke et al. (2012) USA	Passing through: meaning of survivorship and support among Filipinas with breast cancer	To explore meanings of breast cancer survivorship among Filipinas in the US.	<ul style="list-style-type: none"> Multiple qualitative methods (observation and interviews and focus groups) Ethnography 	<ul style="list-style-type: none"> N=63 breast cancer support group (observation) In-depth qualitative interviews with support group facilitators and staff (N =6), persons who had attended a support group (N=27; 21 women, 6 males family members) 	<ul style="list-style-type: none"> Four dimensions of survivorship were identified: (a) surviving cancer is one of the challenges they faced in their lives as family and job problems; (b) it is not about self, but about taking care of family; (c) it resembles rebirth or giving a second chance; and (d) it means cancer-free. 	<ul style="list-style-type: none"> This study supports the influence of social context on women's understandings of breast cancer and the meaning of survival. It did not show the interaction of focus group since there were different members like male, group facilitator, staff and family members.
10.	Culture, Hiding cancer Fear of death New life Body image Challenges	Vargens and Bertero et al. (2007) Brazil	Living with breast cancer its effect on the life situation and the close relationship of women in Brazil	To identify and describe the impact of breast cancer from the perspective of the women's experience particularly in body image and intimate relationships.	<ul style="list-style-type: none"> Qualitative, Interpretive Phenomenology, in-depth interviews Heidegger's existential analysis 	<ul style="list-style-type: none"> N=11 diagnosed with breast cancer between 1993 and 2001. Older than 18 years 	<ul style="list-style-type: none"> Fear of death (cancer stigma). Start seeing the world in a different way. Some were recognized as women with certain needs. Physical challenges in terms of lymphedema. Body and self-esteem were altered. Because they view their body as tool to communicate with the world. They tried to hide their disease from their friends/ family. 	<ul style="list-style-type: none"> The sample was not clear in terms of cancer stage. Time since diagnosis is varied which affect the study's representativity Very comprehensive analysis. Findings were interesting.
11.	Culture, Experience, Feeling of lose. Information need Lack of support	Doumit et al. (2010) Lebanon	Living with breast cancer, a Lebanese experience	To provide in-depth understanding of the experience of Lebanese women living with breast cancer	<ul style="list-style-type: none"> Qualitative, descriptive and interpretive phenomenology Utrecht School of phenomenology 	<ul style="list-style-type: none"> N=10 women between II-III who varied in time of diagnosed and treatment 	<ul style="list-style-type: none"> Living with loss (hair loss causing losing identity as a woman, fear of losing husband, losing normal life). Living with uncertainty of cancer recurrence, death. Living of guilt feeling which was associated with fear of alteration their daughters' chances of getting marriage or maybe they will get the disease because of cancer 's gens. Living with the need to know about their disease and sharing their experiences with other cancer survivors. 	<ul style="list-style-type: none"> This study highlights the impotence of culture in impacting the cancer experience. The findings of this study are similar to study done in Bahrain, Iran and China. Participants were in different in diagnostic, treatment and post treatment phase which altered the study's representativity. The sample size was small for heterogenic study.
12.	Culture, Emotional concerns, Challenges, Spirituality, support	Mollica and Nemeth (2014) USA	Transition from patient to survivor in African American Breast cancer survivors	To examine the experience and coping of African American women as they transition from being patient to being a breast cancer survivor.	<ul style="list-style-type: none"> Qualitative, grounded theory, semi-structured interviews Inductive analysis 	<ul style="list-style-type: none"> N=15 women with breast cancer, aged (35-75 years) and completed treatment (6 - 18 months) prior interview. 	<ul style="list-style-type: none"> Faith. Altered physical activity. Different needs were reported such as, psychosocial support, information needs, communication with others AA breast cancer survivor. Emotional concerns such as fear of recurrence, guilt, depression and loss of safety net that comes with the end of treatment. 	<ul style="list-style-type: none"> Addressed than main aspect of the process of survivorship and how cancer journey begging from diagnosis until follows up able to produce short and long-term challenges.

13.	Culture, Muslim Experience, Relations	Joulae et al. (2012) Iran	Living with breast cancer: Iranian women's lived experience	To explore the meaning of living with breast cancer	<ul style="list-style-type: none"> •Qualitative, phenomenology, interviews •Thematic analysis 	<ul style="list-style-type: none"> •N=13 breast cancer patients, aged (34-76 years) and recruited after 2 weeks of finishing treatment. 	<ul style="list-style-type: none"> •Negative aspects are: loosing feminine part as breast, losing hair, and loosing relationship with husband. •Fear of death, cancer recurrence, divorce or her husband getting married. •Confused feelings about their new body. •Positive aspects are: accepting the disease, being more religious, exploring new life aspect, living the moment, and helping others. 	<ul style="list-style-type: none"> •The study did not mention the criteria for recruitment e.g., cancer stage. •Women were only recruited from private clinic that could be represent specific socio-economical class. •Did not fully explain the interview guidance. •The findings of this study are similar to study done in Bahrain, Iran and China.
14.	Quality of life Cultural believes Experience The meaning of cancer, Impact of cancer	Jassim and Whitford (2014) Bahrain	Understanding the experiences and quality of life issues of Bahraini women with breast cancer	To explore the experiences of Bahraini women who have survived breast cancer and their perception of quality of life after diagnosis.	<ul style="list-style-type: none"> • Qualitative, semi -structured interview Narrative approach 	<ul style="list-style-type: none"> •N=12 Bharani breast cancer patients •Purposive sampling 	<ul style="list-style-type: none"> •Perception of cancer as a deadly disease. •Link the cause of cancer to Evil's eye. •Chemotherapy side effect was the worst chapter of cancer treatment. •Being spiritual and believing in God was their coping strategy. •Family and social impact (cancer affect her identity as a wife and caregiver and relationship with husband). •Quality of life means able to do all the daily duties and activates normally. 	<ul style="list-style-type: none"> •No limitations were placed on either the length of time since diagnosis or the stage of their disease. •This is the 2nd qualitative study that showed the experience and impact of cancer in the gulf. •Due to the conservative culture of Bahraini women, the interview was limited on answering some questions.
15.	Breast cancer experience Culture Stigma	Banning & Tanzeen (2014) Pakistan	Living with advanced breast cancer perceptions of Pakistani women on life expectations and fears	To explore the psychological impact of advanced breast cancer in women receiving follow-up care in an oncology hospital in Pakistan	<ul style="list-style-type: none"> •Qualitative, semi-structured interview •Thematic analysis 	<ul style="list-style-type: none"> •N=21 Pakistani women with breast cancer (33-83 years) •Finished treatment and diagnosed with advance stage •Purposive sampling 	<ul style="list-style-type: none"> • Reaction to the diagnosis, stigma • Change in outlook • Living life positively, and motivating factors 	<ul style="list-style-type: none"> • This study is significant because it shows the impact of culture and cancer stigma on women's experience. • Similar findings to my study. •Np back translation
16.	Culture Religion Gender role Hidden living	Banning et al. (2009) Pakistan	The impact of culture, sociological and psychological issues on Muslim breast cancer patients in Pakistan.	To examine the experience and coping strategies employed by breast cancer patients in relation to its impact on their physical, mental health, religious and family issues	<ul style="list-style-type: none"> •Qualitative, semi structured interview and focus group. •Thematic analysis 	<ul style="list-style-type: none"> •N=30 Pakistani breast cancer patients (22- 60 years) and Muslim •Purposive sampling 	<ul style="list-style-type: none"> • Shock of diagnosis. • Role of religion and family support to cope. •Isolation because of chemotherapy side effects and financial burden. • Family life. •Spiritual support. 	<ul style="list-style-type: none"> • Similar findings to my study. Showed the impact of culture on their lived experience with breast cancer. • The role of focus group was not explained. • The inclusion criteria were not specific

17.	Experience Culture Coping	ALqaissi & Dickerson (2010) Jordan	Exploring common meaning of social support as experienced by Jordanian women with breast cancer	To explore the common meaning of social support as experienced by Jordanian women with breast cancer	<ul style="list-style-type: none"> •Qualitative, semi-structured interviews. • Heidegger hermeneutic approach of Diekelmann et al. 1989 	<ul style="list-style-type: none"> •N=20 Jordanian women with breast cancer stage (I, II or III) and completed treatment •Purposive sampling 	<ul style="list-style-type: none"> • Breast cancer is a stigma. •Social support from group members. • Being strong for self and others. • Controlling information for protection. •Spiritual meaning. 	<ul style="list-style-type: none"> •Did not show the Linguistic interpretations. •Showed new themes reflected the Arabic culture and the family structure.
18.	Culture Coping	Goldblat et al. 2013 Israel	Being within or being between? The cultural context of Arab women's experience of coping with breast cancer in Israel	To study how Arab women, cope with breast cancer and how the illness and its personal, familial and social implications and to examine their coping strategies within the religious and traditional cultural context.	<ul style="list-style-type: none"> •Qualitative, semi-structured interviews. 	<ul style="list-style-type: none"> •N=20 women with breast cancer, aged (32-50 years) •Diagnosed with stage (I,II,III) 5 years prior the study 	<ul style="list-style-type: none"> • Family comes first. • Faith in God as a source of coping. •Jewish women were open in interaction with health care team more than Arab women. 	<ul style="list-style-type: none"> •Good to have a cross-cultural research •The recruitment process was not clear. •It did not mention the analytic framework.
19.	Religion Culture Meaning-making	Liamputtong & Suwankhong (2015) Thailand	Living with breast cancer: the experiences and meaning-making among women in Southern Thailand	To discuss the lived experiences and meaning-making of breast cancer among women in southern Thailand.	<ul style="list-style-type: none"> •Qualitative, in-depth interviews with BCS •Feminist approach • Thematic analysis 	<ul style="list-style-type: none"> •N= 20 women with breast cancer •Snowballing sampling 	<ul style="list-style-type: none"> • Meaning-making and the Buddhist belief about bad karma. • Bad deeds were believed as the cause of cancer. 	<ul style="list-style-type: none"> • Most of the participants were mothers, which I believed, that could affect the validity of the study. • Interesting use of drawing to express women's experiences.
20.	Survivorship Meaning Culture	Dyer (2015) Puerto Rico USA	"Surviving is not the same as living": cancer and Sobrevivencia in Puerto Rico	To explore what it means to live after cancer diagnosis and treatment in Puerto Rico using in-depth interview data collected during a larger ethnographic study on cancer-related infertility	<ul style="list-style-type: none"> • Qualitative study, Ethnography •Semi-structure interview •Grounded theory analysis • Interviews 	<ul style="list-style-type: none"> •N= 23 young participants with mixed cancer including breast. •Snowballing sampling 	<ul style="list-style-type: none"> • Survivor identity. •Alternative linguistic meanings of survivorship in English were limited reflecting only the stat of survival more than the thriving meaning. Others noted that survivorship in English implied limitation and was not the same as living because the latter interpreted as living a full life with joy and taking advantages from being live. 	<ul style="list-style-type: none"> •Linguistic interpretation. •The use of language in exploring the meaning of survivorship. •Heterogeneous sample
21.	Survivorship Experience	Davis et al. (2014) USA	The meaning of survivorship as defined by African American breast cancer survivors	To describe and understand the meaning of survivorship among African American Women	<ul style="list-style-type: none"> •Qualitative study •Phenomenology • Interviews 	<ul style="list-style-type: none"> •N=155 women recruited from supportive group 	<ul style="list-style-type: none"> • Embracing the idea if being survivor and thriving for living. • Strong spiritual base. • Being altruistic. 	<ul style="list-style-type: none"> •The sample size is large for a qualitative study. •participants were recruited only from supportive group.
22.	Culture barriers God's will Experience	Patel-Kerai et al. (2015) UK- India	Exploring the lived experience of breast cancer diagnosis and treatment amongst Gujarati-speaking Indian women	To explore the experiences of five Gujarati-speaking Indian women with regard to their breast cancer diagnosis and treatment	<ul style="list-style-type: none"> • Qualitative study, phenomenology •In-depth Interviews •IPA 	<ul style="list-style-type: none"> •N=5 women with breast cancer, aged (55-76 years) and diagnosed with primary stage 	<ul style="list-style-type: none"> •Making sense of the cancer (limited understanding, god's will, karma). • Importance of support and body image concerns. • Depending on others. 	<ul style="list-style-type: none"> •No linguistic interpretation. •Study was not conducted in the country of origin.

23.	Transition of care Decision making	Williams et al. 2015 USA	Lived experiences of breast cancer survivors after diagnosis, treatment and beyond: qualitative study	To understand the lived experiences of women who are breast cancer survivors.	•Qualitative Semi -structured interview	•N= 15 women with breast cancer •Purposive sampling	<ul style="list-style-type: none"> • Women realize the importance of being alive. • Support system from family. •Over control their health by making decision about treatment and keeping up with screening. 	<ul style="list-style-type: none"> •Bias in recruiting women who had long survival length because some could not recall their experience with the transition from being patients to survivors. •The length of survival was varied.
24.	Health care Challenges Primary care	Roundtr-ee et al. 2011 USA	Problems in transition and quality of care: perspectives of breast cancer survivors	To explore breast cancer survivors' perception and attitudes about their current healthcare utilization.	•Qualitative, Grounded theory Focus groups •Grounded theory analysis	•N=33 women with breast cancer who completed treatment	<ul style="list-style-type: none"> • Barriers in screening. • Feeling limbo in the healthcare system. • Problems with communication. • Modelling other behaviours. 	•The study did not describe sample inclusion and exclusion criteria
25.	Communication Decision-making Survivorship care plans Uncertainty information needs	Royak-Schaler et al. (2008) USA	Exploring patient-physician communication in breast cancer care for African American women following primary treatment	To investigate patient-physician communication from the patient's perspective about guidelines and sources of information used in developing survivorship care and preferred avenues for information delivery to African American breast cancer survivors.	•Qualitative, 4 focus group	•N=39 African American diagnosed with breast cancer	<ul style="list-style-type: none"> •Most of the participants desired to be more involved in the decision-making. •There strategy to reduce the risk of recurrence is by doing regular mammogram, while only 21% reported doing diet and exercise. •They received more information from cancer survivors. •Lack of survivorship care coordination •More than 90% reported a lack of specific recommendations from healthcare providers for reducing their risk of cancer recurrence, highlighting a missed opportunity to develop feasible plans of on-going care and promote long-term health. 	•Findings highlight the need expressed by breast cancer survivors for comprehensive guidance from healthcare providers and oncology and primary care teams to develop plans of care that improve quality of life and target the risk of cancer recurrence.
26.	Follow up Survivorship Preference	Beaver et al. (2010) UK	Telephone follow-up after treatment for breast cancer: views and experiences of patients and specialist breast care nurse	To explore the views of patients and specialist breast care nurses on telephone follow-up after treatment for breast cancer.	•Qualitative semi-structured interviews	•N=28 breast cancer patients and N=4 specialist breast care nurses	<ul style="list-style-type: none"> •Continuity of care was important. •Speaking on the telephone was perceived as a more 'normal' activity than attending hospital outpatient clinics. 	•Specialist nurses emphasised the high level of skill required to deliver the intervention and perceived that the telephone approach was well able to meet the individual needs of patients.

27.	Survivorship, support, service	Tompkins et al. (2016) UK	Survivorship care and support following treatment for breast cancer: a multi-ethnic comparative qualitative study of women's experiences	To explore experiences and expectations of a multi-ethnic sample of women with breast cancer regarding post-treatment care.	<ul style="list-style-type: none"> •Phenomenological qualitative, in-depth interviews •Data were analysed using Framework Analysis 	<ul style="list-style-type: none"> •N= 66 women who completed treatment for breast cancer in the 12 months prior to the study 	<ul style="list-style-type: none"> •Women described their transition to follow-up as 'abandoned', 'cast-adrift' and out of the 'safety net' of the hospital. •Challenges were reported in terms of communicating with HCPs at follow-up, information needs and accessing supportive service. •Disappointment with lack of breast care nurse (BCN) contact and care continuity. •Focusing on the physical - little opportunity to discuss emotional concerns. 	<ul style="list-style-type: none"> •The study did not fully explain the sampling inclusion and exclusion criteria in terms of the social statuses, economy and breast cancer stage. •The study showed the cultural differences regards breast cancer follow-up experience.
28.	Follow up Survivorship Preference Health care Providers	Kwast et al. (2013) Netherlands	Breast cancer follow-up: from the perspective of health professionals and patients	To explore opinions and preferences about the purpose, the duration and frequency of breast cancer follow-up and which examinations should be done, by whom	<ul style="list-style-type: none"> •Qualitative- semi structure interview 	<ul style="list-style-type: none"> •N= 23 breast cancer patients and N=18 health professionals 	<ul style="list-style-type: none"> •HPs were happy following the current guidelines of follow-up. •Examination of the breast, reassurance and guidance are important for the patients. •Most patients were uncomfortable with the idea that follow-up could become shorter than 5 years. Many patients preferred an even longer follow-up period. •Some additional investigations such as blood tests or a total body scan viewed to be important for some women. 	<ul style="list-style-type: none"> •Although using the qualitative design to reveal perceptions of both patient and HPs was appropriate for the purpose of the study, doing mixed methods with focus groups would give greater representative results.
29.	Survivorship Surveillance Breast imaging	Brandzel et al. (2017) USA	Women's experiences and preferences regarding breast imaging after completing breast cancer treatment	Assessing women's experiences and preferences about breast cancer surveillance imaging	<ul style="list-style-type: none"> •Qualitative, focus group, thematic analysis •Six focus groups 	<ul style="list-style-type: none"> •N= 41 women aged 38-75 years, stage 0-III breast cancer within the previous 5 years, and had completed initial treatment •Convenience sampling 	<ul style="list-style-type: none"> •Anxiety during breast imaging. •Fear of cancer recurrence. •Trust and depend on health care team on imaging decision-making •Information need related to surveillance 	<ul style="list-style-type: none"> •The sample is diverse in terms of age, breast cancer stage. •Factors like genetic, family history and health insurance were overlooked.
30.	Survivorship Care Survivorship Consult Experience Perception	Wiljer et al. (2013) Canada	Exploring the use of the survivorship consult in providing survivorship care	To explore participant experiences in engaging in a collaborative dialogue with a supportive care clinician	<ul style="list-style-type: none"> •Qualitative, Grounded theory •Semi structured interview. •Grounded theory analysis+ thematic analysis 	<ul style="list-style-type: none"> •N=26 breast cancer patients. interviewed within 2 weeks following their survivorship consult (SC) •Purposive sampling 	<ul style="list-style-type: none"> •A collaborative dialogue with clinicians creates a supportive experience. •Development of personalized goals motivated individuals to implement recommendations. •SC provided survivors with an enhanced understanding of their health condition, team and options. •SC helped participants identify needs. •Positive impact on survivors' sense of confidence to manage issues 	<ul style="list-style-type: none"> •This service reflects positively on patients; experience and serve as a tool to meet and explored patients' needs. •It was better to conduct control randomized trial to see the difference in experience because some women expressed that some given information was repetitive so needs

							related to care. • Preferred scheduling of the SC varied widely.	assessment measurement should be involved before the SC clinic.
31.	Follow-up Survivor Meaning Health Continuity, Survivorship care Plan	Brennan et al. (2011) Australia	Survivorship care after breast cancer treatment: Experiences and preferences of Australian women	To explore preferences and attitudes to alternative models of long-term care including the use of tailored survivorship care plans (SCPs) and involvement of primary care physicians (general practitioners, GPs) and breast care nurses.	•Qualitative, descriptive. Semi-structured telephone interviews	•N=50 breast cancer patients recruited from cancer foundation	•Reactions to the terms 'survivor' and 'survivorship' were varied. •The need to discuss psychological well-being and menopausal symptoms during consultations. •Communication between team members was poor. •Receiving survivorship care plan (SCP) was important. • Potential benefits of GP involvement in care.	• The participants were recruited from supportive group who may already have information and positive experience. Also, the authors assumed that those participants were informed and committed to improving breast cancer services, and are likely to give considered opinions about the survivorship issues raised.
32.	Survivorship Experience Culture	Ashing-giwa et al. (2004) USA	Understanding the breast cancer experience of women: a qualitative study of African American, Asian American, Latina and Caucasian cancer survivors	To in depth understanding of experience of breast cancer survivors among different ethnic groups	•Qualitative •Phenomenology • Focus group	•N=102 breast cancer survivors •Focus group interviews (24 African Americans, 34 Asians, 26 Latinas and 18 Caucasians); 20 health professionals	•Altered physical function •Uncertainty and fear of recurrence, worry about family •Body image and sexual concerns •Spirituality •Lack of information •Financial issues (health insurance) •Discrimination (colour, language) •Communication barriers	• Similar to Satti 2013 •Large sample size • Translation issue
33.	Follow up Experience service rural area continuity of care communication	Lawler et al. (2011) Australia	Follow-up care after breast cancer treatment: experiences and perceptions of service provision and provider interactions in rural Australian women	To provide in-depth exploration of the experiences and perceptions of service provision and interactions with health professionals in a regional/rural Australian context.	•Qualitative, Phenomenology •Telephone interview	•N= 25 women with breast cancer completed treatment (5 years) prior telephone interview	•Transition in care (Returning home after active treatment was described as a difficult time by several women). •Several women thought that an appointment every 3– 6 months was a good timeframe for follow-up •Women perceived there were too many health professionals involved in the delivery of follow-up care and in some instances unnecessary overlap occurred during consultations. •Need to involve dietician, psychologist and physiotherapist in the health care providers during follow up plan. •Breast cancer care is viewed as a patient advocate who help and coordinate patient follow up. •Women commonly expressed the importance of being remembered and seen by the same health professional at subsequent appointments especially for those coming from private health sector. •Lack of community-based support programmes was a key concern for many women.	•It highlights the perception of rural women with breast cancer in survivorship care. •It will be more interesting if the authors compared between rural and urban breast cancer survivors.

34.	Survivor Experience Identity	Smith et al. (2015) USA	The salience of cancer and the "survivor" identity for people who have completed acute cancer treatment: a qualitative study	To explore the salience of cancer in such people's self-concept as an important element for creating patient-centered care for those living with a cancer history.	<ul style="list-style-type: none"> Quantitative, Phenomenology Semi-structured interview Data analysed by a constant comparison approach 	<ul style="list-style-type: none"> N=53 individuals aged between 45 and 74 who were diagnosed with non-Hodgkin's lymphoma or breast or prostate cancer at least 3 years prior and had completed acute treatment Purposive sampling 	<ul style="list-style-type: none"> "Survivor" identity is complex. Meanings of "survivor" based upon participants' narratives (factual, beaten, functional, temporary, adversity, passage of time, and lucky or blessed). 	<ul style="list-style-type: none"> Different opinions about survivor identity by giving different definitions of cancer survivor. A new approach to analyse the data.
35.	Breast cancer Experience survivorship	Williams et al. (2016) USA	Lived experiences of breast cancer survivors after diagnosis, treatment and beyond: qualitative study	To explore the lived experiences of breast cancer survivors from diagnosis, treatment and beyond	<ul style="list-style-type: none"> Qualitative, Phenomenology In-depth interview 	<ul style="list-style-type: none"> N=15 breast cancer patients completed treatment Purposive sampling 	<ul style="list-style-type: none"> Factors from the diagnosis and treatment management impacting survivorship, relationship and support system and implication of survivorship. 	<ul style="list-style-type: none"> Similar to Kaiser 2008. Very basic thematic analysis.
36.	Breast cancer, health care	Meade et al. (2017) Ireland	Survivorship care for postmenopausal breast cancer patients in Ireland: What do women want?	To identify the concerns of postmenopausal breast cancer patients in Ireland and inform the development of a survivorship care plan.	<ul style="list-style-type: none"> Qualitative, 6 Focus group 	<ul style="list-style-type: none"> N= 51 women who finished treatment Two phases study, nominal group technique Thematic analysis 	<ul style="list-style-type: none"> Meeting the same healthcare professional at each review visit. A physical examination and blood tests, advice on diet, exercise, healthy lifestyle and advice on coping and pacing yourself Information and management of side effects of therapy-long and short term. 	<ul style="list-style-type: none"> Interesting because it uses nominal group technique in the follow-up phase. Only recruited white Irish women.
37.	Breast cancer, experience, Post-surgery	Elmir et al. (2010) Australia	Against all odds: Australian women's experiences of recovery from breast cancer	To explore women's experiences of recovery from breast cancer-related breast surgery	<ul style="list-style-type: none"> Qualitative, phenomenology Semi-structure interviews Thematic analysis 	<ul style="list-style-type: none"> N=4 women who undergone breast surgery Under age 50 years 	<ul style="list-style-type: none"> Being overwhelmed with their daily activities. Living with fear and uncertainty. Finding strength through family support. 	<ul style="list-style-type: none"> Small sample size. Did not specify the type of surgery.
38.	Breast cancer, experience, return to work	Caron et al. (2017) Canada	Perceptions of Breast Cancer Survivors on the Supporting Practices of Their Supervisors in the Return-to-Work Process: A Qualitative Descriptive Study	To describe the perceptions of breast cancer survivors on the practices put in place by their supervisors to support them during their return-to-work process.	<ul style="list-style-type: none"> Qualitative, Semi-structured interview Thematic analysis 	<ul style="list-style-type: none"> N=10 women who had returned to work after treatment and were still at work more than 18 months later 	<ul style="list-style-type: none"> Maintaining communication during their period of absence. Working together to structure their return-to-work process before their actual return. Allowing flexibility in work schedule. 	<ul style="list-style-type: none"> Recalling problem Women were from middle to high socioeconomic status.

Chapter 4 Research design and methods

4.1 Introduction

This chapter presents an outline of the methodology and research methods used to explore the experience of breast cancer survivorship as lived by young Saudi Arabian women. A critical analysis is presented of the theoretical and philosophical approaches that include the social constructivism paradigm, the interpretive phenomenological methodology, and IPA perspectives that underpinned the research process. The chapter also includes a detailed account of research methods, such as the ethical review issues, process and permissions, inclusion and exclusion criteria, sampling, and the recruitment process. Finally, it describes the nature of the interviews and how they went through, and explores feasibility and reflexivity in order to demonstrate quality and validity. Also, it illustrates my reflective personal experience with the conduct of the study and engagement in the philosophical and methodological process.

4.2 Research aim:

To explore the experience of breast cancer survivorship lived by young Saudi Arabian women who are younger than 50 years.

4.3 Research questions:

- What are the unique lived experiences of breast cancer survivorship of pre-menopausal Saudi Arabian women?
- To what extent does the Saudi culture impact on the experiences of pre-menopausal Saudi Arabian women who have survived breast cancer?

4.4 Research objectives:

- To identify how Saudi Arabian women perceive their survivorship from breast cancer.
- To understand their experience, e.g., challenges, identities, feelings, benefits, and relationships of being breast cancer survivors in Saudi Arabia.

- To identify the role of culture in either helping or hindering women's breast cancer survivorship experience.
- To explore what strategies from health care providers may support the breast cancer survivor's experience.

4.5 Research design

Since the research's focus is on exploring the lived experience of breast cancer survivorship, a qualitative-interpretive method seems to be the most suited for developing this area of research. Employing a qualitative design helps the researcher to better understand the participants' experiences and allows flexibility in pursuing both researchers' ideas about the topic and understanding the meanings that emerge from the data (Creswell 2012; Esterberg 2002). The advantages of using qualitative design include open, exploratory, unlimited and emergent descriptions, and discovering new conditions or phenomena as versus confirming what was hypothesised (Elliott and Timulak 2005). Qualitative research highlights the significance of meanings and a unique perspective that each individual attributes to their lived experiences in a rich subjective context rather than empirically (Antoniou 2009), especially in breast cancer survivorship. A quantitative method would not be appropriate in this thesis because it seeks causal determination, prediction, and statistical generalisation of findings.

Qualitative studies provide a deeper understanding of breast cancer survivor's lives by opening up questions about changing identity, practices of gender, and the social and cultural differences in women's lives (Kaiser 2008). A qualitative inquiry is also useful when there is little known about a particular research area or when a research topic is highly complex, such as surviving breast cancer in Saudi Arabia (Saati 2013). Through conducting a qualitative design, Antoniou (2009) claimed that this approach:

Honours, understands, and emphasises interpretations that individuals make of their own experiences within various contexts, including: social, cultural, political, geographical, familial, educational and religious contexts to name a few (p. 58).

4.6 Research Paradigm

A research paradigm is defined as a set of beliefs that determine how the holder perceives the world (Guba and Lincoln 1994). A paradigm includes epistemology, ontology, and methodology (Guba and Lincoln 1994); the first two terms are discussed

in more detail here. Epistemology is related to knowledge – how we know what we know about the world. The application of epistemology or knowledge generation in phenomenology is possible through subjective experience and insights (Kafle 2011). Ontology is related to the state of being and reality – what we know about the world (Guba and Lincoln 1994). Cohen et al. (2011) claim that reality might be either external or produced by individual consciousness. The application of ontology in phenomenology is grounded in the ability of an individual to construct multiple realities to different situations (Kafle 2011).

My role as a researcher is shifting from an epistemological position, developing a bigger phenomenological picture of breast cancer survivorship experience to an ontological question which aims to understand the reality of being a breast cancer survivor in Saudi Arabia, and how the meaning of survivorship experience is constructed. Given my epistemological and ontological positions, I felt that the research questions could be best answered using a constructivist paradigm, the reasons for which are detailed below.

According to the constructivism paradigm, the ‘reality is socially constructed’ (Mertens 2005), which means that the reality as meaning and value are subjective and experiential, which are created, not discovered. This thesis proposes that the meaning of being a breast cancer survivor is mainly constructed by breast cancer survivors themselves, who are the only ones to know the experience of breast cancer from diagnosis until survivorship and what it feels like. In terms of practice, this paradigm is concerned with broad and general questions, such as ‘what’ and ‘how’ (Silverman 2013), i.e., what is the meaning of being a breast cancer survivors, and how the culture has impacted that meaning. Creswell (2012) claimed that subjective meanings are not only based on individuals’ views, but are also the product of social interaction with others, and historical and cultural customs that influence individuals’ lives. The role of the researcher here is to establish an interactive link with the participants to understand the complex life-world of the lived experience from the point of view of those who survive breast cancer. Thus, the results are the product of a researcher’s attempt to understand a phenomenon from the participants’ perspectives.

4.7 Using narratives in qualitative research

Stories provide a way of making sense of the living experience, particularly an illness narrative that is viewed as a vital branch of qualitative inquiry (Frank 1998). Narratives have gained importance in the study of chronic illness as a means of understanding the patients' attempts to deal with their life situations and, above all, with the problems of identity that chronic illness brings (Hydén 1997). For example, in a narrative by a young woman named Evelyn, who was struggling with her clinical depression and frustrated with the conventional medical approaches to research that she experienced, she passionately asked, "...*have you really, really been down to our level? Do you know how we live? How we feel? Because so much of [what we are told] is way up in the clouds, and just doesn't apply to us*" (Stoppard and McMullen 2003, p.139). As Evelyn emphasised, research grounded in the lived experiences of this specific population is critical in order to provide more meaningful and adequate support. On the other hand, the narrative of living with and beyond breast cancer is not an exception.

Patients' narratives give a voice to suffering in a way that lies outside the biomedical context that includes early detection, diagnosis, and treatment (Hydén 1997). Kleinman (1988, p. 147) proposed that illness narratives are important to study to have a 'witness to a patient's suffering' and to address the questions that relate to "*Why me?, Why now? and What can be done?*" Through storytelling, people can interpret their experience, and justify their own actions and feelings (Creswell 2012). Furthermore, through the narrative, individuals seek to make sense of coherence in their identity over time (Harré 1984) because it is a combined process of being and becoming, belonging and longing to belong (Riessman 2008). Typically, this could be applied to women with breast cancer, who might go through an identity transformation that begins as a patient and might end as a survivor or someone else. According to Riessman (2008), personal narrative could encourage others to act, speak, and make differences of their past experience. Frank (2000) claimed that narrators do not seek analysis of their stories, but they call for other narratives to be discovered, shared in public in order to remind others who do not share their illness stories of what it means to experience such values, meanings, and relationships. For example, Dr. Samia Al-Amoudi was the first Saudi woman to speak in public about her experience with breast cancer. Not only this, she published a book called '*Break the Silence*'. Her personal journey has inspired many

women in Saudi Arabia, including me, to raise breast cancer awareness and improve survivorship.

In this thesis, narrative inquiry was not employed as a methodological approach in considering the sequences of life events (Riessman, 2008). Instead, narrative refers to the way in which individuals make sense of things, how they develop relationships and, eventually, how they interpret events according to these relationships (Laranjeira 2013). For this thesis, women's narratives were used as a method to uncover information and culturally-embedded concepts and practices. In other words, narratives help to understand how women perceive breast cancer survivorship experience within the context of the culture that they are living, as reflected in their stories.

4.8 The social constructivist perspective in research

The social constructivist paradigm emerged from the phenomenological philosophy of Husserl and other German philosophers who studied interpretive understanding or meaning, called 'hermeneutics' (Dowling 2007). According to social constructivism, realities are socially constructed and knowledge is sustained by social process and reflexivity (Guba and Lincoln 1994). Social constructivism has several features (McLeod 1997). First, it rejects approaches to knowledge that are not based on reflectivity. Second, it has a critical position when it comes to making assumptions about the social world. Third, it asserts on the way in which our understanding of the world is a product of historical and cultural interaction and socialisation with other people. Fourth, it represents a movement toward reframing psychological constructs, such as the "mind", 'self' and 'emotions', as socially-constructed processes produced by social discourse.

One of the applications of the social constructivist paradigm within the understanding of the breast cancer survivorship experience was done by Kaiser (2008), who aimed to find out if women with breast cancer had embraced their identity as survivors and to what extent these women created new meanings for their experiences. To do this, she proposed that the meaning of breast cancer survivorship was either culturally constructed or self-constructed. Based on Kaiser's work, it was assumed that women who had experienced breast cancer take an active role in developing a meaning for their survivorship experience through different approaches, such as observing other women

who went through the same experience with breast cancer, social interaction with others, and a reflection of their own experiences from their own world. These approaches could help women to construct the meaning of breast cancer survivorship, which could sometimes be outside of their immediate awareness. Thus, it is important to perceive breast cancer survivorship as a complex interaction between self-concept and society (culture and community, which include activities, interactions, and relationships).

In social constructivism, meaning is a product of cultural, social, linguistic, discursive and symbolic practices (Cojocaru et al. 2012). For Saudi women, the meaning-making process might be influenced by constraints related to different religious, social and gender factors, as discussed earlier in section 2.10 (life of women in Saudi Arabia). Religious leaders apply a constant pressure on maintaining Saudi traditions and values in the form of men ruling over women, continued gender segregation in public places, as well as the restriction of certain activities for women, such as free mobility and sports in schools (Pharaon 2004). Limiting physical exercise activities has increased the prevalence of chronic diseases (Al-Othman et al. 2015). The Saudi culture emphasises the importance of women's roles in keeping the family functioning but, at the same time, it limits their roles when it comes to work, education and mobility. In this thesis, social constructivism was used to understand how the world that Saudi women live in, their interactions with others, the expression of their beliefs, their self and following cultural norms gives meaning to their breast cancer survivorship experience.

4.9 Theoretical perspectives:

4.9.1 Interpretive phenomenology

Phenomenology is the study of a human being's experience, developed by (Husserl 1970). It is a subjective descriptive of reality based on individual perceptions. However, Heidegger (1996) modified and built on phenomenological perspectives by developing interpretive phenomenology; a view that phenomenology could guide meaningful inquiry, which is called interpretive or hermeneutic phenomenology. It goes beyond the epistemological perspectives that concern the issue of how we know what we know, to ontological perspectives of what it means to be a person and how the world is intelligible to us at all (Benner 1994). To illustrate this, Heidegger used a central view

to describe his approach. The term *being-in-the-world* is used to emphasise that humans cannot easily abstract themselves from the world (Heidegger 1996). This world is described as a meaningful set of relationships, experiences, connections, senses, practices, and languages (Van der Zalm and Bergum 2000). Thus, if we want to understand the living experience of women with breast cancer, it is better then to try to understand that person in the context – for example, what women value, challenge, and find significant – and understand their relationships and connections; all these might allow more interpretation of what it means to be a breast cancer survivor. Interpretive phenomenology aims to “*invite the reader to enter the world that the texts would disclose and open up in front of themselves*” (Kafle 2011, p. 192).

Employing interpretive phenomenology is associated with the social constructivist paradigm (Gray 2014), since both are fundamentally concerned with issues of constructing meanings and interpretation. In this thesis, the interpretive phenomenological methodology would be sure to determine the participants’ description of their everyday experience with breast cancer in detail, and explore what might be hidden and difficult to discuss. Simply, it is an attempt to uncover the life-world as experienced by the Saudi women through their stories. From this perspective, the life-world is a world of multiple possible meanings, a process that is never finished, while factors such as body, self, relationship, language, culture, and time are important interpretive tools by which to understand the living world (Ashworth 2003). Life-world fractions were fully explored in Chapter 8.

Self-interpretation and time are important elements for developing an effective interpretive phenomenological approach (Benner 1994). According to Heidegger (1996), self-interpretation is not only based on what our consciousness tells us, but also is a product of what we learn from our culture and tradition, which supports my research questions, which seek to understand the culture’s impact on the meaning of breast cancer survivorship. Time is another important influence on understanding the living experience of women with breast cancer. They are engaged in an interpretive process that moves back and forth, between part and whole, from past experience with diagnosis and treatment to the present phase of survivorship that could be extended into the future.

4.9.2 Interpretive phenomenological analysis (IPA)

IPA has become an established methodological enquiry in the fields of health and psychology, especially to explore experiences of illnesses, such as cancer, chronic pain, and heart disease (Grinfeld et al. 2011). The theoretical foundation of IPA relies on hermeneutic phenomenology, which is described as having both descriptive and interpretive elements. This double hermeneutic focus aims to understand the participant's world and describe what it is like by focusing on the experience, life events, culture, relationships, and language. IPA is to develop an interpretive analysis that shifts the description of data to a more critical, linguistic, and conceptual level of sense-making (Larkin et al. 2006). It offers a structured framework to validate the practical application of phenomenology (Smith et al. 2009).

The researcher's role involves engaging with the data, in other words, trying to step into the participants' shoes (Pietkiewicz and Smith 2014), which implies that IPA acknowledges the role of the researcher's conceptions in interpreting the breast cancer survivor's world. Smith and Osborn (2003, p. 51) claim that "*the participants are trying to make sense of their world, and the researcher is trying to make sense of the participants trying to make sense of their world*". In other words, IPA assumes that participants seek to interpret their experiences into some form that is understandable to them, and the researcher's role is to help the participant uncover and understand the hidden or difficult issues.

IPA also recognises the researcher's role in establishing a balance between detachment and attachment with the participants' world and experiences (Shaw 2010). This approach emphasises the individual's meaning of living in an event and the individual's interpretations which are influenced by the social and psychological discourses related to the event (Smith et al. 2009). IPA is used as the methodological approach for this thesis to provide a structure for exploring the lived experiences of Saudi Arabian women after breast cancer treatment, together with their interpretations of the social world and how they make sense of their experiences.

In conclusion, the phenomenology movement was initiated by Husserl (1970). Later on, Heidegger (1996) shifted the focus on consciousness and essences of experience towards the concept of being and the interpretive perspective. Interpretive phenomenology seeks to understand subjective experience by attempting to uncover the

world as it experienced by the subject (Finlay 2011). Based on this perspective, IPA was developed by Smith et al. (2009) who offered a personal meaning to the lived experience by showing how an individual is making sense of his or her experience. Both hermeneutic phenomenology and IPA share many similarities: they both have an epistemological position and are described as having phenomenological descriptive and interpretive elements. The aim of this double hermeneutic is to understand the participant's world and describe what it is like by focusing on the experiences, life events, culture, relationship, and language of the participant. Meanwhile, IPA seeks to explicate how specific groups of people experience a specific experience. There are specific steps involved in analysing women's stories and different levels of analysis, such as descriptive, conceptual, and linguistic analysis.

My intention was to achieve more than a description of a lived experience of breast cancer survivorship. Thus, I combined interpretive phenomenology and IPA. The essence of experience was identified through a deeper understanding of the meaning of being a breast cancer survivor under the umbrella of interpretive phenomenology. Because I was hoping to fully understand the impact of culture on women's life-world experiences with the help of IPA, a better understanding of women's life-world was granted. Achieving this involved a deep immersion in, and dwelling on, the data and the use of different levels of reflection, which is entirely congruent with the principles of IPA, as outlined by Smith et al. (2009), and discussed in the next chapter.

4.10 The use of language in IPA

Smith et al. (2009) clearly highlight the importance of using linguistic analysis in IPA by showing the ways in which the content and meaning were articulated. The purpose of considering the language in IPA is to understand how the person makes sense of the lived experience, and following that, how the researcher makes sense of the participant's sense-making (Eatough and Smith 2006). In other words, the linguistic approach is committed to considering 'how' and 'what' contributions of the text could add to the lived experience's meaning behind the participants' words. Also, because of the cultural aspects of the study, it is important to consider the expression and use of language.

The linguistic analysis suggested looking at metaphors, metonymies, and binary opposites used by the participants in the transcripts. Smith et al. (2009) claim that metaphor is a linguistic element which helps to link the descriptive notes to conceptual notes, and that has been proved in a number of studies to highlight the relevance of analysing metaphors across the health and psychology disciplines, to describe the lived experiences. For example, a recent IPA study done in Ireland by McTiernan and O'Connell (2015) explores the lived experience of individuals dying from terminal cancer. Emer is one of the participants who has drawn a metaphor to describe his feeling with cancer:

‘Gallop ahead’ and how at times you just wanted to curl up and just say “*I’ve had enough*” (p. 645).

McTiernan and O'Connell (2015) explain that the metaphor used above – ‘galloping ahead’ – indicated the high degree of connection Emer had with his body, facilitating the realization of his forthcoming death.

Another two IPA studies helped me to understand how the participants expressed their lived experience by either using spoken metaphor or artistic impression. The first study, which aimed to explore the lived experience of alcohol addiction, was done by Shinebourne and Smith (2009). In their study, the use of metaphors helped the researchers to build up a rich picture of the subjective self-experience of engagement with alcohol embedded in the world of Alison (the participant). For example, Alison used metaphors such as ‘flux of oscillation’ and ‘being lost at sea’, reflecting her desire for stability and being safe.

The second IPA study was done by Kirkham et al. (2015), who used metaphors alongside images drawn by the participants to describe their experience with chronic pain. The paper’s artistic analysis was unique because it examined the style, tone, colour, and content of the images. Kirkham et al. (2015) believed that:

Metaphor provides a powerful resource to participants by helping them to further expound on the dimensions of their images (p. 400).

For example, in Kirkham’s study, one of the participants drew a picture of a ball covered in spikes, reflecting her experience with abdominal pain, and said:

I used to say to people, *“if you can imagine swallowing a rugby ball covered in spike which have gone through and that’s how it feels”* (Gill, p. 400).

4.11 Why IPA in preference to other qualitative approaches

For analysing the data, several qualitative data analysis approaches were reviewed and evaluated. The first is grounded theory analysis, an inductive approach to developing theory based on rich data gathered from observations, in-depth interviews, memos, and field notes (Charmaz 2008). IPA has gained importance in this thesis as an approach for seeking to uncover information and culturally embedded concepts and practices that could not be assessed simply by observation. My aim is not to be inclusive and generate a theory that explains the phenomenon of surviving breast cancer in Saudi Arabia. My dataset is not designed to develop a theory on an explanatory level, nor is it gathered from large-scale social settings and people. Neither are the results drawn on to describe the theoretical claim. Rather, my sample is small and homogenous, consisting of young Saudi women who had completed treatment for breast cancer.

The second approach is framework analysis, developed by (Ritchie and Spencer 2002). This approach is suitable for applied policy research which is concerned with describing and interpreting particular situations within a short timeframe. The key purpose of this approach is to establish themes and categories at the outset of the study. However, this method could not be applied to my study as my goal is to first develop preliminary themes after a comprehensive reading and re-reading of each case and then to formulate unique superordinate and subordinate themes. This is explained in more detail in Chapter 5, Data management: principles and procedures.

Thirdly, thematic analysis is a fundamental step in all approaches (Braun and Clarke 2006). Thematic analysis allows flexibility in coding and categorising transcripts, although individuality and meaning are central to my research. My aim is to understand the content and complexity of meanings, rather than to measure their frequency. The thematic analysis does not accord with the ontological position of the researcher who believes that the experience of an individual is unique, but IPA does. Another key function of thematic analysis is to search for themes across entire datasets (Joffe and Yardley 2004). Although doing so can be useful, the aim of my study is to engage in a detailed discussion about the lived experience of breast cancer survivorship and the

meanings of their living worlds, rather than to make more general claims as thematic analysis does. In IPA, the in-depth analysis on the individual level (the idiographic experiences), rather than the group level (Smith et al. 2009), is better suited to address the research questions, which sought to know the unique lived experiences of each breast cancer survivor. The experience of breast cancer survivorship lived by young Saudi Arabian women and whether culture has an impact on their experiences are new research areas in this region. Therefore, IPA may contribute to knowledge, and help to understand what breast cancer survivorship experience means to the participants.

Fourthly, the narrative analysis framework chronologically analyses the story that needs to be told to unfold events and viewpoints. Riessman (2008) proposes analysing narrated data biographically, which entails identifying an objective set of experiences in a person's life, such as from childhood to adolescence. Another narrative analysis approach is to consider the composition of the narrative data, focusing on the linguistic elements and structure of the stories. However, my goal is not to describe, categorise, and order women's stories within the context of the search for meaning, rather, I explored people's experiences in detail on a case-by-case basis. This idiographic approach, focusing on my reflective engagement with the data, is what is unique about IPA (Smith et al. 2009).

4.12 Philosophical framework: the life-world

The life-world framework is based on the phenomenological concept of natural attitude, introduced by (Husserl 1970). He saw natural attitude as the complete immersion in one's experience of being part of existence and the everyday world, without reflecting on what the experience means. By adopting this attitude, phenomenologists attempt to free themselves from the past and theoretical knowledge and to dwell on the immanent experience (what is given), to encounter 'the things themselves' in their appearance (Finlay 2011). This epistemological view is usually employed to answer questions about knowledge and how it is possible to gain access to, and understand, other humans' experiences. Husserl was concerned with the description and the structural analysis of consciousness as it is given (i.e., how it appears) in experience.

Unlike Husserl, who focused on attempting to understand how we know what we know or what we perceive, Heidegger, and many others, including (Merleau-Ponty

1962,1995) and (Gadamer 1997), did not use the term ‘life-world’, but used an existential and hermeneutic phenomenological view of ‘being-in-the-world’. Heidegger (1996) was interested in exploring what it means for individuals to live in a world experienced in their own way. He argued that human existence is more central than human consciousness and knowledge (Husserl 1970; Malpas 2008; Todres et al. 2007) and that immersion in the world can discourage us from thinking and analysing the situation; to the contrary, in fact, we cannot be separated from the world in which we live and exist (Heidegger 1996). The latter claimed that ‘we have fallen away from ourselves and into the world’. In other words, we are thrown in a world that we do not really know; therefore, it is essential to understand our being in the world. To do that, Heidegger (1996) explained, we first have to understand our being as existing, become aware of possibilities, and find meaning and time for ourselves in the world. Next, attunement entails adapting our minds to the situation and playing a character, which includes being part of the world. Finally, we discourse about our being in language and sharing it with other human beings. For example, the women in my research have been thrown into an unknown world (breast cancer) that altered their reality and meaning of being. They have been cast from a familiar, secure, healthy world into one filled with fear, uncertainty, and a high risk of death. Their world has lost its meaning, they miss their past, and they feel powerless about the present and unsure about the future. Consequently, they try to shape their new being, relationships, opportunities, and identities to fit their new world, which is reflected in their way of communicating and expressing themselves to others. For example, they hide their diagnosis from others to protect them from pain and keep themselves distant from pity feelings.

The life-world can be defined as the meaningful world that is lived and experienced and where people encounter their sense of self, embodiment, relations with others, spatiality, temporality, projects, discourse, and mood (Ashworth 2003). A life-world is ‘*a world that appears meaningfully to consciousness in its qualitative, flowing givingness; not an objective world “out there”, but humanly relational world*’ (Todres et al. 2007, p.55). Our nature as human beings is ‘to be there’, and ‘there’ is the world, located and observable in our relations to a meaningful context (Larkin et al. 2006). From a relational perspective, Merleau-Ponty asserts that to view a human experience meaningfully is not to detach the mind from the body, nor the subject from the object, as ‘man is in the world, and only in the world does he know himself’ (Merleau-Ponty

1962,1995, p.xi). The relationship between the body, self, and world, then, is intertwined in a world that underlines similarities and differences in actions and behaviours, which all result from belonging to a common, shared world (Dahlberg et al. 2008). Gadamer (1997) claimed that we live in the world as ‘historical creatures’ and that our past experiences as human beings form the foundations that structure our subsequent experiences. From this perspective, the life-world is a world of multiple possible meanings, a process that is never finished, while factors such as language, temporality, history, and culture, are important tools by which to understand the living world.

4.13 Life-world fractions

The life-world includes various fractions that enable producing phenomenological descriptions through structural analysis (Ashworth 2003) and provides a framework that helps the researcher to focus while describing different scopes of the women’s experience. The life-world fractions according to Ashworth (2003) are as follows. First, **embodiment** refers to how one’s situation relates to the feeling of the self and the body; how we boldly live with others in the world. Second, **sociality** relates to how one’s situation affects our relations with others. As these relations are developed through language and shared cultural and ethnic histories, sociality describes how the breast cancer experience is viewed from the context of others. Third, **discourse** describes what language, educational, ethical, cultural forms, and discourses are used to illustrate the situation. This supported the thesis question, which sought to understand the extended impact of culture on the experiences of young Saudi Arabian women who have survived breast cancer. Fourth, **temporality** refers to the sense of time as it flows and unfolds in the present, determined by the past and future. Past events that are retained in the individual’s memory that might affect women’s present life, thinking about who she was or who she is now. Fifth, **selfhood** indicates the sense of agency, feeling, and social identity. It is in relation to women’s presence in relation to breast cancer. Sixth, **project** relates to how the activities that a person is doing are important to one’s life and to what extent they are impacted by the situation. (Ashworth 2003)

In summary

- This thesis is grounded in interpretive phenomenology (Heidegger 1996), exploring the lived experience of breast cancer survivors alongside an in-depth examination of how they perceived survivorship, and whether these are consistent with the view of survivorship in Western cultures.
- Interpretive phenomenology is an approach that seeks to establish explanations and understanding of a living experience of breast cancer that is based on needs, concerns, and meanings instead of causality and relationships.
- IPA supports interpretation of Saudi women breast cancer survivors experience by undertaking descriptive, linguistic, and interpretive analysis.
- The life-world is a meaningful world that is lived and experienced, where people encounter their sense of body, self, social relation, discourse, project and time.

Research methods

4.14 Obtaining ethical approval

The research governance process was ensured by the gaining of ethical approval from Cardiff University, the School of Healthcare Sciences (HCARE) PGR Research Review and Ethical Screening Committee (RRESC) by submitting my research proposal to be scientifically reviewed. The review report was granted on 5 June 2014. Afterwards, my application was processed to the (RRESC) as a final step for getting the ethical approval. Following receiving the ethical approval from the School of Healthcare Sciences (HCARE) at Cardiff University (see Appendix C), a national ethical approval was also obtained from a specialist hospital in Saudi Arabia (see Appendix C). The specialist hospital located in Jeddah was chosen as a setting for data collection for the following reasons. First, it provides services for the western region of Saudi Arabia and serves a wide range of patients coming from rural areas within that region. Second, the treatment is free of charge and is accessible by Saudi women with different types of breast cancer. Third, it is equipped with advanced cancer treatment options.

4.15 Negotiating access

Personal communication was carried out with two oncologists who were working in the oncology outpatient clinics in Jeddah prior to accessing the participants. Negotiation with health care providers was important to gain information about the dates, times, and number of patients in the clinics. As requested by the oncology department of the hospital, the researcher made an oral presentation to inform other health care providers about the research proposal.

4.16 Sampling

Participants were recruited purposively for this thesis that was determined by the richness of the individual cases. Purposive sampling is a standardised method to recruit participants since it is the most common sampling technique for gaining access to the most appropriate subjects known to provide rich information or experience (Gray 2014). In IPA, particular participants are selected purposively in order to understand specific phenomena in individual contexts (Smith et al. 2009). For this thesis, purposive sampling involves identification and selection of a group of women who are well-

informed with breast cancer experience. Also, most importantly, women who able to communicate, express, and reflect their experiences.

4.17 Inclusion and exclusion criteria

To consider homogeneity, women were accessed according to inclusion and exclusion characteristics, as shown in Table 5 below. Although women share quite similar characteristics in terms of age, language, nationality, breast cancer stage, and treatment, in IPA, each participant has given a different and personal perspective concerning breast cancer experience (see Chapter 6: idiographic experiences).

Table 5: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Women diagnosed with primary breast cancer who completed their curative treatment 6-47 months prior to the interview	Secondary carcinoma, widespread cancer with poor prognosis
Stage I-II	Stage III- IV (metastasis to other parts of the body such as chest wall, bones, lungs, liver, or brain)
Age group pre-menopausal between 30-50 years	Older than 50 years Less than 30 years
Saudi woman	International women who live in Saudi Arabia
Women who are able to speak, read and write in the Arabic language	Not able to read and write

The section below explores the inclusion criteria in more detail.

The sample selection has based on four criteria:

- 1) The *age* range of 30-50 at diagnosis has been selected according to breast cancer statistics in Saudi Arabia, whereas the mean age for breast cancer incidence is 49 years (Kingdom of Saudi Arabia Ministry of Health Saudi Cancer Registry 2014). Furthermore, this age encompassed an atypically younger population of survivors who are of

childbearing age, had not reached menopause, and/or had children of school age (Bloom et al. 2004) .

- 2) *Treatment* is defined as surgery, chemotherapy, or radiation. Individuals undergoing adjuvant treatment with curative intent, such as those taking Tamoxifen, or individuals undergoing reconstruction following mastectomy, were eligible for the study.
- 3) Diagnosed with breast *carcinoma all types* in localised and regional stages I, II, allowing the researchers to focus on issues surrounding adjustment to their daily lives as opposed to issues about mortality that may be more apparent at a more severe stage of cancer, such as stage IV.

Participants' times since completing medical treatment for breast cancer is in the range 6 months to 47 months. Thus, all participants were in their first five years of survivorship. The time immediately following treatment is thought to be an important period when they are likely to be working through the meanings of cancer and actively working to make sense of survivorship (Kaiser 2008). Whether or not this process has an endpoint for cancer survivors is debatable (Mullan 1985). Women who had finished their treatment 6 to 47 months previously were obliged to follow the same surveillance guidelines (a physical examination and mammography every 3 to 6 months for the first 3 years and every 6 to 12 months for the next 2 years (Runowicz et al. 2016)). However, the impact of breast cancer experiences over time might be an issue that needs to be acknowledged in further research.

- 4) *Nationality*. Only Saudi women are chosen because though international women live in Saudi Arabia, it does not necessary mean that they have been integrated into the Saudi culture that is often governed by the religion of Islam. They are coming from different backgrounds and their residency is fixed by a period of time that might not be enough for them to be impacted by the culture. The sample is typical of women with breast cancer in Saudi Arabia because they

have been recruited from a governmental hospital; any Saudi citizen can receive free healthcare.

The inclusion criteria were set according to evidence of the disease in Saudi Arabia, such as age and cancer stage. The only differences could be argued to be those related to level of education, marital status, and level of income.

4.18 Recruitment process:

Following receiving the ethical approval from a specialist hospital in Saudi Arabia and the School of Healthcare Sciences (HCARE) at Cardiff University, the women were recruited from the oncology outpatient clinics in a specialist hospital in Jeddah, Saudi Arabia, that provides a private room in the clinical area to maintain confidentiality and privacy during the recorded interviews. Between the period 10-10-2014 to 10-01-2015, women were recruited every Monday morning and Thursday afternoon, which were the clinics' running times. I had approached all women at the oncology outpatient clinics waiting area to hand them an Introductory Sheet (see Appendix D) in the Arabic language that explains the purpose of the study and participants' inclusion and exclusion criteria. The participants who were willing to participate in the study and met the inclusion criteria either talked with me and had given the participation information sheet to read, or wrote their contact numbers on the introductory sheet. To make sure that the potential participants met the inclusion and exclusion criteria, collaboration with two oncology consultants was obtained.

Each participant was given a participant informational sheet in the Arabic language that explains the purpose of the study, sets out their rights, confirms if they choose to participate, introduces the interview approach, and explains the procedure for consenting (see Appendix E). The right to self-determination is based on respect for a person's autonomy. Therefore, participants in the research were allowed to make a free and informed choice, without coercion, and had the right to ask any questions concerning the study, refuse to give information, and withdraw from the study at any stage. All the above information was documented in the participant information sheet that was provided for interested participants. Women were provided with my contact number to ask any questions they may have prior to agreeing to take part in the study. Also, they had approximately one week to consider their decision to take part. I then

contacted the eligible participants by telephone to provide a detailed explanation of the study. Thereafter, an interview was scheduled at a mutually suitable date and time.

In IPA, researchers have tended to use a small size, ranging between 6 and 10 participants (Smith et al. 2009); this number is consistently seen in other IPA studies, which used 9, 8 and 6 participants respectively (Hearn et al. 2015; Ustundag-Budak et al. 2015; Zaidman-Zait and Curle 2016). However, for this research, I used 18 for the following reasons. The sample size of 18 depends on the richness of the individual cases and the ability to support internal comparison between women. The points when the same themes continuously reoccur and when no new information can be added were considered. The women differed in the richness of the information provided, as some were open and others were not, and the duration of each interview varied between two hours and 30 minutes. Each woman has a different and unique perspective and some perceived the experience of being interviewed as a counselling 'healing' process. Thus, I felt ethically responsible for raising these women's voices and I added more participants to be interviewed. Furthermore, a number of interpretive phenomenological analysis studies have used more than 10 participants, such as, 17, 12 and 11, respectively (Brunet et al. 2013; Emiliussen et al. 2017; Hawamdeh and Fakhry 2014).

On reflection, during the recruitment process, 21 breast cancer survivors were identified and approached. Among those who were accessed, 18 agreed to take part in the study, two women refused because they did not want the interview to be recorded, while one woman could not be involved because her husband refused to permit her to do so.

4.19 Data collection method

Face-to-face interviews

In-depth, face-to-face interview was used to gain an understanding of the lived experience of breast cancer survivorship of young Saudi Arabian women. In-depth interviews were relevant for research interested in uncovering participants' perspectives of events, in describing the process as breast cancer survivorship, and in discerning how events, actions, and meanings are connected in the context of participants' lives (Creswell 2012). Kvale and Brinkmann (2009) described two contrasting metaphors of the interviewer as either a miner (where knowledge is a given) or traveller (where the knowledge is constructed). The traveller metaphor appears to fit with my interpretive

phenomenological study, which is based on the social constructivism paradigm. Kvale and Brinkmann (2009) describe the interviewer as a ‘traveller’ who:

Wanders along with the local inhabitants, asks questions that lead the subjects to tell their own stories of their lived world, and converses with them in the original Latin meaning of conversation as ‘wandering together with’ (p. 48).

The interview questions were generated from gaps in the literature, in line with IPA and open discussion with experts in the field from Cardiff University and Saudi Arabia. They were designed to elicit women’s experience and understanding. The interview guide includes open-ended questions with probes to encourage expansion of ideas and get more depth in the participants’ stories about breast cancer (see Appendix F). Typically, the interview was structured as a conversation, with logical transitions between events. Different types of questions were used to structure the interviews: narrative – *“please tell me about your experience with breast cancer beginning with how you came to be diagnosed with cancer?”* and evaluative – *“How was it for you, when your treatment ended?”*

The interview questions were designed in a chronological order, funnelling to sensitive questions (Kvale and Brinkmann 2009), beginning with diagnosis, treatment, and finishing with health care experience. The interview guide was divided into two parts. The first section covers some of the patient's history with breast cancer, including specifics of diagnosis, treatments, decisions, experiences, and social functioning within her family, work, and community to prepare and encourage women to lead up to the topic. The second part includes questions about survivorship perception: identity, the meaning of being a survivor, and the challenges that those survivors may encounter in light of the culture’s influence to allow the participants to have self-conscious reflection and understudying of the experiences they were describing. Also, it includes questions about the health care experience and how the health care providers help survivors cope with their illness. The interview ends with a question allowing respondents to comment on any topic covered in the interview or on the interview itself.

4.20 Feasibility study

The interview guide was translated into Arabic and was pilot tested on two English and Arabic speaking women to ensure the clarity of the translated language of the questions.

It was important for me to obtain feedback from the participants regarding their willingness to participate in repeated interviews, the length of the interview, the need for inclusion or exclusion or modifying questions, the clarity of the questions, and whether these questions captured their experiences. Via a snowballing sampling – asking friends, colleagues, and respondents to recommend women to me who might be interested in the study – I was able to access three eligible women diagnosed with early stage of breast cancer and that had finished treatment five years prior to the interview as a way to test and revise my interview guide.

From these interviews, I found that my opening interview question, *“to start off, tell me about your experience with cancer, beginning with how you came to be diagnosed with cancer and following through the treatment you received”*, worked well. Through this question, women were able to describe how they received their diagnosis, their reactions to the diagnosis, how they disclosed the news to their families and the treatments they received. The first woman I interviewed said that she had a family history of breast cancer; her cousin died from breast cancer. She was afraid of death and thus decided to hide the diagnosis at the beginning from family. Based on that, I added the following questions: *“have any member of your family, friends had cancer” if yes, could you please tell me about it?”* and *“were there people in your life who you avoided talking to about your condition?”* Women were confused by the question of survivor’s identity and during the initial analysis of some of the first interviews, I noticed that women had little to say about it. In subsequent interviews, I explained to the women the variation of breast cancer patients’ identity as cancer survivors or heroes, victims, and someone who has had cancer. This is followed by the question of *“what does the word survivor / survivorship mean to you in general?”*. As the interviews progressed, I became more comfortable with probing and questioning their responses until the participants had no further details to offer. Consequently, the interview times increased as the study progressed.

4.21 The interview process

When I met the participants, I went through the information again before gaining their consent to participate in the study. Each woman had agreed to participate, the consent written in the Arabic language (see Appendix G) had been obtained prior to the interviews, describes the study and its objectives, the potential risks and benefits to

participants, as well as the data management process to maintain confidentiality. The consent sheet ensured participants' agreement with the researcher accessing their medical notes (diagnosis and treatment type). Also, it informs participants about the option of withdrawal from the study at any time without compromising their health care. Before the interview started and digital audio recording took place, I talked with the participant about general topics not related to her condition in order to break the ice and establish a trustful relationship.

Elliott (2005) stressed the importance of telling the interviewees from the beginning about the timing as to make them aware of how much information to share. Women were given time to talk by scheduling a suitable interviewing time, rest break, and providing a safe and private environment. The Interview duration lasted between one and two hours, including pausing because some women were emotionally affected. The interviews' private setting at the hospital helped the recordings to be clear with minimal noise and distractions.

Talking about experience with breast cancer may cause emotional distress to the participant because of its sensitivity. To minimise the risk of psychological harm to the participants, a working relationship was established with a multi-disciplinary team at a specialist hospital who was aware of the research process to provide either psychological or social support to the participants. Also, I did background reading about how to conduct an interview about a sensitive topic (Kvale and Brinkmann 2009), and took a qualitative research course provided by Cardiff University that explained the principles of interviewing.

The data gathered from the interviews were varied in depth; some participants talked openly about their experience, while others were reserved about some issues. A number of participants were comfortable talking with me about their personal experiences and private issues and found it very useful to express their emotions. However, some women commented about being uncomfortable discussing issues related to financial and social circumstances. Some women tend to give socially pleasing answers; this type of response was noted mostly when they describe their position as cancer survivors.

Therefore, further questions and asking for examples were used to elicit deeper understanding.

Women's reactions (verbal and non-verbal) during the interview and the uncovered issues were captured by the use of reflective field notes (see Appendix H). Field notes were made immediately after each interview to reflect on the process and my experiences. I was aware of the bodily aspect or language of the interview and learning about the silence that occurs before discussing hard events that might cause distress and the long deep breath prior talking about diagnosis experience. During the time that women tried to express their negative emotions, their voice's tone was tense and the eye contact was disconnected, as some women did not want me to see their eyes filled with tears. All these were noted, and helped me to be aware of the impact of the interview not only on them, but also me. For example, in the interview with one of the breast cancer survivors, I became aware of the sensitivity of revealing information about sexual life and intimate relationships because they are not openly discussed in public. Therefore, I consider through the interviews the Saudi culture implications involved in exposing sensitive topics and gave the participant the complete freedom to talk about the issues that she found appropriate. After turning off the recorder, a short chat occurred about the impact of breast cancer, with an agreement made for further contact with two participants. This was conducted by phone as a second phase of data collection because the interviews with these women were disturbed by their husbands, who were waiting outside the room. This affected the flow of the interview and the ability of both the woman and the researcher to concentrate.

4.22 Practicalities

Records and data containing personal data, such as participants' names, personal addresses, and telephone numbers were kept secure against unauthorised or unlawful access, accidental loss and damage in order to comply with the (Data Protection Act, 1998). During data analysis, publication, and presentation, the participants were given different names to protect their identities, to prevent being recognised by their peers and preserve anonymity.

In Saudi Arabia, all manual files and recordings were locked in a secure cabinet at the assigned hospital, with controlled access by the researcher until transcribed and verified

and were then destroyed before going back to Cardiff. In addition, the researcher used a laptop computer to save the audio-recordings, transcripts and any documents related to the study's participants. This laptop was password protected and was only used by the researcher herself. An encrypted area was created on the laptop where all the data were securely stored (Data Protection Act, 1998). Following Cardiff University guidelines, electronic data and paper documentation were securely stored at Cardiff University until its destruction occurs at the end of the holding period, which is 15 years from the end of the project. All electronic information was encrypted and securely saved in the Cardiff University H drive server and locked by a password. A personal laptop was password protected and only used by the researcher. The interviews were recorded using an MP3 digital recorder and a lapel microphone and were downloaded directly onto a computer hard drive. My aim from the recorded interviews is to understand how women response and interaction with my questions, enabling the collection of rich data. Data were secured against unauthorised or unlawful access, accidental loss, and damage in compliance with the Data Protection Act (1998) to which Cardiff University adheres.

4.23 Researcher involvement: reflexivity

Reflexivity is the process of conscious self-reflection of social and cultural background, personal and professional experience and assumptions and values that might impact the research process (Hennink et al. 2010). Because IPA involves an interaction between the researcher's understanding of the participant's lived experience and the participant's perception of the sense-making process (Smith et al. 2009), researchers are called upon to reflect on and make themselves aware of their own assumptions (Smith et al. 2009). In this thesis, reflexivity is an important element of where the researcher is located from her study and whether self-reflection could impact the data. It is linked to research quality and credibility, to which Yardley's (2002) guidelines and criteria in assessing the quality of IPA are further discussed in Chapter 9.

Reflexivity suggested that the researcher had a dual role, as both an 'insider' and an 'outsider', during data collection (Roulston 2010). My insider knowledge of the psycho-social issues pertaining to women living with breast cancer was gained from my social position as being a young Saudi female who shared similar backgrounds, beliefs and values with them. This helped other women to feel more comfortable and free to talk about such a sensitive issue as breast cancer. From my personal experience, I am deeply

aware of the struggles and challenges faced by young women in adjusting and attempting to succeed in Saudi society. Furthermore, being a Saudi who is able to speak the Arabic language and recognise the cultural background ensures rich insight into the data. I have repeatedly witnessed the relief on patients' and families' faces on meeting a healthcare provider who speaks their language and comes from the same culture; patients have often expressed appreciation and a sense of relief in knowing that they can call and depend on someone who is able to understand their concerns and who can facilitate communication. For example, Saati (2013) found that Saudi Arabian women with breast cancer expressed difficulties in communicating with healthcare providers due to language barriers.

As an outsider, being a nurse who able to understand the impact of treatment on women's experiences and the currently available healthcare services helped me to deal with patients with sensitive diseases and to understand their distress. As a researcher, it enables an interpretive outlook that aids the exploration of the meaning of breast cancer survivorship. In addition, my professional role as a researcher is not related to the clinical field, since I am not a member of any local oncology team that might affect the data. Although all the participants had not experienced being in an interview before, they agreed to have the interviews recorded. For them, it was the first time they had spoken openly to a person outside of their circle of family and friends about their experience.

During the data collection, certain ethical issues emerged during the process of carrying out the study. Some of this was to do with the distress that patients were feeling about their diagnosis, the treatment and the stigma surrounding this and its impact on their social lives. From an outsider's perspective, specifically one of a student like me who has spent a considerable time in the West thinking about feminism and women's empowerment, these distinguishing features became much more obvious when I listened to the women's stories and realised how dominant men were in the community. However, I reminded myself to focus on the women's experiences and on creating a space where their voices and experiences are heard and valued.

Awareness of the structure of my own experience with a long-term chronic condition and family experience provided me with insight, as described at the beginning of this thesis, in the 'preface'. There were moments during interviews when I understood my own health condition - a realisation that had not occurred to me when I started the research. Although I knew that the interviews might raise topics that would be difficult to talk about, such as sexual issues, I did not expect the level of pain that I observed from my participants. After collecting the data, I was overwhelmed with the amount of personal and deeply sensitive issues that I encountered and I felt reasonable for raising awareness of these women's experiences and for giving them a voice. Because of this, I aimed to be as objective as possible, whilst also being sensitive and compassionate. Shaw (2010) indicated that:

Through making ourselves aware of our own feelings about and expectations of the research, we can begin to fully appreciate the nature of our investigation, its relationship to us personally and professionally, and our relationship as a researcher and experienter in the world (p. 235).

I tried to remember that my research topic, and an approach like IPA, point to the necessity for openness in revealing the participants' experiences. As I reflected on my experiences during the study, however, I became increasingly aware of the importance of finding a balance between the insider and outsider perspectives. This was achieved by using a reflexive journal or diary to document all the research activities, such as the handling of transcription issues and translational challenges, the data analysis and synthesis and any emotional responses to the interviews. A week's space between interviews was necessary to analyse the data, to write the reflective notes, to manage missing issues and to determine what needed to be covered in the next interview. To reduce the risk of psychological harm and disengaging from the participants after completing the interviews, talking either with supervisors or any trusted person about my feelings were helpful during data collection for counselling and debriefing.

4.24 Conclusion

This chapter has described the research design and methods used to explore the experience of breast cancer survivorship as lived by young Saudi Arabian women. In this qualitative research, the constructivist paradigm was used to understand how the reality of breast cancer experience and survivorship meaning and value were created by

the Saudi women. To achieve this, Interpretive phenomenology (Heidegger 1996) and IPA (Smith et al. 2009) as theoretical perspectives were employed to understand the sense of being breast cancer survivors in Saudi Arabia and how they make sense of their experiences. All helped to understand the constructed meaning of breast cancer experience shape by the cultural elements. In terms of the research process, ethical considerations concerning collecting data, informed consent, participants' rights, and reflexivity were all illustrated. Through purposive sampling, participants were recruited from oncology outpatient clinics in Jeddah. 18 young Saudi Arabian women who finished breast cancer treatment 47 months prior to the interview were invited to participate in one-to-one interviews.

The next chapter explores the data management process, including maintaining confidentiality, transcribing, and translation issues. It offers an outline of the specific steps of data analysis using IPA.

Chapter 5 Data management: principles and procedures

5.1 Introduction

This chapter describes the process of managing large amounts of data in this research. It explains the process of data analysis using IPA that supports idiographic, descriptive, linguistic, and interpretative elements in order to get closer to participants' experiences. In this chapter, the subordinate themes that reflect the descriptive experience of all participants are described in tables. This chapter also presents the final master table of superordinate and subordinate themes that showed the balanced use of the descriptive phenomenological and interpretive elements.

5.2 Data management

Recruitment, data collection, and transcription took place over a period of almost six months. Qualitative data were transcribed in Arabic and then translated verbatim into English within a week after data collection was completed. The transcripts indicated hesitations, pauses, laughter, and emotional sounds.

I translated the data myself, following Roulston (2010) suggestion to translate data at the point of transcription and conduct the analysis and interpretation in the language of the representation. The translation process was challenging, especially looking for words in English to reflect the complex meaning of the original Arabic. I made every effort to translate the Arabic idioms into appropriate English language. To ensure credibility, data analysis and coding were conducted in Arabic before translation into English. Accordingly, any inconsistencies in the translations were discussed and corrected with academic supervisors in Saudi Arabia. Back translation was not performed due to the length of each interview and the use of slang. To achieve familiarity and comprehension, I thoroughly read the transcribed documents multiple times, repeatedly listened to the recorded interviews, and re-read the transcribed texts as necessary for data analysis. This method helped maintaining the accuracy of what the women said and reduce the impact of researcher bias. Furthermore, my academic supervisors from Cardiff University were informed through regular meetings about the data analysis process and how the themes were generated. They reviewed the themes' audit trails, which were supported by verbatim extracts from each participant to ensure

the appropriate application of IPA. However, they could not check the transcripts against recordings because they were in Arabic.

5.3 Data analysis

In dealing with large amounts of data from 18 participants for particular purposes, Microsoft Word for Mac 2011 was selected for data management. Qualitative data management software packages were not used as they are not suitable for IPA, where it is recommended to use a hard copy of the transcript in data analysis (Brunet et al. 2013; Smith et al. 2009). IPA has a flexible set of stages which suggests moving from the transcripts to a table of themes and finally to a table of superordinate themes. These stages move from individual to shared experiences and from the descriptive to the interpretive level (Smith et al. 2009).

The data analysis process in this research was intended to identify the descriptive themes that illustrate how these women came to terms with their situation and the conceptual themes that explain their lived experience with breast cancer. Three levels of IPA were identified through reading and group discussion while attending different workshops about IPA, such as ‘Theoretical and philosophical underpinning - locating your thesis’ in April 2015, with Virginia Eatough, and ‘The advanced IPA workshop’ in March 2016, with Dr. Rachel Shaw:

- Idiographic and biographical - starting with a detailed examination of one case to get high degree of understanding before moving to the next case.
- Descriptive - explicating a descriptive, shared narrative by undertaking a broad thematic analysis and low-level interpretation.
- Conceptual - involving detailed, in-depth, hermeneutic analysis of significant events.

5.4 Process

1. The first step of data analysis involved reading and re-reading the transcripts and listening to the audio recordings at least once so that the researcher can be close to the data and familiar with the text.
2. The researcher attempted to keep an open mind for any interesting notes in the transcript. Smith et al. (2009) describe three ways in which

initial noting can be conducted: descriptive comments focusing on the content of what the participant has said; linguistic comments exploring the specific use of language by the participant; and conceptual comments, which engage with the data at a more integrated, conceptual level. Each individual transcript should be formatted with the transcript in the middle, another column for the linguistic comments, wide margins on the left and right for the descriptive comments and conceptual comments. It is important that the researcher combine these notes of all different levels in one transcript in order to be immersed in the participants' life world. In this study, to understand the individual's experience, the content of the interview was described by identifying the main issues that seem unique to the participant's story without the researcher making interpretations. Description notes recorded the initial thoughts and beliefs that influenced each woman's experience and show the uniqueness of her story (see Chapter 6 for the idiographic experiences). Each transcript was analysed independently with notes from the previous transcripts. This strategy helped the researcher make specific statements about each individual, showing the uniqueness of their experiences. The participants' use of language of metaphors and binary opposites was outlined. Participant's statements that indicate important matters that might be used in the written report, such as descriptions, beliefs, ideas, quotations, metaphor, paralanguage, and emotional responses, were highlighted in yellow.

3. Each transcript was treated as a single case and analysed line by line to identify the emergent themes. The themes were connected and clustered to detect patterns in each participant's transcript, as seen below in Figure. 5.

Case 1: Aisha

<input type="checkbox"/> Role of woman	<input type="checkbox"/> Role model	<input type="checkbox"/> Cancer makes you different	<input type="checkbox"/> God's Will	<input type="checkbox"/> Health care context
<input type="checkbox"/> A wife	<input type="checkbox"/> Mother's breast cancer experience	<input type="checkbox"/> Body image	<input type="checkbox"/> My destiny	<input type="checkbox"/> Breaking news
<input type="checkbox"/> A mother		<input type="checkbox"/> Physical activity	<input type="checkbox"/> Surviving from death	<input type="checkbox"/> Language barriers
<input type="checkbox"/> A patient		<input type="checkbox"/> Growth		<input type="checkbox"/> Doctors are source of information
				<input type="checkbox"/> Care continuity
				<input type="checkbox"/> Reassuring before revealing the result

Case 2: Alaa

<input type="checkbox"/> Breast cancer after birth	<input type="checkbox"/> Family history	<input type="checkbox"/> Hidden to survive	<input type="checkbox"/> Health care context
<input type="checkbox"/> Ignoring symptoms	<input type="checkbox"/> Negative role model	<input type="checkbox"/> Un-expressed feelings	<input type="checkbox"/> Communication
<input type="checkbox"/> A mother		<input type="checkbox"/> Husband's ignorance	<input type="checkbox"/> Reassurance
<input type="checkbox"/> A patient		<input type="checkbox"/> Conservative family	<input type="checkbox"/> Supportive group during treatment period

Case 3: Amar

<input type="checkbox"/> Feeling different	<input type="checkbox"/> Living in fear	<input type="checkbox"/> It's not over when it's over	<input type="checkbox"/> Health care service	<input type="checkbox"/> Patient identity
<input type="checkbox"/> Young age	<input type="checkbox"/> Fear of breast cancer recurrence (cancer wouldn't leave you alone)	<input type="checkbox"/> War is still going	<input type="checkbox"/> Family involvement in cancer care	<input type="checkbox"/> I'm still on hormonal treatment
<input type="checkbox"/> Having a conservative surgery	<input type="checkbox"/> Fear of developing a new cancer	<input type="checkbox"/> Beating cancer	<input type="checkbox"/> Regular mammogram and blood investigations	
<input type="checkbox"/> Feeling unsecured after her husband's death			<input type="checkbox"/> Diet and weight control	
<input type="checkbox"/> Position as a second wife with breast cancer			<input type="checkbox"/> Supportive group	

Case 4: Anoud

<input type="checkbox"/> Living in denial	<input type="checkbox"/> Losing control	<input type="checkbox"/> Hidden to survive	<input type="checkbox"/> Cancer happens for a reason	<input type="checkbox"/> I'm not nearly to death to call me a survivor	<input type="checkbox"/> Cancer makes me different	<input type="checkbox"/> Health care
<input type="checkbox"/> Ignoring symptoms	<input type="checkbox"/> Family on charge	<input type="checkbox"/> Limiting her friendship relationships	<input type="checkbox"/> God's will	<input type="checkbox"/> Fighting cancer	<input type="checkbox"/> Physical change	<input type="checkbox"/> Lack of prosthetics
	<input type="checkbox"/> Using alternative therapy	<input type="checkbox"/> Marriage stigma	<input type="checkbox"/> Loving message		<input type="checkbox"/> Cognitive function	<input type="checkbox"/> Good health access
		<input type="checkbox"/> Breast cancer stigma			<input type="checkbox"/> Being a volunteer and positive role model	
		<input type="checkbox"/> Infertility			<input type="checkbox"/> Setting goals	

Case 5: Asera

<input type="checkbox"/> Refusing chemotherapy	<input type="checkbox"/> Victim of cancer or society!	<input type="checkbox"/> Woman's position	<input type="checkbox"/> Husband's dealing way with cancer
<input type="checkbox"/> God's will	<input type="checkbox"/> Life filled with tears	<input type="checkbox"/> Wife responsibilities	<input type="checkbox"/> Agitation
<input type="checkbox"/> Family history	<input type="checkbox"/> Marriage disturbance	<input type="checkbox"/> Husband's centrality	<input type="checkbox"/> Second marriage
	<input type="checkbox"/> Blaming cancer	<input type="checkbox"/> Exposing breast	

Case 6: Asma

<input type="checkbox"/> Doctor's attitude would make a difference	<input type="checkbox"/> Woman's position	<input type="checkbox"/> Coping	<input type="checkbox"/> Challenges	<input type="checkbox"/> I can breathe. I'm a survivor	<input type="checkbox"/> Health care context
<input type="checkbox"/> Breaking news	<input type="checkbox"/> Husband's rights in marriage	<input type="checkbox"/> Expressing feelings	<input type="checkbox"/> Showing people that you are fine	<input type="checkbox"/> Learning experience	<input type="checkbox"/> Developing supportive group based on cultural believes.
<input type="checkbox"/> Explaining long terms side effects	<input type="checkbox"/> Being expired	<input type="checkbox"/> Children support	<input type="checkbox"/> Conservative surgery	<input type="checkbox"/> Independent	<input type="checkbox"/> Long time between appointments
			<input type="checkbox"/> Taking medication		
			<input type="checkbox"/> Psychotherapy stigma		

Case 7: Azizah

<input type="checkbox"/> You are not the only one who had cancer	<input type="checkbox"/> Hidden to survive	<input type="checkbox"/> You are not done yet with cancer	<input type="checkbox"/> Cancer change me	<input type="checkbox"/> Health care context
<input type="checkbox"/> Family history with breast cancer	<input type="checkbox"/> Hidden disease	<input type="checkbox"/> Fear of recurrence	<input type="checkbox"/> Stranger with new body	<input type="checkbox"/> Diet
<input type="checkbox"/> Living in the shadow of her sister's cancer experience	<input type="checkbox"/> Living in silence	<input type="checkbox"/> Fear of cancer inheritance	<input type="checkbox"/> Mother's role	<input type="checkbox"/> Care continuity
<input type="checkbox"/> Shifting from being cancer patient caregiver to care receiver	<input type="checkbox"/> Isolation	<input type="checkbox"/> Passing Five years post- treatment	<input type="checkbox"/> Sensitivity	<input type="checkbox"/> Psychological care stigma
			<input type="checkbox"/> Loneliness	<input type="checkbox"/> Public education
			<input type="checkbox"/> hopelessness	

Case 8: Haia

<input type="checkbox"/> I know what to expect, my mother have it	<input type="checkbox"/> Feeling different	<input type="checkbox"/> Dealing with problems	<input type="checkbox"/> Life vs. death
<input type="checkbox"/> Previous experience	<input type="checkbox"/> Spirituality	<input type="checkbox"/> Husband ignorance	<input type="checkbox"/> Passing God's test
<input type="checkbox"/> Keeping her disease hidden	<input type="checkbox"/> Physical function	<input type="checkbox"/> Financial problems	<input type="checkbox"/> Rebirth
<input type="checkbox"/> Negative impact on son		<input type="checkbox"/> Living in a rural area	<input type="checkbox"/> Death is a finalised concept
<input type="checkbox"/> Health care			

Case 9: Lama

<input type="checkbox"/> Male's dominance	<input type="checkbox"/> Breast cancer myths across culture	<input type="checkbox"/> My body let me down	<input type="checkbox"/> Survivorship	<input type="checkbox"/> Health care context
<input type="checkbox"/> permission for accessing health care	<input type="checkbox"/> breast cancer is a disease of old women only	<input type="checkbox"/> Infertility	<input type="checkbox"/> God's mercy	<input type="checkbox"/>
<input type="checkbox"/> Doing plastic surgery	<input type="checkbox"/> chemotherapy would kill me	<input type="checkbox"/> Daily activity	<input type="checkbox"/> God takes something and replace it with best one	<input type="checkbox"/> Discussing survivorship plan
<input type="checkbox"/> lack of female involvement in health care	<input type="checkbox"/> religious treatment Vs. chemotherapy	<input type="checkbox"/> fear of cancer recurrence	<input type="checkbox"/> Better outcomes than others	<input type="checkbox"/> Communication
<input type="checkbox"/> gender issue				<input type="checkbox"/> Shared decision making
<input type="checkbox"/> fear of divorce				

Case 10: Leena

<input type="checkbox"/> Private health care	<input type="checkbox"/> Living with cancer	<input type="checkbox"/> Cultural believe system	<input type="checkbox"/> Not expected to happen	<input type="checkbox"/> Breast cancer is a family disease	<input type="checkbox"/> Physically survived but not yet emotionally	<input type="checkbox"/> Health care context	<input type="checkbox"/> Missed cancer patient rights
<input type="checkbox"/> First choice for public to go	<input type="checkbox"/> Loss of control	<input type="checkbox"/> Devil's eye	<input type="checkbox"/> Pregnancy	<input type="checkbox"/> Negative impact on family	<input type="checkbox"/> Life is short	<input type="checkbox"/> No family consultation	<input type="checkbox"/> Privacy
<input type="checkbox"/> Lack of expertise	<input type="checkbox"/> Leaving home	<input type="checkbox"/> Lack of breast prosthesis	<input type="checkbox"/> Daughter's behavioural change		<input type="checkbox"/> Fear of cancer recurrence	<input type="checkbox"/> No patient preparation	<input type="checkbox"/> Governmental services
<input type="checkbox"/> Wrong diagnosis	<input type="checkbox"/> Dealing with family issue				<input type="checkbox"/> Being a burden	<input type="checkbox"/> Breaking bad news	
	<input type="checkbox"/> Losing the part and then the whole				<input type="checkbox"/> Being mutual	<input type="checkbox"/> Social and psychological care	
					<input type="checkbox"/> Being vulnerable	<input type="checkbox"/> Care continuity	

Case 11: Maha

<input type="checkbox"/> Cancer stigma	<input type="checkbox"/> Family history with cancer	<input type="checkbox"/> Surviving	<input type="checkbox"/> Patient vs. survivor	<input type="checkbox"/> Health care
<input type="checkbox"/> Cancer metastasis	<input type="checkbox"/> Negative thoughts	<input type="checkbox"/> Being blessed	<input type="checkbox"/> Media's influence	<input type="checkbox"/> ER
	<input type="checkbox"/> Learning experience	<input type="checkbox"/> Cancer happened in the past	<input type="checkbox"/> Role models	<input type="checkbox"/> Expectation vs. reality
	<input type="checkbox"/> Accepting sympathetic look in people eyes.			<input type="checkbox"/> Healthy lifestyle
	<input type="checkbox"/> Son is over protective			

Case 12: Noura

<input type="checkbox"/> Cancer diagnosis	<input type="checkbox"/> Family support	<input type="checkbox"/> Setting challenges	<input type="checkbox"/> living haunted by the devil's eye	<input type="checkbox"/> Cancer is not the only health problem	<input type="checkbox"/> Health care
<input type="checkbox"/> False hope	<input type="checkbox"/> Hiding bad news	<input type="checkbox"/> Rural area	<input type="checkbox"/> Not showing in public as breast cancer survivor	<input type="checkbox"/> Dealing with obesity	<input type="checkbox"/> Patient rights
<input type="checkbox"/> Shock	<input type="checkbox"/> Overprotection	<input type="checkbox"/> Transpiration issue	<input type="checkbox"/> Fear of devil's eye	<input type="checkbox"/> Poor coping	<input type="checkbox"/> Far follow-up appointment
<input type="checkbox"/> Denial		<input type="checkbox"/> Financial issue	<input type="checkbox"/> Hypochondriac	<input type="checkbox"/> Limited mobility function	<input type="checkbox"/> Support from noun profit charity
		<input type="checkbox"/> Away from family			

Case 13: Ohoud

<input type="checkbox"/> What you feared have come upon you	<input type="checkbox"/> Coping	<input type="checkbox"/> Hidden to survive	<input type="checkbox"/> Feeling different	<input type="checkbox"/> Health care
<input type="checkbox"/> Discovering cancer	<input type="checkbox"/> Life and death concepts in Islam	<input type="checkbox"/> Being passive	<input type="checkbox"/> Weight gain	<input type="checkbox"/> Priority in care
	<input type="checkbox"/> Husband support	<input type="checkbox"/> Protection from cancer stigma	<input type="checkbox"/> Breast shape	<input type="checkbox"/> Barriers in accessing health care fitness.
	<input type="checkbox"/> Faith	<input type="checkbox"/> The right to live normally		<input type="checkbox"/> Barriers in establishing supportive group
		<input type="checkbox"/> Unable to deal with the community		
		<input type="checkbox"/> Lack of trust on others		

Case 14: Sahara

<input type="checkbox"/> Hidden to survive	<input type="checkbox"/> Who is she	<input type="checkbox"/> Back to normal	<input type="checkbox"/> Feeling different	<input type="checkbox"/> Health care context
<input type="checkbox"/> Putting heavy make up	<input type="checkbox"/> A daughter	<input type="checkbox"/> Getting married	<input type="checkbox"/> Cognitive function	<input type="checkbox"/>
<input type="checkbox"/> Short hair cut	<input type="checkbox"/> A wife	<input type="checkbox"/> Divorce	<input type="checkbox"/> Lonely	<input type="checkbox"/> Communication
<input type="checkbox"/> Wearing a wig	<input type="checkbox"/> A fighter	<input type="checkbox"/> Work	<input type="checkbox"/> Physical appearance	<input type="checkbox"/> Lack of breast prosthesis
<input type="checkbox"/> Eye barrows tattoo	<input type="checkbox"/> Patient	<input type="checkbox"/> Dealing with People crustily	<input type="checkbox"/> Fighting against cancer	<input type="checkbox"/> Conservative surgery
<input type="checkbox"/> Benign tumour	<input type="checkbox"/> Dependent on male	<input type="checkbox"/> God's will		

Case 15: Sara

<input type="checkbox"/> Lack of breast cancer awareness	<input type="checkbox"/> Coping	<input type="checkbox"/> Life under evaluation	<input type="checkbox"/> Positive impact	<input type="checkbox"/> Devils' eye is taking over
<input type="checkbox"/> Ignoring the symptoms	<input type="checkbox"/> Husband's support	<input type="checkbox"/> Cancer is God's test	<input type="checkbox"/> Self-growth	<input type="checkbox"/> Why me ?
<input type="checkbox"/> Private health care	<input type="checkbox"/> Finding a comfort zone	<input type="checkbox"/> Patience	<input type="checkbox"/> Health orientation	<input type="checkbox"/> Fear of cancer recurrence
	<input type="checkbox"/> Different roles	<input type="checkbox"/> Thinking of past present-future	<input type="checkbox"/> Following a healthy lifestyle	
		<input type="checkbox"/> God's Reward		

Case 16: Shahd

<input type="checkbox"/> Travelling abroad	<input type="checkbox"/> Living in fear beyond cancer	<input type="checkbox"/> I'm not a survivor	<input type="checkbox"/> Health care	<input type="checkbox"/> I'm not bothered from
<input type="checkbox"/> Running away from cancer stigma	<input type="checkbox"/> Fear of cancer recurrence	<input type="checkbox"/> Cancer is a test from God	<input type="checkbox"/> Decision-making	<input type="checkbox"/> Breast appearance
<input type="checkbox"/> Better health outcomes	<input type="checkbox"/> Worried about her daughter	<input type="checkbox"/> Cancer is a death sentence	<input type="checkbox"/> Conservative surgery	<input type="checkbox"/> Infertility
		<input type="checkbox"/> Surviving from poor prognosis		<input type="checkbox"/> Lack of health education

Case 17: Shamas

<input type="checkbox"/> It was not a cyst	<input type="checkbox"/> Gender issue	<input type="checkbox"/> Living in fears	<input type="checkbox"/> God's will	<input type="checkbox"/> Change during treatment	<input type="checkbox"/> Health care
<input type="checkbox"/> Typical diagnosis for breast mass in the private hospital	<input type="checkbox"/> No shared decision making	<input type="checkbox"/> Implanted silicon	<input type="checkbox"/> Love testing for others	<input type="checkbox"/> Feeling pain	<input type="checkbox"/> No preparation before surgery
<input type="checkbox"/> Listen to your body	<input type="checkbox"/> Marital separation	<input type="checkbox"/> Cancer recurrence	<input type="checkbox"/> God's mercy	<input type="checkbox"/> Being a burden on others	<input type="checkbox"/> No patient care involvement
	<input type="checkbox"/> Amenorrhrea	<input type="checkbox"/> Losing attention		<input type="checkbox"/> Being the focus	<input type="checkbox"/> Positive shared breast cancer stories
				<input type="checkbox"/> Moody	

Case 18: Shatha

Was not a benign tumour	Cancer change you	Feeling different	I'm just like you	Health care context
<input type="checkbox"/> Wrong diagnosis	<input type="checkbox"/> isolation	<input type="checkbox"/> Having breast cancer at young age	<input type="checkbox"/> Survivorship is not a medical outcome	<input type="checkbox"/> Private Vs. governmental health care
<input type="checkbox"/> Grapple with grief	<input type="checkbox"/> body image	<input type="checkbox"/> Amenorrhea is not a big deal	<input type="checkbox"/> Cancer is just like any other form of diseases	<input type="checkbox"/> Delaying in construction surgery
	<input type="checkbox"/> independence	<input type="checkbox"/> People's view	<input type="checkbox"/> Survivorship is an outcome of religious treatment	<input type="checkbox"/> Arm physiotherapy
		<input type="checkbox"/> Hiding her weakness	<input type="checkbox"/> Being normal	<input type="checkbox"/> Lack of family consultation
			<input type="checkbox"/> Surviving cancer is not a privilege	<input type="checkbox"/> Supportive group
			<input type="checkbox"/> Cancer cannot define me	<input type="checkbox"/> Private Vs. governmental health care

Figure 5: Case by case analysis

4. The next step in the analysis process was to move away from the transcripts and use this larger data set representing participants' responses to form emergent themes. Women's comments were grouped, linked, and compared with the themes (see Appendix I). This process involved searching for patterns across transcripts and laying all the themes on a large surface and reviewing them. Using a mind map was helpful in listing the themes that emerged chronologically according to the transcript's structure and my notes (see Figure. 6 below).

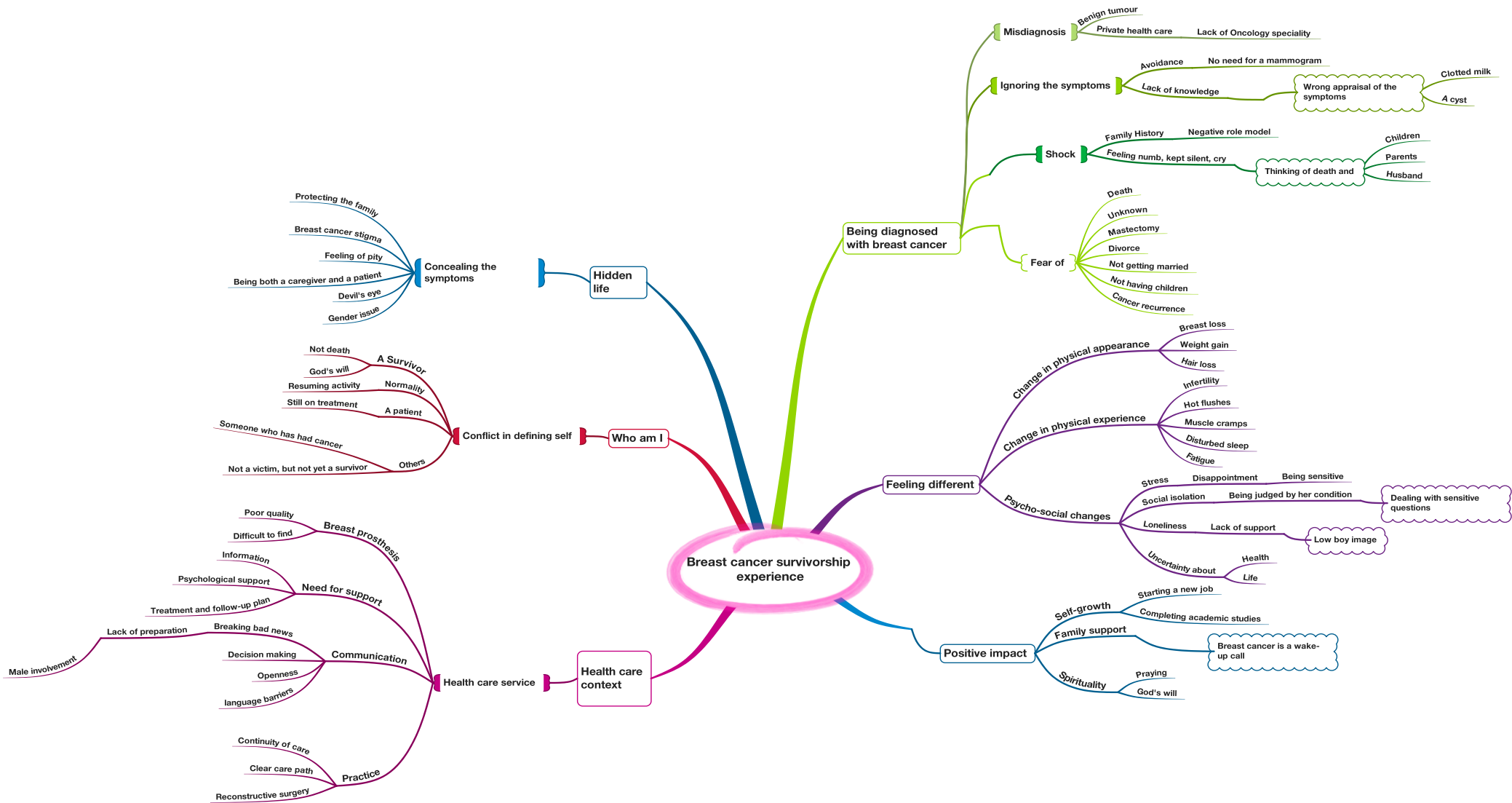


Figure 6: Mind map of breast experience survivorship

5. After the idiographic and descriptive phase, the analysis shifted to a higher level of conceptual analysis and shared experience. This involved ‘dwelling’ on the data, looking for ‘gems’ that captured the essence of the lived experience, possibly a phrase or metaphor (Smith et al. 2009); and using my experience to think critically. Conceptual comments required re-analysing the data and reflecting on and moving away from exactly what the participants said. Smith et al. (2009) recommend conducting a dialogue between the researcher pre-understanding and understanding of the participant’s world. Smith et al. (2009) suggest a useful way of thinking in IPA, moving between:

The part	The whole world
The single word	The sentence in which the word is embedded
The single extract	The complete text
The particular text	The complete oeuvre
The interview	The research project
The single episode	The complete life

(Smith et al. 2009, p. 28)

6. Conceptual analysis is based on identifying patterns and connections between the emergent themes. This entails abstraction, putting like with like and naming for the theme; polarization, identifying relationships and differences (negatives and positives); contextualisation, developing the contextual and narrative themes; and numeration, noting the frequency with which a theme is mentioned, which could indicate its relative importance (Smith et al. 2009). Finally, a master table of the subthemes and superordinate themes was created which were listed in Table 7 (see Chapter 7 shared experiences).

5.5 Conclusion

The data management process involved collecting data, verbatim transcribing, translating into English, writing reflective journals, and selecting the most appropriate framework for data analysis. IPA was used to interpret the data using different levels of

analysis (descriptive, linguistic and conceptual analysis). This chapter has described the process of descriptive and conceptual data analysis in IPA. The next chapter reviews the participants' main idiographic experiences, showing the uniqueness of each woman's story.

Chapter 6 Their idiographic experiences

6.1 Introduction

This chapter provides a description of the experience of Saudi Arabian women who had finished breast cancer treatment. It gives short biographical details of each of the breast cancer survivors before describing their unique experiences. It is worth noting that writing the women's stories in English was a challenging task because I conducted the interview in Arabic, and some words do not translate well into English.

6.2 Participant characteristics

Personal data, such as name, as given by the researcher, age at time of interview and marital status, and medical data, such as tumour stage, time of diagnosis, treatment types and time since completed treatment when interviewed, are all described below in Table 6.

Table 6 Women characterises

Name	Age	Marital status	Family history of breast cancer	Stage	Treatment	Survivorship (time since completed treatment when interviewed)	Reconstructive surgery
Nourah	43	married	No	II	Lumpectomy, chemotherapy, radiation, hormonal therapy	2 years	No
Aisha	40	married	Yes	II	Lumpectomy, chemotherapy, radiation, hormonal therapy	1 year and a half	No
Sahara	38	divorce	No	I	Lumpectomy, chemotherapy, radiation, hormonal therapy, biological therapy	2 years and 3 months	Yes
Shatha	35	married	No	II	Lumpectomy, chemotherapy, radiation therapy	8 months	No
Asma	45	married	No	II	Lumpectomy, chemotherapy, radiation therapy, hormonal therapy	3 years and 2 months	No
Anoud	33	single	Yes	II	Mastectomy, chemotherapy, radiation, hormonal therapy	1 year and a month	No
Lama	37	married	No	II	Lumpectomy, chemotherapy, radiation therapy, hormonal therapy	4 years	No
Asera	45	married	Yes	II	Lumpectomy, chemotherapy, radiation therapy, hormonal therapy	8 months	No
Shahad	46	married	No	II	Mastectomy, chemotherapy, radiation therapy, hormonal therapy	3 Years and a month	Yes
Leena	37	married	No	II	Mastectomy, chemotherapy, radiation,	1 year	No
Ohoud	48	married	Yes	II	Lumpectomy, radiation, hormonal therapy	9 months	No
Shamas	48	Separated	No	II	Mastectomy, chemotherapy, radiation therapy, hormonal therapy	8 months	No
Alaa	40	married	Yes	II	Lumpectomy, chemotherapy, radiation therapy	4 years	No
Sara	49	married	No	II	Lumpectomy, chemotherapy, radiation therapy, hormonal therapy	3 years	No
Amar	38	A widow	No	II	Lumpectomy, chemotherapy, radiation therapy, hormonal therapy	1 year	Yes
Haia	44	married	Yes	II	Mastectomy, chemotherapy, radiation therapy, hormonal therapy	8 months	No
Maha	44	married	Yes	II	Mastectomy, chemotherapy, radiation therapy, hormonal therapy	1 year and 4 months	No

6.3 Breast cancer survivors' idiographic experiences

6.3.1 Nourah

Nourah is in her early forties, is married, has four children, is a housewife, and describes herself as struggling with being overweight, to the extent that her ability to move freely is inhibited. She was diagnosed with breast cancer, stage II, after initially being told by a general physician that a lump in her breast was likely to be a benign 'cyst' – similar to the experience of some other women in my study. Her family is very important to her; they were the first concern to cross her mind when she learned of the diagnosis. She thought about what would happen to her young twins if she dies. For her, having breast cancer was a shock, especially at a younger age. Nourah lives in a rural area and that doubled the burdens, as she had to travel and leave her children to have the treatment; which also brought financial and transportation problems.

Nourah was very warm (friendly and kind) and talked openly about her experience with breast cancer, but was guarded in answering my questions about the impact of the disease on her family. She expressed her discomfort with family and close friends asking about her marital relationship. Here, I realized that I should be very careful discussing this issue with her, and also in the future with other participants. She was the first participant who mentioned fear of the devil's eye and believed that it could be the cause of breast cancer. Interestingly, Nourah refused to wear the pink ribbon because it is a symbol of breast cancer:

I can't see myself as a survivor, wearing the pink ribbon and going out in public, talking about my experience and saying "*hey, yes – I was sick*" (Nourah).

Her life after the breast cancer treatment is characterised by a mixture of feelings: hope, and fear of cancer recurrence. Her understanding of the importance of being healthy was agreed, but there was a lack of control and motivation to lose weight. In the more personal elements of the interview she confided that she ate more to forget her disease, as a way to cope with it.

6.3.2 Aisha

Aisha is 40 years old, married, and has three children. She has a diploma certificate in education and recently found a job as a secretary in one of the elementary schools. She

is warm, open, and social. She was diagnosed with breast cancer stage II in late 2011 and finished treatment in 2012. She had a lumpectomy, chemotherapy and radiation therapy. Aisha presents a model of the good wife (which is defined culturally in terms of attending to a husband's needs), who cares about her husband and considers him a priority in her life.

At the beginning, she describes her experience with her breast cancer diagnosis and how the doctor avoided telling her the result of the test unless she came with a male relative. Here, her tone filled with anger because the doctor's attitude was unprofessional. Her mother died from breast cancer and that was negative for a breast cancer patient, as she thought that her destiny would be the same as her mother.

Although I was surprised at how open Aisha was to share her story with me, she was not comfortable revealing personal events about her sexual life. She cried and I had to stop the interview several times to keep her calm. It appeared that the supportive husband's role that was supposed to be present was actually absent. She described it as the biggest disappointment in her life because he was unsupportive; he sent her to stay at her parents' home during treatment, avoiding any contact, and confronted her with his future plan to get divorced and marry again.

My biggest fear was to be ugly in my husband's eyes and that's what happened. I didn't feel any compassion and support... he didn't like to see me. He was sleeping in a separate room (Aisha).

It appears that Aisha has taken action to make sense of her experience with breast cancer and perceive it as a learning experience, such as finding a new job to be independent and productive, performing spiritual/religious activities, and involving herself more in her children's lives. Aisha's unique perspective about survivorship is related to accepting God's will, surviving death, and accepting that there is nothing to do to control the disease as it is within God's hands. In talking, her experience with the healthcare services during diagnosis and treatment was characterised by a lack of support during breaking the news, and the health information was not sufficient.

6.3.3 Sahara

Sahara is in her late thirties, twice-divorced, a pharmacist, and the youngest in her family. She has three boys living with their father (her first husband). She had a lumpectomy and received chemotherapy, radiation therapy, and hormonal treatment.

The interview with Sahara was characterised by some caution, nervous laughter, and mystery in some parts of her story. For example, I did not understand how she was able to hide her disease away from her sick mother since they lived in the same house, and how Sahara was able to deal with the side effects of treatment alone and events preceding this. On reflection, I realized that Sahara did not want to upset her mother, who was seriously ill, and to show weakness to her parents who depend on her. She talked about living in a double identity, where the first one is the ‘hidden identity’ that looks weak and needs support from others, and the ‘visible identity’, which is the strongest one that people can depend on.

Alone among 18 participants, Sahara was very open about her personal experience with loss and I was emotionally impacted by her story. She lost her mother, who did not know about her daughter’s disease, during the last course of radiotherapy; she lost a feminine part (her breast); and lost her self-esteem from a disappointing marriage. She justified her choice of getting married by looking to be loved and feeling lonely, especially after her father’s new marriage after her mother’s death. She was the second wife and the concept of marriage here is based on fulfilling sexual needs. Sahara expressed her fears to her husband of getting pregnant, which may not be totally safe. But her husband ignored her fears and continued to practice the intimate relationship with no precautions and expressing that abortion might be an option if pregnancy occurred.

Sahara was clear that the term ‘survivor’ does not fit her as well as the term ‘fighter’ because she believes that ‘fighter’ involves either winning or losing the battle against cancer, even after finishing the treatment. She describes herself in her profession as the ‘pharmacy’s butterfly’ [*her words*], being active and professional. However, the diminishing of her cognitive ability as a result of having chemotherapy affects her

ability to memorize medication information, which became a challenge since she went back to work.

6.3.4 Shatha

Shatha is 35 years old, married, and has four children. She is a housewife and has a high school degree. She was diagnosed with breast cancer stage II in the middle of 2013 and finished treatment in 2014. She had a lumpectomy, chemotherapy, and radiation therapy.

Shatha's breast cancer journey began when she discovered a lump in her left breast. She received a response from the general doctor that it was unlikely to be anything of concern and it was just a benign tumour that could be removed surgically. However, Shatha listened well to her body and sought a specialist's opinion, and she was diagnosed with breast cancer. The impact of the diagnosis left Shatha with a sudden awareness of her mortality and her thoughts turned to what she may lose. During treatment, there was a constant state of pain, isolation, sleep deprivation, and lack of appetite. This long-term exhaustion altered her relationship with her husband, who did not know how to comfort his wife.

For her, there was a resistance to using the term 'survivorship' because she believes that breast cancer is just like any other disease that anybody can get. Also, she claimed that survivorship is culturally influenced by God's will and not related to personal influence. She wants to be treated as a normal person, just like before having the disease. During the interview, Shatha started to reflect on her experience, make sense of it, and feel different:

As I'm talking to you right now, I feel as if I'm telling you a story about a different person and not about myself. I'm feeling sorry for her... because she had a serious disease and had gone through tough treatment (Shatha).

While being treated, what Shatha cared about was finishing the treatment as soon as possible and staying alive, but when she moved beyond the treatment period, she started to think differently and regret not having the strength and the positive attitude to cope well when she was dealing with the diagnosis and treatment issues.

6.3.5 Asma

Asma is 38 years old, is married, and has three boys. She was diagnosed with breast cancer stage II in 2012. She had a lumpectomy, chemotherapy, and radiation therapy.

Initially, Asma was very measured in her responses and sought clarification of the questions. When I asked her to tell me her story of breast cancer, she was nervous and asked if there was a particular thing I need to know. I told her that I'm interested to know her story with breast cancer before, during, and after breast cancer treatment. She was reassured when she knew that the interview would not be formal and she was free to tell her story in the way she liked.

Asma was misdiagnosed at a private hospital and then transferred to a government hospital specialising in oncology. When I asked her to tell me her story and the impact of the diagnosis on her family, her eyes filled with tears. Here, I noticed that her personal experience with breast cancer was not easy. She was suffering alone with no support from her husband, who believes that her disease is contagious. She stated that she is watching her husband planning to get married to someone else once she finished treatment. She claimed that her husband did not want to look selfish publicly, since people may comment that he left his wife when she needed him. On the other hand, her boys were very supportive, and it is clear from the tone of her voice how proud she was of her children when they shaved their heads just to support their mother. She talked about her plans to travel around with her children and establish a studio at home to practise her hobby as a painter.

6.3.6 Anoud

Anoud is 33 years old, is single, has a diploma degree in computer science and lives with her family. She was diagnosed with breast cancer stage II in mid-2012 and finished treatment in 2013. She had a mastectomy, chemotherapy, and radiation therapy, and is currently on hormonal treatment.

She described her misleading thoughts about the tumour when she felt it; she told herself that it could be just a cyst, which developed from hormonal changes; she was still young to get cancer. According to her, she was afraid and did not have the courage to ask, so she ignored the symptoms until the tumour had become larger than her other,

normal breast. Being diagnosed with breast cancer was shocking for her as well as for her parents, who were very worried about losing their child.

Anoud is the youngest participant who has not been married. The interview was very open and warm. Since we are close in age and share the same culture, this helps me to understand her experience. The uniqueness of Anoud's story lies in her position as a woman dealing with the negative criticism from friends in relation to fertility, body image, and low chances of getting married:

A married woman who has breast cancer wouldn't accept this disease easily. So, can you imagine how this would be for a young single woman like me! (Anoud).

Anoud believes that breast cancer is not a deadly disease and surviving should not be linked to death. Instead, she perceived her experience with breast cancer as a 'fighting battle' not against the disease itself, but also against the negative cultural beliefs. This was evident when she talked about her participation in a breast cancer campaign as a way to present a positive role model to the community. She developed improved self-esteem that helps her to be less affected by negative comments from people she perceived as ignorant.

6.3.7 Lama

Lama is 38 years old, married, has 3 girls, and works as a schoolteacher. She was diagnosed with breast cancer stage II and finished treatment two years ago. She had a lumpectomy, chemotherapy, radiation therapy, and is still on hormonal therapy.

Her family, especially her sisters, were disturbed and advised Lama not to start the chemotherapy because of its severe side effects. Instead, she tried herbal and religious treatments, like drinking holy water and going to a religious man – based on her husband's advice – but with no benefit. Later, she realized that having chemotherapy would be necessary to control her disease, so she agreed to have it. Lama reflected on how nervous she became when people asked about future pregnancy plans and her relationship with her husband. This irritation made her isolated and she had hidden the infertility issue from her husband until now. This was evident when she lowered her voice for fear of being heard by her husband, who was waiting for her outside the room. In terms of her experience with the healthcare service, it appeared that health

information about chemotherapy, diet, and physiotherapy are needed. She claimed that the healthcare service post-treatment has changed; doctors became less inclined to answer her questions about cancer recurrence.

6.3.8 Asera

Asera is 45 years old, married, a housewife and has two adopted children. She was diagnosed with breast cancer stage II in late 2013 and has a family history of cancer. She had a lumpectomy, chemotherapy, and radiation therapy, and is still on hormonal therapy.

At the beginning of the interview, it was not easy for Asera to start telling me her story because she was confused about where to start, and hesitant also. I gave her time to calm down and be less distressed. Firstly, she talked about her husband's shock and worry when he knew about the diagnosis, and then how he was forced by his family to have a second wife. She describes how restless her husband became during treatment. On reflection, Asera was giving an excuse for her husband's change and putting the blame on breast cancer and her zero chances of getting pregnant, as acknowledged before in Lama's case.

The interview with Asera was emotional and it felt very husband-centric. I was interested to try to understand if the breast cancer experience has had a positive impact on her: she was clear that losing her husband and seeing him getting married to another woman was harder than losing her breast. Here, she perceived herself as a 'victim' and has a life filled with tears and pain. This was evident when I asked her during consenting what she liked to be called in the study and her answer was 'Asera' which means 'captive' in English:

All these physical problems can't be simply compared with what I'm feeling right now. I'm spending 85%, most of my time now crying ... crying while I'm praying, crying while I'm sitting with my family. My life now is filled with pain and tears (Asera).

The healthcare service experience post-treatment was less apparent during the interview, as some points were given more emphasis during treatment, especially those related to feeling shy when exposing her breast to a male doctor, due to shortage of female medical staff.

6.3.9 Shahad

Shahad is 46 years old, married, and has five young children. She was diagnosed with breast cancer stage II, had conservative surgery, chemotherapy, and radiation therapy, and is still on hormonal treatment.

Shahad was very calm and welcomed participating in the interview. When I first asked her to tell me about her experience, she took a deep breath and then cried. I gave her time to be less distressed and then asked if she wanted to stop the interview, but she refused and was happy to continue. After a break, she explained that she never talks about her experience after finishing breast cancer treatment to anybody, including her family.

Before Shahad had received the treatment in Saudi Arabia, she decided to have it abroad for two reasons. The first reason was her belief that abroad has better healthcare than Saudi Arabia. Second, she wanted to keep her diagnosis hidden from her parents and friends. Here, I understand why she is more guarded in opening up about her experience and sharing her story with others if they requested to in the future. This is a conflict issue between her and her daughter, who supports the idea of being open about breast cancer.

Her experience with the healthcare service is satisfactory; she was lucky having a conservative surgery to save the normal breast appearance, unlike many other participants. Also, having a family relative working for the hospital as a physician has helped her in coping well with the disease by gaining information.

6.3.10 Leena

Leena is 37 years old, married, and has four children. She was diagnosed with breast cancer stage II, and had a mastectomy, chemotherapy, and radiation therapy.

The interview with Leena was warm and open, although it was interrupted by her husband who was in a rush. So, we agreed to continue the interview by phone. Important elements were identified which helped me to understand the lived experience of a breast cancer patient. For her, the most important element that helps her to cope with the disease is her husband's support. She describes how he took a break from work

to be with her at the hospital. Her daughter was the family member most impacted by her mother's disease; she becomes irritated and has low school performance.

For me, one of the most revealing issues of Leena's interview was the narrative related to getting pregnant six months after finishing treatment. She describes it as the most unexpected thing that could happen to her, and then decided to keep the baby. On reflection, she assumed that having a new baby might give her hope and a way to start a new experience as a mother, which would help her to be distracted from thinking of her breast cancer experience.

Her experience with the healthcare service was not satisfactory. It appears that genetic consultation is not provided at this stage to give Leena information about the risks and benefits of having a baby. She needs social and psychological consultations to deal with many issues:

I'm wondering whether I'm doing good or bad things in my life or if that disease is a blessing or punishment from Allah [God] (Leena).

6.3.11 Ohoud

Ohoud is 48 years old, married, and has one girl and three boys; she is a retired schoolteacher. She was diagnosed with breast cancer stage I in the middle of 2013 and finished treatment in 2014. She had a lumpectomy, radiation therapy, and hormonal treatment.

Ohoud is the only participant who was diagnosed at a very early stage and did not have to deal with chemotherapy side effects as all the other participants did. She describes how she used to wear loose clothes to manage skin burn after radiation therapy. Despite that, she decided to live hidden and keep her diagnosis secret from friends and extended family. This decision was based on the negative cultural image of breast cancer held by the community, and protecting her family from dealing with this stigma.

Ohoud feels pessimistic about developing a breast cancer support group because she thinks that the Saudi community is not prepared to accept the concept of support as Western cultures do. Ohoud is passive in dealing with the identity of a breast cancer

patient and does not want to be identified by a disease that she is already cured from. In contrast to Anoud, who took part in breast cancer campaigns, Ohoud was insecure, as she was doubtful about people's thoughts about her, and could not have trust in people in terms of protecting patient confidentiality in support groups. Also, she claimed that this decision had not only come from her side, but her family also agreed.

Ohoud perceives her experience with breast cancer as a 'wake-up call' [*her words*] to be more involved in religious activities, to be closer to God, and to spend more time with family. She described how busy her life was before the disease; thinking about financial issues such as mortgages, going out, and being socially active.

6.3.12 Shamas

Shamas is 48 years old, separated, has three boys and one girl, and is a housewife. She was diagnosed with breast cancer stage II. She finished treatment eight months prior to the interview. She had a mastectomy, chemotherapy, and hormonal treatment.

Shamas is a reserved person and spoke in a constant tone; some points were given more emphasis, especially those related to being spiritual and accepting God's will. Some issues were less apparent in the interview, such as the impact of cancer on family. Her experience with the healthcare provision was not positive as she claimed she had been diagnosed with a benign tumour by a general physician and waited for a year before knowing that it was breast cancer. For her, doctors were not professional in terms of breaking bad news and preparing her for the treatment plan. The gender issue, raised first by Aisha, also appeared in Shamas's story; she claimed that the doctor tended to involve her son in the decision-making process more than her. For example, the surgeon asked the son to tell his mother about the surgery process, date, and time. On the other hand, Shamas perceived removing the tumour surgically as a sign of surviving and God's mercy. However, she expressed her fears of having breast cosmetic surgery and the risk of cancer recurrence because of the implanted silicon object. This issue was reported among many participants, who expressed their fears of having surgery again.

Her life with breast cancer was perceived as a lesson to keep an eye on the people who are most important to her. She expressed feelings of loneliness and change in the family support system that she used to depend on:

My eldest son and I used to sit and chat; he was very close to me. Just before my surgery, he celebrated his wedding. What upsets me most is that although he is living just nearby, sometimes he would come to visit me just in order to do what he is expected to do as a son... to whom shall I express my feelings now? (Shamas).

6.3.13 Alaa

Alaa is 40 years old, married, has three children, and is a housewife. She was diagnosed with breast cancer, stage II, three months after giving birth to her child. She had a lumpectomy, chemotherapy, and radiation therapy.

Alaa was warm and was happy to share her story with me. She never expected to have a cancer, especially when she thought the tumour was only clotted milk, until it became large in size over time. Alaa has a family history with cancer; her sister died from lymphoma and that has negatively influenced her experience with breast cancer; she thought about death and losing her children. Here she cried and I knew that talking about her sister's experience was not comfortable, so I paused the interview until she became calm:

My sister had cancer and she had a painful experience. She used to undergo chemotherapy on and off. Her case deteriorated, she was admitted to the ICU and never got out from it; later... she died [tears] (Alaa).

Alaa coped with the treatment side effects by being spiritual and putting 'trust in God' [*her words*]. However, it appears that Alaa could not live beyond her experience and move forward. This was evident when she talked about her fears of cancer recurrence and being neglected again by her husband if the cancer comes back. She feels lonely, especially after her sister's death, as her sister was her source of support and the person who understood her feelings. Also, living in a conservative family as she described it was one of the causes of feeling lonely; her social life is very limited. Thus, she refused to share her story with other women, justifying that she needs help first in order to help others in future.

The challenges that she dealt with in terms of healthcare practice were lack of communication and information about physiotherapy. She describes how her role as a mother was impacted by lymphedema:

I had a problem with my arm; I couldn't lift it up and I couldn't comb my daughter's hair either (Alaa).

6.3.14 Sara

Sara is 50 years old, married, is a housewife, and has five children. She was diagnosed with breast cancer stage II in late 2010 and finished treatment in 2011. She had a lumpectomy, chemotherapy, radiation therapy, and hormonal treatment.

The interview with Sara was characterised by a fast pace, with little hesitation in her answers. Like Sahara, Sara's diagnosis was kept very private from her mother until she had finished treatment, to protect her mother from being sad; performing her role as a good daughter as she stated "*it's expected for me as daughter to make my mother happy not to upset her with my disease, especially when my extended family linked cancer with death*". Her individual viewpoint of survivorship is like many others, influenced by accepting God's will and finding a spiritual meaning for her experience.

Her answers about the impact of breast cancer on her life demonstrated confidence, strength and self-growth:

To beat cancer, you have to be in a good or stable psychological status and that's what I'm trying to do (Sara).

She described how supportive her husband was during treatment and made her feel normal and attractive, though their sexual activities stopped. It is clear that her husband's role was central in shaping her positive experience with breast cancer and presenting a positive image about the husband's support.

Unlike Alaa, Sara is very keen to participate in breast cancer awareness activity, as she perceives it as her new mission to support other women. For example, she talked about her experience participating in student parents' meeting to share her experience with other mothers and raise awareness. She is positive about developing a breast cancer survivorship programme, focusing on empowering women physically, socially, and mentally.

6.3.15 Amar

Amar is 38 years old, a widow, a housewife, and has two children. She was diagnosed with breast cancer stage II in 2011 and finished treatment in late 2013. She had a conservative surgery, chemotherapy, radiation therapy, and hormonal treatment.

Amar discovered her tumour while doing breast self-examination, and did not wait until she found out that it was breast cancer. Having breast cancer at such a young age makes her feel different, especially when she was surrounded by elder patients during treatment and questioning herself; ‘why me?’ [*her words*].

In relation to her personal experience with healthcare services, she was clear that having a conservative surgery has a positive impact on accepting the disease. On reflection, Amar feels lucky to have had the conservative surgery done, in contrast to other women who would wish to have the chance to do it:

I was lucky because I completed the surgery and the plastic surgery for my breast at the same time. My family and husband encouraged me to do it and I’m glad that I listened to them (Amar).

The uniqueness of Amar’s story presents itself in her self-growth in relation to completing her bachelor degree after finishing treatment. Also, she was able to cope well with her disease without her husband’s support, as he sadly died during her treatment. The experience with breast cancer left her thriving, determined to be alive for her children and to try new things in life.

6.3.16 Azizah

Azizah is 50 years old, is married, has five children, and is a housewife. She was diagnosed with breast cancer stage II in early 2011 and finished treatment in 2013. She had a lumpectomy, chemotherapy, radiation therapy, and hormonal treatment.

Azizah has a strong family history with breast cancer since her younger sister had breast cancer. Azizah is aware of the genetic association with breast cancer, thus she is worried about her daughters having breast cancer. The unique element of Azizah’s experience is the extent to which her sister’s experience with breast cancer has influenced hers too:

I don't know how I can explain it to you. Hmmm, I had a feeling that one day I would be just like my sister and it happened (Azizah).

She described how her role doubled by being the caregiver of her sister with breast cancer and the patient at the same time. Azizah decided to keep her diagnosis hidden from her family, especially from her sister who was in her second cycle of chemotherapy. The consequences of this decision left her suffering alone and in need of family support, which was only focused on her young sister:

Her situation was better than mine because she was surrounded by my family who were all praying for her. I wish I could have told them, "*please pray for me too,*" but I couldn't bring myself to do it [tears] (Azizah).

She claimed that only her husband and children know about her disease. In order to be hidden from family and friends during treatment, she did the following: wearing a wig in every meeting; making eyebrow tattoos; isolating herself at home and excusing herself by being outside the country for a vacation. Having tried many things to feel normal, she felt different, especially when it comes to body image. She described how she gained weight as a result of having hormonal therapy and how she looks older than her actual age. Feeling different, and comparing her looks to before cancer, makes her vulnerable to any negative comments.

6.3.17 Haia

Haia is 44 years old, is married, has six children, and is a housewife. She was diagnosed with breast cancer stage II in early 2013 and finished treatment in 2014. She had a mastectomy, chemotherapy, radiation therapy, and hormonal therapy.

Haia discovered breast cancer by chance; her mother was diagnosed with breast cancer and her oncologist advised Haia to have the mammogram. She was shocked at having breast cancer, so she decided to keep her disease secret from her mother because she would not be able to handle the shock. Her experience with the treatment was not easy on her or her elder son, who was scared of losing his mother. She described how her son was afraid of chemotherapy side effects and begged her not to have it:

He told me to stop having the chemotherapy because he was afraid of losing me. I used to hide my medication so he [her son] couldn't see it [tears] because I didn't want him to get worried and see that I was seriously ill (Haia).

Haia is not open to talk and express her feeling to others, including her husband, who just reminded her to accept God's will, which is what she did. She claimed that praying to God is the only way to express her feelings instead of sharing her emotions with others who do not understand her experience. When I asked her about health concerns, she answered that there are no guarantees in life:

Death is a finalised concept and it will happen sooner or later, either by having a serious disease or as a result of something else like a car accident (Haia).

6.3.18 Maha

Maha is 47 years old, is married, has four children, and is a housewife. She was diagnosed with breast cancer stage II in the middle of 2013 and finished treatment in 2014. She had a mastectomy, chemotherapy, radiation therapy, and hormonal treatment.

The interview with Maha was characterised by short, direct answers and I tried hard to get more information, especially those related to her strong family history with cancer. She claimed that her mother had breast cancer 10 years ago and that her daughter had leukaemia two years ago. Thus, having breast cancer was not a big issue, as she described. Fear has no room in her life; she fights cancer by being highly spiritual just to be alive for her children. Having previous experience with cancer helped her to know what to expect, especially in relation to long-term treatment side effects:

After the radiation therapy, I started to do physiotherapy exercises to my arm, because my mother's arm had got worse because she stopped doing the arm's exercises (Maha).

Her experience with the follow-up plan was good, as she was informed by the healthcare team about the plan, including investigations and appointments. However, she expressed her disappointment in the poor service of emergency room care and long waiting hours there.

6.4 Conclusion

Both positive and negative individual experiences of breast cancer appear to be shaped by the culture. For example, all women expressively explained that their experience was shaped by certain cultural elements, like family, relationships, religion, gender, and women's position. Each woman has a unique element in her story developed from

certain beliefs, previous cancer experience, cancer meaning, and relationships. Most of the women describe their lived experiences with a retrospective approach, but felt real as I was there. The next section views the main shared experiences and linguistic interpretations.

Chapter 7 Their shared experiences

“Let that old story go, so that a new story, a truer story can be told” (Jarvis 2014).

7.1 Introduction

Following the presentation of the unique individual experiences in the previous chapter, this chapter views the common shared experiences of 18 Saudi Arabian women who had finished breast cancer treatment. Any shared comments reported through interviews were grouped and linked with superordinate themes which described the subordinate ones. Each theme reflects the essence of participants’ experiences is shown below in (Table. 7).

Table 7: Superordinate and subordinated themes

Survivorship experience	<ul style="list-style-type: none">• Meaning of cancer• Hidden to survive• Living with reminders
Cancer change me	<ul style="list-style-type: none">• Fear of cancer recurrence• Confusion and loneliness• Body image• Infertility and menopausal symptoms• Positive changes
Identity	<ul style="list-style-type: none">• Women’s position• Age• Role• Being a survivor
Faith and beliefs	<ul style="list-style-type: none">• God’s will and religion• Devil’s eye• Coping• Spirituality
Health care experience	<ul style="list-style-type: none">• Health care path• Health care service• Patient’s preparation• Patient needs• Communication

7.2 Breast cancer survivors’ shared experiences

7.2.1 Survivorship experience

All the women described their experiences of breast cancer as being very difficult and distressing. For all women, having breast cancer was an unexpected thing, which

prompted feelings of shock and confusion. It was important to understand the concept of cancer and how women make sense of their experiences.

7.2.1.1 Cancer meaning

The date of receiving the results was relevant for all the participants in shaping their experiences and social identities. At the time of diagnosis, each woman's understanding of breast cancer was very negative. The diagnosis of breast cancer deeply influenced women in this study to think of their mortality – once they heard the word 'cancer' – because they considered it a life-threatening illness. For women who linked breast cancer with death, the moment of diagnosis was very shocking:

She told me it was cancer; I asked her “How?” I held her hand and continued, “How could it be cancer?” She explained later that it was a small tumour beginning to grow. I started to weep, while my mother was trying to comfort me and she [her mother] was actually crying more badly (Nourah).

Others thought about the chemotherapy and its side effects:

I thought that I would die... I refused having the chemotherapy. What was the point of taking it? [chemo].... I surrounded and said to myself that it was our God's will (Asera).

My family advised me to not have the chemotherapy because of its severe side effects, and instead I should go with the religious / herbal treatment ... you know, like drinking holy water and praying (Lama).

Although some women kept silent and had not expressed any reactions once the results were revealed:

I didn't have any information about breast cancer except that it would make me bald. I kept silent.... I didn't cry... I just said “*thank you, doctor*” and went out from the room ... I was shocked (Lama).

All the women thought about death and leaving their loved ones behind:

I thought about my children, life and death, but mostly about my children. I thought if that thing [breast cancer] found its way into my body, it would spread outside my breast (Nourah).

I was worried about my small daughter. She was eight years old; who would take care of her if I died? (Sara)

I wasn't as afraid of losing my health as I was afraid of losing my parents or making them sad (Sahara).

Having previous experience with cancer had negatively influenced women's reactions towards cancer. Many women express fears of breast cancer because they were in touch with cancer patients within the family and know how much they would undergo, especially during treatment:

My mother had the disease 10 years ago and my daughter had leukaemia two years ago. Their experiences affected me... I was afraid of cancer and of suffering just like them (Maha).

On the other hand, Nourah's cousin's positive experience with cancer helped her to accept her disease and be hopeful:

She had leukaemia and I felt sympathy for her when she went through different types of treatments for so long, but she is fine now, thank god. When I thought about her experience at that time, I thought that I might survive and get rid of the cancer just the way she did (Nourah).

In terms of the meanings held by the community towards cancer, different myths and stigma related to cancer were reported. All participants claimed that people perceived them as patients who would nearly die:

At the hospital, one lady started to ask me a question about how many children I have, and said to me in a tone filled with sorrow, "*oh, I hope you have enough time to live and raise them up*". It felt like I was going to die tomorrow! (Shatha).

She [the technician] couldn't hide her facial reaction when she saw the tumour... she said, "*oh, this is a huge tumour and it could spread very fast – oh, you are still young*". At that time, I didn't know that I had breast cancer... her attitude wasn't professional at all. I went out from the room crying, and said to my husband, "*I hope it [cancer] won't reach my bones*". She wasn't supposed to tell me any information, until the doctor wrote the final report (Leena).

People whom I know, said behind my back that I had travelled abroad not for a vacation, but to have treatment because I'm seriously ill, and I had a silicon implant in my breast [laughs] (Sahara).

Some women in the study claimed that people thought that cancer is a contagious disease:

My husband didn't want me as a wife anymore... he thought that I had an infectious disease and he would catch it. I felt that I was an expired or useless person to him, and he would go and search for another woman (Asma).

When she [her friend] found out that I had breast cancer, she just broke off our relationship... she used to believe in stuff like the devil's eye and magic, and she thought that this disease [cancer] could be transferable or infectious (Sahara).

7.2.1.2 Hidden to survive

Women perceived breast cancer as a source of suffering and shame for themselves and their loved ones. Having this stigma led all the women in this study to live in silence. Justifications of living hidden varied from woman to another, but the majority decided to hide their disease to protect themselves from pitying feelings and negative comments, by becoming less social and limiting their friendship circle.

I didn't want my extended family to know. I didn't want anybody to feel sorry for me. It's true that some people don't know how to comfort you. I wanted to protect myself from any words that could hurt me (Ohoud).

She added:

You know, sometimes I'm sharing my experience with breast cancer with others, without saying that it was in fact my story and that I was the patient. Instead I was just telling them that I knew a lady who had breast cancer and who is now alive and living her life normally, but without ever saying that it was me! [Justifying] (Ohoud).

Anoud decided to be at home instead of meeting friends who used to treat her differently during the chemotherapy period:

Could you believe that some of them [friends] went out of the room because they didn't like to see me? I didn't know if they were scared or sorry for me...I never asked why. That's why I limited my relationship to my family and spent most of the time reading books instead of seeing lots of people who are feeling sorry for me. You know, in our community there is a stigma linked to cancer and death (Anoud).

Shahad planned to have the treatment abroad just because of her fear of the sorrowing look that she used to give to cancer patients before having the disease:

My plan was to get the treatment in the US and stay there for two years and then come back, because I didn't want people to know that I had the disease and then start to feel sorry for me (Shahad).

Another woman had to lie to her extended family and said that she was on a vacation outside the city:

My husband and I used to invite friends and family to our house on special occasions to celebrate... all that had changed after cancer. I didn't want people to know that I was sick. I used to give them a false excuse, like we were outside the city (Azizah).

Some hid their experience with breast cancer because they want to live normally and not feel different in a society which held a negative image about them.

I don't want to be judged based on my experience with the disease. I can't be sure if people would see me as a normal person; our community is very curious... I don't want to remember that I was a patient. Is it a label stuck to me forever? (Ohoud).

Several women take precautions to cover the side effects of treatment, like wearing a wig or a headscarf, doing eyebrow tattoos and wearing loose clothes:

It is not good to show people that you are sick, because they would say: "*oh, I felt sorry for you when I knew what happened*". I need them [people] to pray for me and treat me as the same person that they used to know before cancer (Shahad).

I prefer to keep my experience private and don't share it with anybody. I don't like to sit in the waiting area of the hospital because I'm afraid of being seen by someone I know. I didn't tell my family about the disease so how come I would tell a strange woman? (Ohoud).

Others hid their disease to protect their loved ones from sadness and worries. Sahara and many others did not tell their mothers about breast cancer even after they finished treatment:

I used to have long hair... I did that because I was trying to protect her... I told her that my hair became weak and I would like to follow the trend as some of my friends have short hair [that was a lie] but thank God she believed me. Can you imagine that my mother died in my first session of radiotherapy without knowing that her daughter was diagnosed with breast cancer?... [tears]... I had no support... nothing (Sahara).

Another form of hiding was to conceal feelings and needs and that let some women suffer even more in silence. Aisha and many other women suffered from a lack of support from their husbands, and that made it hard to express their feelings:

He [her husband] didn't show me his compassion or his sorrow. I tried to talk to him and explain how I really do need his support in this difficulty, but he rejected me by saying: "*you are not the first or the only one who got sick*" (Aisha).

I would like to have some attention... all I need is support, but at the same time I cannot express my needs and talk freely, because people may perceive it as weakness and I don't want that (Sahara).

7.2.1.3 Living with reminders

Finishing treatment was not the last chapter of the women's experience and it was not the end of their recurrent thoughts of cancer, especially with the presence of reminders of their experiences with breast cancer that hinder their ability to cope and move on with their lives.

Body changes after breast cancer serve as daily reminders of the experience that participants went through. Some women avoid long looks in the mirror or old albums, because these generate feelings hard to forget:

Sometimes, I looked at my old album and I could see how chemotherapy had affected my life... I refused to have my picture taken during treatment. Oh, I missed my long hair (Shatha).

Some physical symptoms, like feeling pain or tumours, could be a trigger, putting the breast cancer survivor under stress by thinking of cancer recurrence:

Two months ago, a new tumour came out. I was really scared, but the doctor told me that it was an accumulation of solution. I thought that the cancer had come back to drown me again, but it didn't happen, thank God... I'm alive (Shahad).

Other reminders of cancer experience were associated with cancer treatment, like taking medication, having conservative surgery, and performing physiotherapy:

My husband advised me to have plastic surgery, but I refused because I'm afraid of having surgery again. I don't need it. (Lama)

After finishing the treatment, I hate taking medications, even for simple complaints like a headache (Leena).

I'm sick of taking many pills every day; I have a big box full of medications... Oh, God, when will this end! (Azizah).

Doctors advised me to do physiotherapy, but I didn't listen to them... I don't want to go regularly to the hospital, I hate hospital... I had had enough (Anoud).

Many women wished to forget their past experiences with breast cancer, but this is hard because people around talked about sad cancer stories:

Patients with advanced disease used to sit with me and told me their stories so I thought that I might reach their stage later on. Even now, I'm still worried (Nourah).

Many women expressed their inability to forget the disease, while there are people who keep treating themselves as patients even after finishing treatment:

Sometimes they ask private questions; my friend asked me about the relationship with my husband and if the chemotherapy had affected our relationship, especially after I lost my hair... I said to her, "*that is none of your business. Please don't ask me these questions again, and respect my privacy*". People expected that my husband would leave me (Nourah).

I don't like to be treated as I was having the chemotherapy. My brother asked me once if I was ok and said "*yes, I'm fine*". Then he said, "*so, why do you have to take pills and go to the hospital... you said you are fine*". He can't see that I'm a normal person just like him, and I'm only going to the hospital for a check-up (Amar).

7.2.2 Cancer changed me

This theme serves to describe both the positive and negative issues that are quite common among breast cancer survivors. This part covered all the experiences that came from diagnosis, treatment, and post-treatment to see how participants' lives changed over these periods.

7.2.2.1 Fear of cancer recurrence

Fear of cancer recurrence is a commonly reported issue among all the participants. Participants were not asked directly about their fear of cancer recurrence, as I did not want to introduce this to those who do not consider cancer recurrence a source of concern. I asked the participants if there were any difficult or worrying issues that they felt or thought about when they had finished their treatment.

All the participants expressed their fear of cancer recurrence in the future. That feeling was prompted by periods of contemplation by the participants, usually before a follow-up appointment and when feeling pain. Here, two participants described how their lives were disturbed by the thought of cancer recurrence:

My deepest fear is that cancer will return; it becomes like an obsession for me. I'm really anxious... I'm feeling my breast every day to check if there is a tumour. You know, if I felt something wrong... I can't wait. I will go out immediately to the doctor to check. I often asked the doctors if the cancer might come back after five years, and they try to reassure me that everything is fine... I don't know, but sometimes I don't believe them (Shahad).

I used to be very funny, open to life. I used to love going out and meeting my friends... I was a very social person. But now, all I ever think about is the disease [cancer], death... I don't want to be surrounded by lots of people who I don't know very well (Nourah).

Fear of cancer recurrence has put some women like Ohoud and Shatha under stress. They were struggling to find useful resources that answered their questions about the causes of cancer return:

I don't know how or when and why the cancer might come back [confusion]. This unanswered question makes me feel worried. When I asked my doctors about this issue... They tended to reassure me and said, "*there is nothing to worry about*" and "*the reasons why cancer comes back are unknown*". I heard that cancer could be from environmental pollution or the devil's eye (Ohoud).

My biggest fear is that cancer will come back... I'm reading a lot about cancer cases on the internet and get scared and confused because I believe that each case has a different scenario. So, I decided to stop reading more in detail about breast cancer (Shatha).

Other women like Sara believe that there is no sure way of preventing cancer from returning after finishing treatment:

With cancer, my life has taken a turn and that's left me wondering why I got cancer. Even now I'm still asking the doctors what to do to prevent cancer from coming back (Sara).

On the other hand, Anoud expressed her fear of cancer metastasis, especially when she experienced symptoms in her body:

I'm afraid of cancer coming back and spreading to my whole body, especially my lungs. You know, I got scared when I heard stories about cancer and death, or if I had chest pain or a cough (Anoud).

These persistent thoughts of cancer recurrence are not only stressing the patient, but the family too. Leena described how awaiting the results after each procedure is a stressful experience for her husband:

The follow-up period is stressful, not only for me, but for my husband too. Before any follow-up appointment, I become very nervous and all the painful memories of cancer had returned like a flashback in front of me. I wished I could forget this experience, but I couldn't [tears] (Leena).

Then, she added how she and her husband were nervous waiting for the mammogram result, which is part of the follow-up plan:

I couldn't wait for the next appointment to know the result... I was worried. After insisting, the doctor came and told me that the result was normal. At that moment, my reaction was unexpected – I started to laugh and my husband cried. We were under pressure, but we didn't know how to release it (Leena).

Fear of cancer recurrence was also associated with refusing conservative surgery, an issue reported by Shamas:

The doctor explained the cosmetic surgery, but I refused to have it. I don't like to put any artificial object in my body like silicon... I mean, who knows, this object may cause a problem for me in the future or it could affect my case (Shamas).

While the majority of the women expressed their fears of cancer and uncertainty, for some, especially those who have a strong family history of breast cancer, they were afraid of cancer returning not only to them, but also to their daughters in the future as well:

I'm afraid of cancer returning or one of my daughters could have it... who knows? (Azizah).

7.2.2.2 Confusion and loneliness

Feeling confused after finishing treatment is a common issue among some participants, who struggled during the treatment period and experienced loss of control afterwards.

Many women had difficulty in describing their feelings and making sense of their experience:

Before getting cancer, I had fears of getting the disease because my mother had it. But when you become the patient and what you were afraid of happened... it feels different, when I become a survivor [inconstancy in thoughts] (Aisha).

Leena explained how she is feeling confused in terms of showing her feelings to others during family meetings:

I'm feeling confused. For example, if a happy thing happened to my family, I don't feel happy the same as they do... I don't know why (Leena).

Feeling confused affects many women, including Shamas, in losing control and becoming irritable with their kids, and afraid to lose family attention:

Now my son is planning to get married and he wants me to go with him to the girl's city to propose. Well, I'm not comfortable with that decision. I don't want him to get married now and I'm not ready to go and travel to another city. This issue caused me a headache yesterday. After finishing treatment I've become very agitated, and lose my temper easily and start yelling at my children (Shamas).

Feeling lonely was linked with the loss experience and this was an important part of women's ongoing lives. Many women described their lack of security and support to cope well with the disease. For Amar, Alaa, and Sahara, loneliness seems to be an issue, which is not experienced by all of the survivors. Amar lost her husband last year and Alaa felt lonely after her sister, who was a source of support, died from a lymphoma:

I'm feeling lonely because I lost my husband; he died last year, he was the only one who stood by me from the beginning of the cancer until the end. My source of support has gone [tears] – if the disease comes back, who would support me? (Amar).

For Sahara, the experience of being lonely was intense. She lost her mother during treatment; had divorced for the second time, from a marriage that lasted only six months; and broke off a friendship with her close friend who had changed:

Now I'm feeling lonely. I'm living on memories... I don't know how I can explain it, but I feel confused and am thinking too much about the future, thinking what would happen to me if my father died... he is the one who keeps me safe (Sahara).

Also, feeling lonely is associated with people misunderstanding how to support breast cancer patients; this was repeatedly reported about husbands. Nine participants out of 18 were affected by their husbands' lack of support. Asera suffered from her husband's neglect:

God helped me to accept what was going on in my life. My husband acted as a crazy person – he didn't want to see me during the treatment period...[tears] his reaction shut me down... [stop] (Asera).

For Aisha, the lonely feeling was a result of feeling disappointed by her husband's attitude:

One day he told me that he would ask for a divorce once our children grew up [cries] (Aisha).

Thus, some women wished that they had met breast cancer patients so they could express exactly what they feel:

I wish I knew someone who had gone through the same experience to talk with and support me, while I was having the treatment because, yes my mother would comfort me, but she wouldn't understand what I feel. It feels different if you have someone who had been diagnosed with breast cancer and had experienced chemotherapy (Shatha).

7.2.2.3 Body image

Many concerns about appearance were related to the side effects of treatment that women underwent. Women spoke about the surgery, chemotherapy, radiation therapy, and hormonal treatment and its impact on their body image and their sexual relationship. For example, Lama felt that she had lost an important part of her body, and no longer felt attractive for her husband, who additionally played a role in making her feel low:

You know what hurt me more was the reaction of my husband about my dark skin tone after radiation therapy. At night, I tried to dress up beautifully for him and wear this nice short lingerie, but he was avoiding me. He said that I'm ugly and that really hurt... I have nobody to tell about what I felt [tears] (Lama).

Sahara used to exaggerate her looks and cover any problems in front of her ex-husband and in public because she was not feeling feminine enough:

I used to exaggerate everything in my relationship with him, like putting on heavy make-up and wearing beautiful expensive clothes just to show him [her husband] how pretty I am and to cover my poor body image. I didn't like him either touching my breast or seeing it (Sahara).

Some women also expressed feeling body-conscious, especially when going out in public and, as a result, limited their social activities. Azizah talked about people's reaction to her breast shape:

My daughters used to say that I haven't changed, but I don't believe them. When I look at myself in the mirror, I'm not the same person... I gained weight, though I'm not eating too much; it is because of the hormonal therapy (Azizah).

She added:

Now I prefer to be isolated from people and to be in my own world just with my family; if I go to any occasion, women start to ask "*are you okay? Oh, you look tired or oh, you look old*" – their words really hurt my feelings (Azizah).

Some participants who had undergone a mastectomy felt embarrassed, especially when they could not manage to find a proper prosthesis of good quality. Anoud described how people used to stare at her breast:

I looked wearied, especially if I wore a bra with poorly designed materials... sometimes, the bra stuffing displaced when I moved and then people started to point out that I should fix my bra. I felt embarrassed (Anoud).

Having conservative surgery helped some women to overcome their body image concerns and regain their body shape:

Thank God, the surgery was done perfectly. I was grateful to the surgeon who did the conservative surgery for me; I woke up from the surgery and I couldn't see any big difference between my natural breast and the implanted one (Shahad).

They [family members] told me that I'm young and it was better to do the cosmetic surgery and really, when I saw the result I was amazed – thank God (Amar).

In terms of the chemotherapy side effects, the majority of women suffered from low body image, especially when they lose their hair. Shatha and many others were afraid of chemotherapy side effects and thus they refused to have it at the beginning:

I refused to take chemotherapy because I was afraid that my looks would change. They [family members] told me that everything would come back again and yes, I agreed with them on that, but come on, my appearance was important to me (Shatha).

Some women did not feel comfortable wearing a wig, so they covered their heads with a scarf:

I lost my hair and it was very hard for me; I covered my head with a scarf. My husband bought me a wig, but I couldn't bring myself to wear it in front of people. I was concerned about my relationship with my husband; I thought that my husband would leave me, but thank God, he was there for me from the start (Nourah).

I couldn't get used to the way I look now with short hair. I don't like to see my hair in the mirror; I'm covering it at home (Shamas).

Having radiotherapy left women suffering from skin changes that affected their appearance:

I'm having skin pigmentation after chemo and dark spots over my breast... you know... I would love to have plastic surgery because I had a medical error in my last surgery at the private hospital (Shatha).

7.2.2.4 Infertility and menopausal symptoms

Infertility is one of the consequences of chemotherapy that has been reported by most of the participants, especially those who have not had children or want more children.

Failure to adapt to life with infertility led many women to experience concerns about the future, related to their marriage continuity. Lama and Aisha expressed their fears of future disorientation regarding their husbands' plans to be in a relationship, justifying this by their husbands' wish to have boys. This becomes evident from the quotes below:

I only have two daughters and my husband wants a boy and I can't give him that. You know, I didn't tell him that I was infertile. I told him that I was having hormonal changes and that it would take time to get to normal. I can't tell him the truth... he will go and find another woman (Lama).

I'm worried about my relationship with my husband... we are not okay. I couldn't be pregnant because of the disease; he might want to have more children (Aisha).

Having a period is a sign of fertility and youth and for women with breast cancer, such as Asma, the termination of periods can result in feeling old:

I felt that I was getting old, because I would love to get pregnant and have another girl [justifying her reaction] (Asma).

For Anoud, who is young and has not been married before, it means losing her chance to be a mother:

I wish I could get married and have my own child who calls me 'mum'. To be a mother was my dream, especially when I used to teach children in the past; I would love to have a kid and live the motherhood experience (Anoud).

Losing periods affected many women psychologically and physically, as they suffer from mood swings, hot flushes, night sweats, osteoporosis, and muscle cramps that inhibit their daily activities:

I don't really care whether my periods would come back or not. But when my periods had stopped, I started to have bone pain and hot flushes that make me unable to sleep at night (Shamas).

I'm suffering now from weight gain because of the hormonal therapy and that affects my knees; my movement has become limited. I asked the doctor to give me a referral to an orthopaedist who asked me to do a diet and some exercises (Ohoud).

However, for some women, infertility was not a big issue as long they were cured from cancer and have children before cancer:

My periods have stopped, but that wouldn't bother me because I already have four children (Shatha).

7.2.2.5 Positive change

Many women in this study claimed that the breast cancer experience is a big event that causes a change in different aspects of their lives. Positive transformation occurred in issues related to lifestyle, future plans, family, and self-growth.

Two women expressed their plans to help other women with breast cancer because they understand how much they suffered:

I joined the Saudi Cancer Association, I became a volunteer and started to read more about breast cancer survivors' stories, which helped me a lot to be faithful and hopeful (Sahara).

Now, I have a mission; I want to help other women with breast cancer. I became a volunteer in a breast cancer awareness campaign (Anoud).

Many women reported a range of positive issues that helped them to realise the essence of their experience:

Yes, I'm an independent woman. This disease is a wake-up call to think about myself more than others (Aisha).

Before having the cancer, I was very weak, depending on others. But now I'm independent, going alone to my hospital appointment... I didn't surrender (Amar).

Others perceived the breast cancer experience positively because it has a positive impact on their relationship with family:

I'm trying to enjoy my life with my children and make them happy. I realised that life is too short, so it is better to spend it on something useful. For example, I'm thinking seriously about either continuing my education or getting a job. I start to think about myself more... thinking about my dreams and goals (Leena).

The house responsibilities have been shared. Every member of the family has a task to do. They [kids] have become independent and helpful (Asma).

Many women claimed that their lifestyle became healthy after the disease:

I have become more aware of the importance of wellbeing and eating healthy food. Now I'm more involved in their lives (kids) and spending more time together doing group activities, and that's cheering me up (Shatha).

I don't use the microwave, because you know it may cause cancer. Also, I'm encouraging my family to eat homemade food instead of eating unhealthy food or tinned food (Maha).

Now I'm trying to eat healthy food and encouraging my children to stop eating junk food, and doing some exercises like walking to lose

the extra weight that I gained from having the hormonal therapy (Amar).

However, following a healthy lifestyle was not reported by some women who expressed different excuses like lack of facilities, lack of motivation, and God's will:

Well, for me it is hard to do outdoor exercise, especially in this weather; it is too warm outside and I have difficulty in transportation... my son is busy at the university and my husband is busy at work... I have nobody to take me to the gym (Ohoud).

My doctor is encouraging me to do exercises and follow a strict diet, but I believe that I don't have motivation. To be honest with you, eating food makes me feel good and happy, especially if I was in a bad mood (Nourah).

You know, before I was diagnosed, I was following a healthy lifestyle, but it couldn't prevent the disease. That's why now I'm not really focusing on following a strict healthy diet. Humm, I know that's wrong, but I've decided to just enjoy my life (Sahara).

7.2.3 Identity

The consequences of living with and beyond breast cancer have shaped the meaning of survivorship. Living with the reality of mortality and the cultural stigma attached to breast cancer, age, a woman's position, and role change, have all influenced the identity of participants.

7.2.3.1 Woman's position

From the interviews, it appears that the position of women with breast cancer is critical. Many women suffered from exclusion because of their vulnerable position in society. Gender inequality was reported in the healthcare system, especially when it comes to decision-making issues:

The doctors didn't inform me that the chemo treatment would take a long time. I didn't know why they used to discuss my case with my son more than me... I was the patient and I had the right to know about what was going on [firm tone] (Shamas).

On the day of the result, I went alone to the hospital. Before revealing the news, the doctor asked if I came with my husband or any male relative and I answered "*No, Why? What's wrong?*" He said, "*I can't tell you anything unless you are accompanied by a male. Call your husband to come*" (Aisha).

He [her husband] was not supportive at all, even in our sexual relationship in bed. He wouldn't take precautions like wearing a condom... I was worried about getting pregnant which would be unsafe to my health. Ahhh, I told him about that, and he said if I got pregnant, I could have an abortion. It was hard for me to take the risk and make concessions for someone who didn't care (Sahara).

Many women expressed that they were disappointed in their husbands' attitudes about the consequences of the disease, since many women claimed to be good wives:

I didn't think that my husband could treat me in this selfish way. He is everything to me... I was always trying to be a good wife for him. When I had this disease, I didn't think about myself as I thought about him; I was afraid that he would be upset and sad because of my disease (Aisha).

I have been married for 27 years... there was love... you know, I could not eat or sleep unless he was around me. But now, he's telling me that I have to get used to this situation, as it is a normal thing for me. He said that he will spend time with me and on the following day, he will be with her [the second wife] (Asera).

Dealing with people's curiosity was difficult, especially when it comes to issues considered to be important for the image of the women in the community. These include getting married, pregnancy, and having baby boys.

The society that I'm living in doesn't help me either... people start to ask me private questions like if my period has come back or not... and telling me it is time to get pregnant, to have a boy. They don't know that it is out of my hands and all I'm telling them is to keep praying for me (Lama).

Who would marry a girl who has had breast cancer and is infertile in our community...! [cries] (Anoud).

I'm still young and that makes me wonder if I would love and find someone who really cares for me and wants to live the rest of his life with me (Sahara).

7.2.3.2 Age

Having breast cancer at a young age has influenced women's experience negatively, since most of the participants were aged between late thirties and forties. All the women expressed their shock about having breast cancer, because they thought that this disease only affected older women:

I am the first and the only person in my family who has been diagnosed with breast cancer at this young age, and that's affecting me emotionally because I've been treated differently. I didn't know how I should tell my young children about my disease when my hair started to fall out... they were just kids (Shatha).

I was 34 years old at that time. I would never expect that it could be a cancer because I thought it only affects old women (Sahara).

Shatha's young age was a reason for not being involved in breast cancer awareness campaigns in the past:

I remembered when I told my friend that cancer was something impossible to happen to me, she (friend) had tried to convince me to have a mammogram in one of the breast cancer October campaigns, but I refused. The person always sees himself or herself as immune from getting a serious disease or being in difficulties. I see and hear about this disease, but never thought that someday I would get it. I was scared of it... All I know is that cancer means death (Shatha).

Some of them felt different at the hospital, comparing their conditions with others who were older:

The chemotherapy was hard. I saw people who were older than me and they were coping with it, but I wasn't (Shatha).

There was an old lady with breast cancer and she had been cured. Humm – in the chemotherapy room, most of the patients were old and that was making me wonder why I had cancer at this younger age (Amar).

However, women who were nearly 50 accepted their altered appearance because they perceived that losing a breast was not an issue, except if they were young or married or breastfeeding:

Maybe it would become hard for me, if I was young and I was breastfeeding or planning to get pregnant (Shahad).

7.2.3.3 Role

Having breast cancer affected women in carrying out their roles as mother, wife, sister, and employee. Azizah and Sahrah explained how their roles shifted from being caregivers for their family to being care receivers.

My sister had breast cancer; she was on the second cycle of chemotherapy when I had started the chemo. I couldn't tell her that I had it too. She is my younger sister and I was supporting her, while the reality was that I needed someone to support me too (Azizah).

I struggled a lot in carrying out my role as a mother to my children, a daughter to my parents... a friend to those around me. Sometimes I had to stay with my mother at the hospital when she was getting sick, while I was suffering from the chemo's side effects (Sahara).

Other women felt that breast cancer treatment impacted their roles as mothers in carrying out tasks such as taking care of children and doing home activities:

The chemotherapy experience was really tough. I was weak... I couldn't move or walk. I was depending on my sister to help me and take care of my children (Shamas).

I can't do my house duties as before. Now, I'm depending on the housemaid to do the housekeeping and cooking because, I told you, I can't work too much using my right arm after the surgery; it would become oedematous. I wish that my life would come back like before the disease; I was always taking care of my children and home without any helping hands from others (Aisha).

Other women felt that their roles as wives had changed:

I became very sensitive and didn't want to be a burden on my husband... because he has to make excuses from his job to take me to my medical appointment by driving for two hours, though he didn't complain (Leena).

I was the second wife and he (the husband) was unhelpful. I was still going to hospital appointments alone, he needed me only to fulfil his sexual needs; he didn't understand that all I needed at that time was to have a person who took care of me and showed me love rather than being the one who should give that (Sahara).

7.2.3.4 Being a survivor

Participants rarely employed the term 'survivor' to describe their identity and lived experience, because most of them tried to keep their disease private:

I prefer 'someone who had cancer' because cancer is no longer present (Shamas).

What I have gone through was something temporary and I don't like to talk about it. Because if I talk, it felt as if I'm still living it (life with breast cancer) and that's wrong (Nourah).

In fact, the term 'survivor' was unknown to two participants:

No, I don't mind the term 'survivor', although it's my first time hearing it (Aisha).

Usually I heard of the term 'patient', but not 'survivor'. I mean, if there are any TV shows about breast cancer, people use the term patient (Maha).

The idea of being a 'breast cancer fighter' and celebrating victory in battling through treatment and overcoming the disease was reported:

I think that the word 'fighter' describes me much better, because I'm fighting against the disease, and the issues surrounding me, like the stigma and people thinking about me. I'm fighting to live normally (Anoud).

I prefer a fighter, because it had a strong meaning, but not a 'hero' because it is linked to winning and I'm still waging a war against cancer, so I believe that a fighter is the best term that describes me. Yes, I had beaten cancer in the first round through passing the treatment, but who knows... the cancer could return (Sahara).

Others linked being a survivor by coming back to normality and resuming activities just like before breast cancer:

My life now is normal and the hard memories had faded away. I'm a normal person now and don't like my identity to be linked to a disease (Ohoud).

Surviving is to get rid of the disease, to be healthy and to reach a stage where you feel safe and normal (Lama).

Some women feel that their cancer experience was not severe enough to warrant the title of survivor.

I can't say that women who had breast cancer are survivors, because this experience is a test from God. Now with the advanced medical treatment in Saudi Arabia, the percentage of women surviving from breast cancer is high compared to other types of cancer. That's why I think that those who had colon or liver cancer are the real survivors (Shahad).

I would call myself a victim if I got it in a late stage, but also, I don't think that I'm a survivor until I pass two years of being cured with no signs of cancer returning, and if there is a big gap between my

follow-up appointments. That means that I have become fine and there is no need for close health supervision (Nourah).

Many women call themselves survivors from a physical perspective, but not yet psychologically:

For me, surviving breast cancer isn't associated only with what I feel physically, but also emotionally. This disease mostly affected my psychological wellbeing. All I can say is that I'm a survivor physically, but not from the emotional side... I need a psychological consultation, seriously... [tears] (Leena).

Oh, all I can say is that, yes, I survived cancer medically, but I'm a victim at the same time. Cancer took away many things from me... my happiness, my husband... (Asera).

Inside myself I do believe that I'm cured, but sometimes the negative thoughts about the possibility of cancer returning jump into my mind, and I can't control them (Amar).

7.2.4 Faith and belief

The Islamic faith is central in women's experience with breast cancer. It helped them to make sense of their disease and cope with treatment consequences.

7.2.4.1 God's will and religion

All the women accept their disease because they are obeying God's will:

I was meant to have a cancer; this is our God's will and God gives me a second chance to live (Aisha).

They were sad and they shouldn't be, because this is God's will. I wasn't the one who caused it to myself! (Shahad).

Many women believe that surviving breast cancer is a result of God's will and not a treatment outcome:

The term survivorship is not correct... because I believe in God and accept his will in having the disease. I don't think that a survivor is one who finished the medical treatment, because I heard stories about people who took alternative medicine like herbs, or were treated by religious practices like reading the holy book and drinking holy water (*Zamzam*), and then they survived (Shatha).

It is a mercy from Allah (God) to survive because you know this disease could be deadly (Shamas).

I think surviving means that God put his blessings on the cancer patient to be cancer-free (Maha).

Most of the women believed that having breast cancer was for a religious, peaceful reason:

I perceived this experience as a test from God (Haia).

I believe that this disease was a loving message from God. There are many different types of punishments and difficulties. Some people could face family or financial crises and others had health issues just like me. God tests us to see how strong and faithful we are (Anoud).

However, only one woman was in doubt about her experience with breast cancer, as if she was asking herself “*Why me?*”:

I’m wondering whether I’m doing good or bad things in my life, or if that disease is a blessing or punishment from Allah (God) [asking herself] (Leena).

7.2.4.2 Devil’s eye

Devil’s eye is a belief rooted in the Islamic religion and it means that a person can harm another person by looking at them with envy. Many women believed that the Devil’s eye is the cause of having breast cancer:

I believe that this disease has occurred because someone put a curse on me (the Devil’s eye). My life before cancer was happy; I have five kids and we used to travel a lot. You know, not everyone would say (may Allah be the protector) ...they [people] thought that my experience with cancer wasn’t hard and it didn’t affect my children, and that was wrong (Leena).

Fear of the Devil’s eye makes many women limit their social life and hide their identities as breast cancer survivors:

I don’t like to go to events or occasions; my cousin’s wedding will be next month, but I won’t go. I mean I would love to go, but I just can’t go... I’m afraid of the devil’s eye... people might look at me and put a curse on me. They might say, “*oh, look at her – she survived and it seems like nothing happened to her in the past*” (Nourah).

When I go to places where people know about my disease, I make sure to have a simple look with no make-up because, you know in our society people might put a curse on you (the Devil’s eye) just because of their jealousy (Sahara).

I'm afraid of the Devil's eye. I remember one lady asked me if I had recovered from cancer, and I answered, "*Yes, thank God*". She said: "*you were lucky, because the cancer came back for a lady I knew and she died*". I wasn't sure if I heard her saying '*Whatever Allah Wills, Blessed is Allah*'¹, you know, just to protect me (Amar).

7.2.4.3 Coping

Some women described accepting the disease for the sake of others, who could be parents, children, or husbands:

I believe that I took the right decision in keeping my disease hidden from others. My family supported me and didn't treat me differently. For sure, I couldn't have that strength without my deepest faith in God (Ohoud).

I didn't let the disease destroy me... I was fighting to live for my family. I didn't want to show my family that I was weak... whenever I felt well, I resumed my duties as a mother and a wife (Sara).

The majority of the women claimed that praying to God was the only effective way to cope well with the disease:

Praying to God at night was the most powerful support for me. Every night, I was in pain and my family members were sleeping. To whom shall I express my feelings then? The only things that were able to comfort me was praying to God and reading the holy book, and afterwards I felt fine (Shahad).

All I did was just pray to God to have his mercy on me. I did express my feelings to my husband, of course – he was there for me from the start – but I didn't like the way that he used to comfort me. He often told me that I was exaggerating my symptoms... if I said to him, "*I'm in pain*" he would say, "*no, you are not... you just cannot think beyond this feeling*" (Shatha).

Family and friends who are breast cancer survivors were very important for the participants to overcome the treatment side effects and be hopeful:

I was able to cope and accept the disease gradually with help from my mother, who used to go with me to all my medical appointments, and my caring husband and, of course, my family. Also, my friends helped me a lot and advised me to think positively, and to live my life that I used to have before cancer, filled with joy (Nourah).

¹ Saying in Islam for seeking protection from the evil-eye.

There is a woman who had breast cancer and has supported me a lot until now. It is very helpful to be surrounded by someone who understands exactly your feelings (Anoud).

Dr. Samiah Alamoudi [Saudi breast cancer survivor] gives hope to other women; she proved that breast cancer is not a deadly disease; her story was inspiring. When I heard or watched TV shows about breast cancer survivors, I felt hope (Amar).

7.2.4.4 Spirituality

Breast cancer is a life-threatening illness and is viewed as a traumatic life event where women may lose control. Therefore, most of the women perceived the breast cancer experience as a chance to be more spiritual and faithful, maybe employing religious coping methods as a way of feeling grounded:

I believe that God made me have breast cancer for a reason. God wants me to get closer to him and be more religious (Anoud).

This disease was like a wake-up call for me to pay attention to my spiritual relationship with God. Before cancer, I was busy with raising my children and taking care of my home. Now, I'm thinking more about myself and how to be more faithful and grateful to Allah [God] (Ohoud).

Other women make sense of their experience by engaging in spiritual thinking:

I learned patience, wisdom, and not focusing on small details. I'm thinking in a more spiritual way; believing that we don't have immunity against death. I'm thankful to God for me having this disease instead of my children, because I witness at the hospital the mothers' pain as they watch their children suffering from cancer (Shatha).

7.2.5 Healthcare experience

7.2.5.1 Healthcare path

At the beginning of the diagnosis, many women thought of a benign tumour or a cyst:

I felt a hard lump in my breast. I went to a private hospital and the doctor told me that it was a cyst and nothing to worry about. After a year, the tumour became larger in size (Shamas).

I was shocked – very shocked [assertive tone] ... confused maybe, because I didn't know who I should believe! One hospital told me that I was fine [a cyst] and the other said it was cancer. In fact, it

was cancer from the beginning and I didn't know that... I didn't understand what was going on (Leena).

Patients' unawareness of their medical conditions and lack of oncology speciality in the private sector led to many women suffering from misdiagnosis:

I went to a private hospital and I was examined by a general surgeon who said it was just a benign tumour, without doing a biopsy. He just depended on the mammogram test's result... I felt that there was something in my body, but couldn't understand what that was... I didn't know the surgeon who removed the tumour was following an old typical practice based on his experience only (Shatha).

I discovered the disease at a private hospital that advised me to do the surgery on the following day. There, the surgeon removed the tumour without any further investigations like a biopsy, which was done later on at the government hospital (Sara).

7.2.5.2 Healthcare service

The views of the current healthcare service were varied. A group of the women expressed their satisfaction with the current service, including appointments, investigations, and continuity of care with the same healthcare team:

Being a cancer patient, you have the priority to do all the investigations like the blood test and the mammogram first. The healthcare team didn't make me feel that I was a patient and almost dying... they were all professional (Ohoud).

I was glad that the surgeon did the conservative surgery for me... he (the surgeon) was very honest with me and gave me the freedom to decide either to have the treatment here or go to the US (Shahad).

The good thing is that the healthcare team hadn't changed. They were with me from the beginning of the treatment until now. We already had established relationships and I trusted them (Azizah).

The healthcare team explain the follow-up plan and the importance of doing the investigation every three months, and that if there was any problem I should go to the emergency room (Maha).

On the other hand, some women were unaware of their rights as cancer patients, which included free treatment, transportation, and accommodation, especially for those coming from rural areas:

By chance at the waiting room for the radiotherapy, a woman told me that the hospital provided an allowance, but they [doctors] had

never told me. After that, my husband asked them for a refund and we are waiting to see what will happen. The public should know this information, because these are our rights (Leena).

The hospital in Riyadh provided transportation (a car) to take me and my mother to the hospital...well, I didn't know about this service until my mother complained to the doctor that we have a financial problem. But that happened when I was nearly finishing the radiotherapy. In my own city, there was a foundation called 'Cure' which offers financial support for cancer patients who were in treatment, and that helped me a lot (Nourah).

In terms of the appointment flexibility and preferences, some women were happy with current follow-up plans, while others wished to have close supervision because of their fears of cancer recurrence:

I wish I could know the result sooner instead of waiting for the next appointment, which would be due after two weeks (Amar).

7.2.5.3 Patients' preparation

Breaking the bad news to those newly diagnosed with breast cancer was not done professionally by some of the healthcare team:

I was waiting for the oncologist to come and tell me about the results of the biopsy. He (the oncologist) entered the room and he was in a rush. He said to me straightaway, "*you have breast cancer and we should start chemotherapy*" [talking rapidly]. He [doctor] didn't prepare me for the news. He just delivered it as if it were a simple thing to tell and I had to accept it (Lama).

Patient preparation for the treatment is an important issue to minimize patient anxiety. However, some women claimed that some of the healthcare team were not open in disclosing all the information related to their healthcare:

I met another patient with breast cancer and she told me that her doctors explained everything to her, including the chemotherapy... but in my case, they only gave me a small book to read about chemo that didn't explain everything in detail (Shamas).

It was a tough week... they started by doing different investigations and then told me that I had breast cancer, and I had to have surgery... That was too much for me to handle – all this happened in only one week! [exclamation]. I was like a hypnotised person, saying yes to every decision made by the doctors with no hesitation... I just would try and do anything to be alive for my children (Leena).

The oncologist was simplifying the issues for me, without further explanations. He explained the chemotherapy in a rush, he didn't give me time to ask... he told me that my hair would fall out, but it would grow again. I already knew this information and he [oncologist] didn't tell me anything new (Lama).

However, some women were happy with the attitude that healthcare professionals demonstrated:

There was a nice nurse who used to give me chemotherapy and explained each procedure step by step (Shatha).

The surgeon explained to me the surgery in detail, as I was at the operating room and watching the surgery live (Ohoud).

7.2.5.4 Patients' needs

The majority of women want social and psychological services:

I wish that healthcare providers would consider the need of the breast cancer patient for a social and psychological consultation since diagnosis. Yes, I read some articles on the internet about how to be strong and fight cancer, but that didn't help me. It would be more helpful if you had a doctor or a nurse talking with you face to face, to tell her your needs / feelings / fears (Shatha).

I mean yes, I pray to God and read the *Quran* [the holy book] to feel good, but still I need social and psychological consultations. I just can't move on. It was hard to get an appointment with him (the psychologist); first he was on vacation and then the next appointment was long delayed. I tried to express my feelings to get out all this anger and sadness on paper, but it didn't work because I started to cry every time I remembered my experience (Leena).

Breast cancer is a family disease, since many women claimed that their children were impacted by the cancer and did not know how to deal with the cancer patient:

I think it would be better to have a family consultation to educate the family member about the cancer and process of the treatment and how they could cope with it; my mother was really worried about me, because she didn't have enough information about the disease (Amar).

Many women asked for better service in the emergency room where they used to go to deal with the chemotherapy side effects:

Instead of going to the emergency room and waiting for ages, because of a lack of beds... why don't the hospital have a 'hot-line' so I can, as a cancer patient, call the doctor and ask about her condition or check any test results? (Shatha).

Some women did not know how to deal with weight gain, which is one of the side effects of hormonal therapy, and asked for diet and fitness consultations:

I wish the hospital had provided a special service for those who are under hormonal therapy to lose weight, like fitness gym and diet consultations (Amar).

Being involved in the shared decision-making was a reported issue among women:

The healthcare team weren't completely open about my case. I would love to know more about my treatment plan and what will happen next (Lama).

Many women expressed their needs for prostheses of good quality, which helped them to cover the change of body appearance:

The hospital didn't offer a wig or special bra to wear. I wish the Zahra Foundation for Breast Cancer would think seriously about opening a branch at the hospital to help patients. Psychological therapy should be combined with the medical treatment (Anoud).

The hospital didn't provide me with a bra that was good quality; it was poorly fitted; I didn't feel comfortable. So, my sister bought a special bra stuffed with silicone. I wish there were special shops in Saudi Arabia supplying customized bras for breast cancer patients (Leena).

Some of the women did not know what to expect from the healthcare team and were not aware of their duties:

They [healthcare providers] didn't show me any compassion and support, though they knew why I was sad. Who are the ones who should decide if I need to be seen by a psychologist or not... me or my primary physician? (Sahara).

I was expecting the nurses to give me more information about the chemotherapy, instead of just giving the medication and leaving (Shahad).

Doctors can't do everything for me; that's why I wish that there was a supportive group for breast cancer patients to talk about our experience and feel that we are not alone (Anoud).

Many women were in need for information, especially during chemotherapy, so they called for the need to activate the role of nurses in health education:

I wish we had alternative tools, so we as patients can get information, ask questions, and contact the doctors, instead of going to the emergency room and waiting there for ages. Besides that, I don't like to be seen by new doctors during the follow-up, because I got used to the doctors who had known my case very well from the beginning. Also, I wish the doctor could be prepared and fully aware of my case before seeing the patient (Aisha).

7.2.5.5 Communication

Communication is a vital issue in helping breast cancer survivors to manage their medical and life context (social and psychological symptoms). Most patients with breast cancer experience a complex course of care in the first year after diagnosis. This period is stressful for breast cancer patients and effective communication skills are important, although some healthcare providers are not using them:

The surgeon's attitude was not professional and polite. Before the surgery, he read my file and told me that he would take out my breast. He said in a sarcastic way "*don't you have kids to live for... do you want to live or not?*" He started to mark on my breast, but I couldn't tolerate him... I lost my temper and started to cry and yell at him. Afterwards, another surgeon came in and started to explain the surgery and convince me to do it [anger tone] (Leena).

Some women wish to have breast cosmetic surgery, but some doctors think that it is not urgent, while it matters for these women:

I can't wait to have my cosmetic surgery. I told my doctor after finishing the radiotherapy that I want to have plastic surgery, but he kept postponing it (Shatha).

I asked him (the surgeon) about the type of surgery and whether it would leave a scar or whether I was a good candidate for cosmetic surgery. I explained to him that I'm from the health field, so he could explain and give me more details. Could you believe that he just gave me some basic information with a tone hardened by sarcasm: "*would you like to be spoiled*"! I went to another doctor after this (Sahara).

Breast cancer patients interact with their primary care providers in the process of treatment. For some women there were missed connections between the healthcare specialities:

I told my radiotherapist about the problem with my arm and said that “*the oncologist should encourage me to do the physiotherapy after surgery*”, but he didn’t (Shatha).

Because some of the healthcare team are foreigners and do not speak Arabic, some women struggled with language barriers:

I’m regretting not learning the English language, because some doctors are foreigners and they don’t speak Arabic... they discussed my case with my husband in English to do the translation part (Leena).

There was a language barrier... the oncologist couldn’t speak Arabic and sometimes, the translator from the hospital might be absent (Aisha).

7.3 Conclusion

Having used IPA has helped me to identify different superordinate and subordinate themes along with linguistic comments: those related to cancer meaning and its stigma; living hidden experience; living with reminders; life changes; identity; religion and faith; and healthcare. Breast cancer experience changed women from many physical, social, and psychological aspects. Their experiences with breast cancer put their lives on hold. They were afraid of the devil’s eye and people’s false judgments. Being alive and surviving death were all linked to accepting God’s will. There were a variety of views related to healthcare practices, but the majority of women called for service improvement.

There was a difference in the use of language and metaphors among the participants. It appeared that metaphors were largely used in describing the change of participants’ feelings during the treatment period and less used in illustrating the experience within the healthcare context. The metaphors used by the women in this study to describe their breast cancer experience had a sense of punishment and violence, while the types of words to describe their identity were linked to military concepts, such as fighting to win the battle. The next chapter presents the discussion that is informed by the life-world philosophical framework.

Chapter 8 Discussion

“Just as fish may take for granted the water they swim in, we as humans may find it difficult to notice and articulate the humanly qualitative nature of the world we live in”

(Todres et al. 2007, p.55).

8.1 Introduction

The aim of this thesis is to explore the lived experience of breast cancer survivorship of young Saudi Arabian women. More specifically, to explore how Saudi Arabian women perceive their survivorship from breast cancer, to understand the cultural impact on their experiences, and what strategies used by health care providers may support breast cancer survivors' experiences.

Accessing, describing, interpreting, and understanding women's worlds were successfully achieved by combining interpretive phenomenology (Heidegger 1996), that uses the interpretative lens to understand the sense of being, and IPA (Smith et al. 2009), that helps to make sense of women's experiences through the double hermeneutic approach to data analysis. After presenting the results on the level of understanding of the idiographic and shared themes of young Saudi Arabian women's experiences after breast cancer treatment, I am interested here in how breast cancer survivors understand and make sense of their experience in terms of relatedness to the world they are living in/with. In this chapter, these experiences are analysed from a philosophical perspective of the life-world framework (Husserl 1970). The life-world includes individuals' everyday experiences of self, body, language, feelings, beliefs, thoughts, and relationships (Ashworth 2016).

Exploring these women's life-worlds, their diagnoses, stigma, feelings of death, treatment experiences, identities, long-term treatment side effects, relationships, beliefs, cultural issues, and health care experience are necessary to understand how they develop meaning, choice, and voice in their worlds. All the aspects of the life-world as described by Ashworth (2003) (embodiment, sociality, project, discourse selfhood,

temporality), are explained in detail to access their life-worlds. Finally, the results are compared and contrasted with the literature to identify cultural and traditional perspectives that might not exist in the West, but which help shape women's views of themselves and their worlds. The literature in this discussion chapter are mainly obtained from the core qualitative phenomenological studies presented in the Grid table (see Chapter 2), as well as from some useful Saudi studies, such as (Awan et al. 2013; Awan et al. 2015; Rabah et al. 2012; Saati 2013). Though the latter studies do not address my research aim and objectives, and many are quantitative, they help to give an understanding of the Saudi culture and how it impacts on the women's experience. Their main scope was related to infertility (Rabah et al. 2012), conservative surgery (Awan et al. 2013; Awan et al. 2015), lived experience of HIV (Omer et al. 2014), the nursing profession (Aldossary et al. 2008; Yousuf et al. 2012), and breaking bad news (Al Amri 2009).

8.2 Why life-world in preference to use as a framework to explore women's experiences

When I went home (Saudi Arabia) to collect the data, my aim was to understand the perception of breast cancer survivorship and whether Saudi women were informed by, or embraced, the survivor identity. During the interviews, women shared their stories, which were rich and deep. Their stories allowed me access into their worlds and how it feels like to be a Saudi woman living with and beyond breast cancer. They did not only talk about the meaning of survivorship from a perspective of living and fighting, and the reconstruction process itself. If they did that, the symbolic interactionism could be an option to use as a theoretical framework that emphasises how people relate to each other, focusing on identity construction and social roles (Charmaz 1995). Instead, the women went beyond that and talked about central issues in their lives that were shaped by culture, such as religion, belief, family, gender, women's position in society, identity, relationship, living and coping with breast cancer, treatment side effects, and life beyond that. Consequently, the title of this thesis has been changed from 'Perception of breast cancer survivorship among Saudi Arabian women' to 'The lived experience of breast cancer survivorship of Saudi Arabian women', to reflect the depth of the collected data.

From an interpretive perspective, each woman has a personal experience, a different use of language to express themselves and unique views of living after breast cancer treatment. This suggested different dimensions of 'being', which is encountered in the discussion chapter. For example, being for; being with; being without; being me; being someone else; being towards death; being beyond; being in need. Upon reflection, I realised that the use of a life-world as a framework and its fractions have influenced my thinking in different aspects of being, and resonate with, and inform, elements of the women's lived experiences. All these are discussed, described, and mapped according to the life-world fractions, as shown in Figure 7.

Life-world fractions

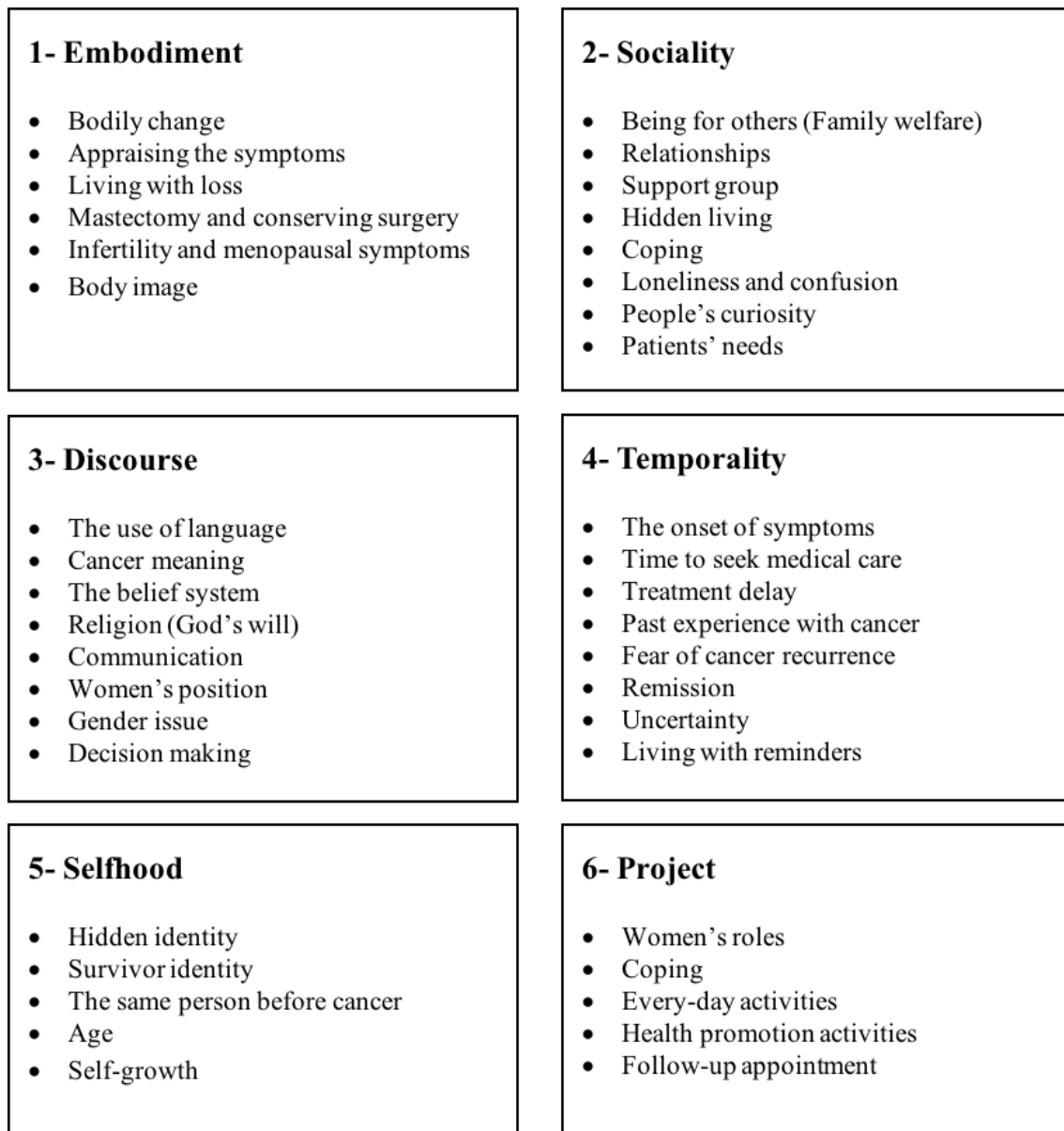


Figure 7: Life-world fractions of breast cancer experience as lived by young Saudi women

8.3 Life-world fractions of the lived experience of breast cancer survivorship

8.3.1 Embodiment

Being with bodily changes

This section discussed women's experience of being with bodily changes as a result of receiving different types of treatment. The women in my research have been aware of changes in their bodies since their diagnosis when they first felt a mass in their breast. Some women, like Alaa, Azizah, and Maha, had experience with other family members who had breast cancer, but it did not help them perceive the genetic risk and seek early

screening. For many reasons, some ignored the growing lump until medical consultation; as Sara claimed, *“I went to the doctor because of my menstrual cycle’s problem and not for the tumour”*. Firstly, they were unaware of the symptoms of breast cancer. Secondly, they held misconceptions of breast cancer and thought it only affected older women, and what they felt was only an early tumour or a milky cyst that might go away with herbal treatment or massage. Thirdly, shyness caused others to hesitate to disclose the symptoms to family members. Fourthly, they held belief of lack of control over their genetic inheritance. These findings are consistent with the Eastern literature reporting that social stigmas, embarrassment, feelings of fear, use of religion, breast exposure to a male doctor, and herbal treatments as a primary option, mean that the nature of a breast tumour in younger women tended to be dense and difficult to detect, and lack of knowledge about breast cancer prevented many women from seeking early detection of the disease (Khan et al. 2015; Mohieldin et al. 2016; Montazeri et al. 2003; Patel-Kerai et al. 2015). Additionally, Khan et al. (2015) claimed that the absence of the feeling of pain in the breast caused many Pakistani women to delay seeking medical attention, as pain is perceived as acting as the body’s alarm system. On the other hand, the evidence of knowledge of breast cancer among Western women helped them to identify their bodily changes and to seek early health assessment (Williams and Jeanetta 2016).

Asma, Lama, Anoud, and many others who underwent a mastectomy expressed the challenges experienced in finding a suitable prosthesis. For example, Leena claimed, *“I wish there were special shops in Saudi Arabia supplying customised bras for breast cancer patients”*. Also, for some reason these women reported that their oncologist either did not give them enough information about reconstructive surgery to regain a sense of normality, or kept delaying the surgery. This is consistent with some of Holland et al.’s (2016) participants, who suggested that their health care teams presumed that, because of their younger age, they preferred conservative surgery as a delayed option, especially if these women planned to get pregnant and breastfeed. From the surgeons’ perspectives in Saudi Arabia, it appeared that less than half (35.5%) of the 51 surgeons recruited from 6 tertiary hospitals in Saudi Arabia referred patients for breast reconstruction, and some (47%) had strong concerns about masking the local recurrence of cancer, despite a lack of evidence for this in published reports (Awan et

al. 2013). These results might explain the lack of information about the procedure available to patients. On the other hand, post-mastectomy breast reconstruction did not appear to be the preferred choice for some women in this research. For example, Nourah, Haia, and Lama, refused to have reconstructive surgery because they felt their bodies had been through enough and were unwilling to undergo additional elective procedures, which were viewed as cosmetic and inessential to their survival. As Shamas claimed, *“I don’t like to put any artificial object in my body like silicon”*. Also, they refused to wear a prosthesis or wig, as these were not part of their natural bodies. Similar points of view were reported among African-American women who expressed their preference of autologous procedures that use ‘what God has given’ as well as they reported difficulty finding prosthesis in their skin tones (Rubin et al. 2013). To understand Saudi women’s views of reconstructive surgery, a quantitative study aimed at investigating the barriers to reconstruction was conducted with 91 Saudi women who had undergone mastectomies (Awan et al. 2015). The main barriers to reconstruction were identified as a lack of knowledge and access to health care providers (63%), concerns about the complications of the procedure (68%), and concerns on breast reconstruction interfering with the detection of cancer recurrence (54%). The decision to either not have or to delay the reconstructive surgery was not only reported among Saudi women, but also among some British and African-American women. For example, in the UK, a study using interpretative phenomenological analysis reported various reasons for delayed breast reconstruction, such as unwillingness to have unnecessary cosmetic procedures, and women wishing to self-examine their bodies without obstruction (Holland et al. 2016).

Breast cancer affected women’s embodied existence with others, as we access the world through our bodies (Finlay and Molano-Fisher 2008). Sixteen women in the current research became body conscious, especially when going out in public. As a result of receiving hormonal therapy, women suffered from weight gain. Many women, like Nourah, Amar, Azizah, and Ohoud, described their struggle with weight gain while trying different types of diets and exercise. They described that the changes in the nature of their bodies created the feeling of being strangers, not only to others but also to themselves. For example, Azizah said, *“my daughters used to say that I haven’t changed, but I don’t believe them. When I look at myself in the mirror, I’m not the same person”*. Some women, like Nourah, Sahara, Shahad, Lama, Leena, and Amar, had to

cover their hair loss by wearing a headscarf or a wig and had an eyebrow tattoo applied. For example, Sahara described her attempt to keep her disease hidden from her mother; *“before having the chemotherapy, I cut my hair shorter as a boy and my mum got angry because, I used to have a long hair.... I did that because I was trying to protect her”*. With all women’s attempts to look normal, the women still felt confused about being in a new body (Joulaee et al. 2012). This feeling of confusion appeared clearly in the stories of the women studied here, such as Shatha’s dislike of seeing herself in the mirror or even in old pictures, and the decision of Aisha’s friends to break off their relationships due to fear of seeing her bald. This sense of loss appeared to be common among different cultures and ethnic groups (Ashing-Giwa et al. 2008; Cebeci et al. 2012; Doumit et al. 2010a; Joulaee et al. 2012).

In this thesis, women’s feelings of being old were triggered by dealing with menopausal symptoms such as infertility, sexuality, vaginal dryness, weight gain, and hot flushes, as these symptoms are associated with older age groups. Some women, like Lama, Asera, and Anoud, discussed their concern about infertility and their faded plans to start a family in the future and getting married. For example, Anoud claimed, *“a married woman who has breast cancer wouldn’t accept this disease easily. So, can you imagine how this would be for a young single woman like me”*. Those women who were in their late 40s and who already had children, the symptoms of infertility and breast loss were perhaps not their greatest concerns. On the other hand, Western literature has offered many solutions for young women facing breast-cancer-related fertility problems, such as egg preservation (freezing) before starting chemotherapy (Oktay et al. 2015). The American Society of Clinical Oncology recommends that health care providers obtain from patients informed consent that addresses the possibility of infertility before starting treatment, and be prepared to discuss fertility preservation options and to refer patients to appropriate reproductive specialists (Loren et al. 2013). However, a different scenario was found in a quantitative Saudi study exploring health care providers’ attitudes towards egg preservation for female cancer patients in Riyadh through a self-administered questionnaire, which was distributed to oncologists at different institutions (Rabah et al. 2012). The results were somewhat unexpected, as half (50.5%) of the health care providers did not discuss egg preservation due to the urgent need to start treatment. The majority (86.4%) did not refer cancer patients to infertility specialists because of their concerns about the well-being of future children.

8.3.2 Sociality

Being for others

The concept of ‘being for others’ indicates how the women’s experience of life-world is altered according to others. The comments made by women when they found out about their diagnosis were related to what would happen to their children if they died; and also what their world would be like if their mothers knew. The women valued their families, especially children and mothers, as they bring meaning to their everyday lives, indicating that their life-worlds concerned them more than the inner experience. Saudi women consider their families’ welfare ahead of their own. This tendency was supported by stories of Maha, Azizah, Asma, Shatha, and Nourah, who thought about their children when they learned of their diagnosis; they tried to live a hidden life and did not tell their family about the diagnosis in order to protect them. For example, Haia claimed, *“I used to hide my medication, so he [Haia’s son] couldn’t see it [cries] because I didn’t want him to get worried and see that I was seriously ill”*. These findings are consistent with those of previous studies conducted in the Middle-Eastern region, especially among younger women (Alqaissi and Dickerson 2010). Goldblatt et al. (2013) explained that women made efforts to protect their family because of their cultural role as the ‘pillar’ of the family.

Existing according to cultural terms, like protecting the family, dealing with people’s curiosity, and the stigmatised view of breast cancer, eventually led some women like Sahara, Leena, Ohoud, and Shahad to be other than who they were before breast cancer. There was a fear of being themselves again among others who might believe that breast cancer patients should stay at home and await their fate. In this situation, some women in my study felt obliged to hide this stigmatising illness and be less social in order to accommodate others’ expectations, avoid embarrassment and feelings of pity, and preserve the family’s reputation, especially if the disease was socially perceived as inheritable or contagious. The misunderstanding regarding cancer contagion was also reported among Greek and Israeli women who had breast cancer (Goldblatt et al. 2013; O’Callaghan et al. 2016).

For Saudi women, keeping their disease hidden enabled them to protect themselves and others. In their world, they were sheltered from the reminders of illness and mortality and focused on a world where they could just be normal. The lack of disclosure of

illness was reported among Saudi people living with HIV. One phenomenological study found that people with HIV hide their disease and are selective to whom they disclose their condition (Omer et al. 2014). Some women in my study, like Ohoud, Shahad, and Azizah, who shared a similar way of living as a HIV patient, were isolated not only from their family support system, but also from any other support systems, such as support groups or counselling, because of their fears of being identified.

Being with others

The concept of 'being with others', in that it relates to the extent of women's lived experience, is influenced by living with and being in contact with others. In the life-world of illness, relationships might grow, change, or end. This was evident in the stories of some women. Friends and family members might contribute to the sense of sympathy, commenting on the woman's looks after treatment, the side effects, and their overall health status, as a result, limiting their social activities. Similarly, numerous studies in Pakistan, Iran, Lebanon, and Jordan identified treatment side effects as a cause of limited social activities (Alqaissi and Dickerson 2010; Banning et al. 2009; Doumit et al. 2010a; Joulaee et al. 2012). In my study, many women like Asma, Nourah, Aisha, Anoud, Shatha, and Sahara expressed their frustration about people's false judgements and avoided speaking with curious people. Many of which made comments about their low risk of surviving, negative marital relationships, and future plans for having children. As Nourah stated, "*my friend asked me about the relationship with my husband and if the chemotherapy had affected our relationship, especially after I lost my hair*". This tendency of dealing with women's personal issues was reported most among older and less educated members (Gurm et al. 2008). On the other hand, the majority of women shared that their relationships with their children and friends improved as they spent more time doing activities together. These results further supported that breast cancer has positive impacts on personal and social relationships (Burke et al. 2012; Dyer 2015). As family members supported each other in accordance with Arabic culture and religious values (Alqaissi and Dickerson 2010; Doumit et al. 2010a), family support was very important in helping women with breast cancer to get through the diagnosis, treatment, and beyond (Patel-Kerai et al. 2015).

Husbands were supposed to be there for their wives and support them through the good and bad times; however, the same cannot be said of all the husbands in my study. Many

women, like Asera, Sahara, Asma, Haia, Shatha, and Lama, described how they needed the support from their husbands, but the latter did not know how to support their wives and, consequently, rejected them. A world that did not include their husbands was a world that they could not comprehend. Exploring the male perspective, Taha et al. (2013) interviewed Jordanian men about their perceptions of women with breast cancer. The views on a man's rejection of a wife diagnosed with breast cancer can be related to the husband's failure to meet the burden of his obligations towards the wife, and the wife's failure to meet the husband's marital needs. On the other hand, Sara and Leena found that support from their husbands during their journeys had positive impacts on their relationship, particularly regarding communication, openness, and shared decision-making. Improvements also occurred in Sara's social life, as Sara became more social and advocated breast cancer awareness in her local community.

Regarding the healthcare experience, which is a vital part of the social context of survivorship, some health care providers were supportive, offering information, answering patients' questions and giving them the needed support. However, some women expressed being in need of psychological and information support in terms of what to expect from the treatment, how to deal with the treatment side effects, and the possibility of cancer recurrence. Turkish women shared the same concern about the lack of information from the health care providers and, instead, women gathered some information from other patients (Cebeci et al. 2012). These problems arose mostly in cases where there was a limited knowledge of the English language, limited knowledge about breast cancer, a particular cultural view of cancer, a lack of a patient-centred care model and decision-making involvement (Doumit et al. 2010a; O'Callaghan et al. 2016; Saati 2013).

Being with breast cancer survivors

There are differences between Western and non-Western cultures with regards to the preference for being with other cancer survivors in subgroup support. This has taken different perspectives, such as an open willingness to help others, applying cultural conditions to share their stories, and a refusal to be part of the social community support. The results showed that some women, particularly Sahara, Anoud, and Sara, expressed a willingness to meet and share stories with other women with breast cancer

and be a source of hope. Their attitude was quite similar to Western women who use active coping skills that include behavioural and psychological responses to reduce stress (Doumit et al. 2010b). This could be due to their social status, health care experience, educational level, and employment status. For example, both Anoud and Sara had their familial support; Sahara and Sara had a positive health care experience and support from health care team; Sahara works as a pharmacist and Anoud is studying and doing part-time job. However, when some women asked about their experience of attending support groups sessions, it appeared that the women underused this service. This can be explained by the women's lack of knowledge about the support groups available in their local communities and about what to expect from this service, particularly in the expression of their feelings, information acquisition, and coping tips. To explain more, Williams and Jeanetta (2016) reported some reasons given by women with breast cancer for not finding supportive groups useful. For example, women described the meetings as depressing, boring, and lifeless, while others felt guilty about having a better prognosis than the others.

Another group of women used an avoidant or suppressive coping style that inhibit the experience and the expression of negative feelings, thus they tended to keep themselves from directly addressing stressful events (Moore and Spiegel 2004). Ohoud and Shahad showed an interest in helping other women, but according to the cultural perception of hidden. For example, Ohoud explained, *“you know, sometimes I'm sharing my experience with breast cancer with others, without saying that it was in fact my story and that I was the patient”*. A similar scenario was reported by Maria, a woman in Israel who had breast cancer, who claimed that it would be complicated for her to talk with a woman relative diagnosed with cancer, while instead she did not mind talking about it with a woman she did not know by phone to support her, of course without revealing her name and identity (Goldblatt et al. 2013). On the other hand, African-American women showed that their experience gave them a sense of urgency to help others (Davis et al. 2014).

At the same time, instead of joining supportive groups, many women, like Maha, Haia and Alaa, reported using a different support system, including deep religious–self–family support, suggesting that they could appraise their own coping resources to manage their psychological distress. These results reflect those of (Nápoles-Springer et

al. 2007), who examined the association of predisposing, enabling, and need factors with the use of cancer support groups among 330 Latina breast cancer survivors, who participated in a cross-sectional telephone survey. The results showed that 225 (32%) participants used a support group, while 68% did not (Nápoles-Springer et al., 2007). The reasons for not using a support group included receiving enough support from other sources (20%), not needing a support group (18%), and being unaware of local groups (17%) (Nápoles-Springer et al., 2007).

The above discussion suggests that each breast cancer patient is different in terms of what she needs, when she needs the support, and how it is supposed to be delivered. It is necessary to take into account the basic values and cultural norms between women, such as depending on the family and others for social support, and the value of individual vs. group effort (Moore and Spiegel 2004). This distinction is important to consider when examining the ways that women who had breast cancer use to cope with their illness.

8.3.3 Discourse

Discourse relates to the sort of terms and language that are used to describe one's experience and to identify the cultural forms underpinning the experience (Ashworth 2016). Culture has a central impact on relations and daily behaviours (Moore and Spiegel 2004), and breast cancer experience is not an exception. Culture affected women's world, where they respond differently to breast cancer and its treatment, health, and relationships. In this thesis, women's stories of breast cancer have found a place in their culture, and they used different social, religious, and racial terms to describe their experiences.

Being towards death

The women's stories and their use of language help to understand their being and their life-world. This appears when some women in my study used terms like 'the disease', 'the tumour', and 'the thing', but never called it breast cancer, which relates to the stigma attached to its meaning. All the reactions to cancer involved shock, death, and the possibility of it spreading to another bodily part. These results are in keeping with a previous phenomenological study that looked at women's understanding of cancer, which prompted feelings of shock and confusion (Liamputtong and Suwankhong 2015;

Patel-Kerai et al. 2015). The possibility of being-towards-death generated feelings of fear and uncertainty and this was evident in the women's metaphors. 'The phantom of death' was reported in my study of Amar and Azizah. Similarly in Brazil where women used the same metaphor of 'living side by side with the phantom of death' (da Costa Vargens and Berterö 2007). The stigma of breast cancer was not only associated with the high risk of death, but also its occurrence in a private area of the body like the breast, which is a body part that we do not speak about culturally. This is explained by the modesty, which is an important element of Islam, that requires women to cover their bodies (Yosef 2008). According to the Korean tradition, women's breasts or genitalia are considered something shameful to talk about and need to be covered up (Suh 2013). Therefore, in the latter study, the discourse of breast was associated with using terms such as 'chest', 'milk room', and 'breast milk'.

Different perspectives were reported regarding the cause of breast cancer, as every culture has its own method of managing loss, which is to be viewed as a matter of preference, but which is a vital connection to the community and heritage (Moore and Spiegel 2004). When breast cancer strikes, some women linked their illness with their belief of the devil's eye, as did Nourah, Samar, Shahad and Leena. The phenomenon of the evil eye in the Saudi culture, refers to a gaze associated with envy, jealousy, and extreme admiration from one person to another that may cause suffering as well as either physical or mental problems. Some women in this study perceived the devil's eye as the cause of their breast cancer, because this is the only reality in which they believe. This belief affected their mode of living by keeping a distance from unwanted social possibilities with people who may envy them. Bahraini women have reported the belief that the devil's eye was the cause of cancer (Jassim and Whitford 2014). Thai woman believed that their breast cancer was the result of bad deeds (Liamputtong and Suwankhong 2015), while Mandarin cancer survivors believed it was because of body acidity (O'Callaghan et al. 2016). In Korea, women showed a fatalistic perspective in relation to their predestined fates (Suh 2013). Some Indian women shared the same views in that their illness was out of their control, thus they did not want to understand the cause (Patel-Kerai et al. 2015). However, Western women rejected integrating this belief into their being and, instead, created a new sense of life that involves embracing family, opportunities and, of course, their health (Kaiser 2008; Sabo and Thibeault

2012).

Saudi women's religious beliefs in God's will shaped their lived experience of surviving breast cancer. For instance, Nourah, Shahad, Alaa, and Shamas identified God's will as the cause for their survival of breast cancer and preferred to continue their same lifestyle as before breast cancer, without taking precautions to prevent cancer recurrence. Women who held this perspective explained that matters of illness, life, and death are in God's hands and that, if a woman is destined to have cancer again, it will happen regardless of all her precautions. In Islam, it is believed Allah (God) has plans for each person and death is one of them and that, according to one's deeds, he or she might be sent to heaven or hell (Silbermann and Hassan 2011). Such differences were also apparent within the Western context, whereby Latino women exhibited the same fatalistic belief in a qualitative study; however, even though many participants perceived their destiny to be in God's hand, they also took an active role in personal health promotion, driven by the belief that 'God helps those who help themselves' (Flórez et al. 2009 , p. 294). Fatalism can impact negatively on women's health-seeking behaviours (Banning and Tanzeen 2014). In contrast, many previous studies in Europe and the US did not address the religious or cultural influences shaping the meaning of breast cancer survivorship, but emphasised the individual's fighting spirit to beat breast cancer as the main factor in survival, in addition to receiving proper treatment (Burke et al. 2012; Davis et al. 2014; Documet et al. 2012; Khan et al. 2011).

Being involved in health care plan

The results showed that the relationship between patients and physicians was run within the context of Saudi culture and gender, specifically in issues like breaking bad news, women's position, communication, and involvement in decision-making. Both the public and some health care teams had relatively negative attitudes towards full disclosure. The results showed that some physicians used a hierarchical and protective method of communicating with their patients. For example, during the intense period of diagnosis and treatment, some doctors did not openly communicate or fully disclose information about treatment side effects. Direct disclosure of cancer diagnosis to patients in Ethiopia, for example, was considered as being harmful to patients and took away any hope they had, while clinicians even encouraged patients with the advanced stages of the disease to consult alternative healers in order to seek comfort for their

condition (Beyene 1992). In Saudi Arabia, Saati (2013) suggested that the results concerning the poor communication between Saudi breast cancer patients and health care providers was because of the latter's attempt to use simple language to deliver information to the patients, especially for those who did not have a formal education. Further, Saati (2013) explained that these results could be due to language barriers and cultural differences as the majority of oncologists were males and nurses that were non-Arabic speakers. In Jordan, women expressed their need to know the truth about their illness, despite the intention of the doctors to control information for the patient's protection (Alqaissi and Dickerson 2010). This inference is consistent with the results of a quantitative study on 114 patients at a teaching hospital in the Eastern Province in Saudi Arabia: virtually all patients (99%) opposed the withholding of information and wanted to know the benefits and treatment side effects (Al Amri 2009). Based on these results, I can infer that women preferred disclosure, as most of them preferred to be involved in the decision-making process.

In terms of breaking bad news and the process of decision-making, there were issues that were culturally interpreted and valued in terms of patient protection. Some women were unhappy with their oncologists' unprofessional attitudes, especially while disclosing the diagnosis. Some oncologists tended to involve male family members in patient care. For example, Aisha, Lama, and Shamas explained how their doctors asked a male relative to be present while they broke the bad news and while discussing treatment options. These results are expected, as a previous quantitative Saudi study found that, among 234 cancer patients, 44.21% preferred to be first informed with relatives present, while 33.48% preferred to be alone (Mohieldin et al. 2016). However, the latter study did not show cancer patients' preference for type and gender of the present relative. It only showed that the most common relatives who shield cancer patients from painful truth – by asking oncologists to withhold information – were either sons or daughters (Mohieldin et al. 2016). Their actions were influenced by their perception that cancer patients, especially females, are vulnerable and unable to deal the pressure of the diagnosis and making decisions (Aljubran 2010). Even acculturation could not prevent the Canadian Punjabi-speaking South Asian women to express their disapproval of being told without preparation and without having a relative present (Gurm et al. 2008). The main reason for Indian women in the UK to rely on others to

accompany them to the hospital was for them to act as a translator, because of their limited knowledge of the English language (Patel-Kerai et al. 2015).

Another scenario of dependence was reported by some women, such as Asera, Lama, Asma, and Leena, on the health care providers, especially doctors, as a source of information, decision-making, and advice. Previous studies have reported similar findings (Bessen et al. 2014; Wiljer et al. 2013). During follow-up appointments, Black-African women showed less challenges in health care communication, which suggested that they were more likely to depend on health care providers to lead the discussion, unlike white women who showed their need for interactive communication (Tompkins et al. 2016). Saati (2013) explains that the role of male doctors was more autocratic than female nurses in Saudi Arabia, thus breast cancer patients tend to depend on them and not question their treatment plans. In Asian culture, because of the autocratic relationship between the physician and the patients, many women felt rushed into making a decision about their treatment (Lam and Fielding 2003). To minimise the high demand on doctors for information, Aldossary et al. (2008) suggested increasing the nursing workforce so that culturally appropriate holistic care can be delivered to Saudis. Also, Yousuf et al. (2012) emphasised the importance of investment in the nursing profession by increasing nurses' knowledge about breast cancer and providing them with the well-training programmes for attending the public's needs. Increasing the number of Saudi nurses and improve their knowledge might enable them to advocate for breast cancer patients or empower them to make their own decisions. This contrasts with Western societies, where nurses take the lead in primary care and health promotion (Amir et al. 2004). Patient autonomy, shared communication, and decision-making are important elements of the health care model (National Cancer Survivorship Initiative (NCRI) 2013). In other words, the cancer patient is usually the first to be informed about the diagnosis and agrees to receive treatment. Also, different self-management interventions are implemented to support cancer survivors to take the lead in managing their own health issues (Fenlon et al. 2015).

8.3.4 Project

Taking care of the husband

The women in this study extended themselves into additional roles to help maintain normal functioning in the family; they care for others and they care about themselves.

Saudi culture emphasised women's fulfilment of their prescribed roles, such as wife and mother, and so losing a breast was difficult to accept. Losing part or all of the breast was shocking and changed women's approach to life, their opportunities, and relationships, often resulting in a feeling of being less feminine, especially in the roles of women and wives. This finding has broad support in the Eastern and Western healthcare literature that has taken a descriptive phenomenological, rather than an interpretive, approach (Alqaissi and Dickerson 2010; Ashing-Giwa et al. 2008; Jassim and Whitford 2014; Mollica and Nemeth 2014). The latter literature supports the view that breast cancer survivors find difficulty carrying out their role as wives.

Some women in this study concealed their feelings, suffering inwardly in order to feel connected to their husbands and compensate for their feelings of low body image. In terms of the perception of sexual functions, changes in sexual desires, and changes related to body image, the Saudi women with breast cancer reported poor functioning in sexual enjoyment (Al-Mutairi et al. 2016). Therefore, Aisha, Asera, Sahara, and Lama described their attempts to fulfil their obligations and roles as wives and to put their husbands' needs ahead of their own. For example, lama described her attempt to fulfil her husband's needs, "*at night, I tried to dress up beautifully for him and wear this nice short lingerie, but he was avoiding me*". Women in Korea incorporated their husbands' perspective and expressed their concern about their sexuality, and their feelings of not being attractive to their husbands after mastectomy (Suh 2013). These results might be explained by women's gendered socio-cultural roles in marriage and family, which are focused on meeting the husband's needs. Another possible explanation is the need to maintain financial security as represented by a husband (Alqaissi and Dickerson 2010).

The negative impact of breast cancer on the women's sense of who they are, as well as their body image and sexuality, was socially constructed through interactions with others. Infertility serves as an example of this process. Confronting infertility was a challenging experience for some women, like Anoud, Aisha, Lama, Asma, and Sahara, as they projected onto themselves the public perception that they would have fewer opportunities to get married, or less chances of continuing their marriage; consequently, they perceived they had failed in their roles of wife and mother in their society. Previous studies in Lebanon and Pakistan uncovered the same concerns (Banning et al. 2009).

Taking care of the family

In my study, when women were diagnosed with breast cancer, they felt the need to take over the mothering role by hiding their illness and protecting their mothers from pain, thus the sense of the mother/daughter dynamic was altered. As Sahara said, “*I wasn’t afraid of losing my health as I was afraid of losing my parents or making them sad*”. Also, they cope with cancer and carry out performing the same household activities because they want to be a mother for their children, despite the limitations imposed by lymphoedema. Some women, like Sara and Nourah, began educating their young daughters about breast cancer and the importance of breast self-examination, although they have not a proven genetic link to their breast cancer. Lebanese women surviving breast cancer, they expressed their feelings of guilt because of the genetic predisposition (Doumit et al. 2010a).

The women’s projects, their roles and activities within their cancer worlds, were shaped and motivated by care, as well as the accepted cultural role of the women. For example, Turkish women surviving breast cancer explained their duties according to the Turkish society attitude towards housework, taking care of the husband and children and fulfilment of their needs (Cebeci et al. 2012). The concept of care and living for their children influenced Thai women when making a decision to have a mastectomy and go through chemotherapy (Liamputtong and Suwankhong 2015). Also, in Brazil women carried out their household activities despite the limitations imposed on them from the treatment side effects (da Costa Vargens and Berterö 2007). They carried on to show people that they were still strong and could live a normal life.

Taking care of themselves

Some women in my study decided to step up and slightly shift their focus from their family’s needs to their health and personal goals. This was part of the process of finding meaning to their lives; they incorporate their risk into their sense of self-care and experience a new perspective of independence. For example, Aisha described how breast cancer experience and the lack of husband’s support have made her search for a job and be financially independent. The sense of self-care can be seen in the women’s increased health awareness and care for themselves, their exploration of risk management techniques, and a fresh evaluation of the importance of what is important

to them in their lives. For example, some women, like Maha, Ohoud, and Asma, reported that their breast cancer experiences have taught them lessons about how important it is to follow a healthy lifestyle, including taking exercise, like walking and limiting their consumption of fatty and canned food. Some women have created for themselves a new sense of 'normal', by incorporating their risk and being-towards-death in a functional way. For example, Ohoud, Anoud, Sara, and Shamas showed that keeping the follow-up appointment was a priority. Similar results from Turkey revealed that women appreciated the importance of health after breast cancer (Cebeci et al. 2012).

Surviving breast cancer may be considered to be a step towards discovering new life opportunities and hoping for better future. In my study, some women, like Anoud, Asma, Aisha, Sahara, and Amar developed self-growth as they were able to return to work after treatment, find a job, or complete their degree studies. Similarly, Brazilian women opened themselves to life and appreciated every single moment of being alive (da Costa Vargens and Berterö 2007).

There were moments of realisation and opening-up questions by women about their current way of living, and how their relationship with Allah was essentially perceived. From a spiritual well-being perspective, the women in my study felt stronger and more spiritual, in that cancer was perceived as 'God's test' of human patience and a 'wake-up' call about what was important in their lives. All the women emphasised the importance of practising religion, such as praying and reading the holy book. Similarly, previous studies have demonstrated that faith in God was considered to be a source of support and strength (Goldblatt et al. 2013; Joulaee et al. 2012).

For all the women in my study, being diagnosed with breast cancer was seen as a test from God and the confrontation with their own vulnerability drove them to become more spiritual. For instance, Shamas, Maha, Asma, Shatha, and many others perceived their breast cancer experience as a chance to be more spiritual and faithful, such as reading the holy Quran and visiting the Great Mosque in Mecca. Anoud claimed, "*I believe that God made me have breast cancer for a reason. God wants me to get closer from him and be more religious*". However, African-American and Muslim women

reported feelings of self-doubt regarding their relationship with God and wondered whether God was punishing them (Ahmad et al. 2011; Gallia and Pines 2009).

8.3.5 Selfhood

Being a breast cancer survivor

Constructing an identity depends on the degree of the illness, the meaning of the illness experience, the consequences of the illness, and interactions with others (Charmaz 1995). The results showed that some women, like Shahad, Sahara, and Haia, struggled to hide their breast cancer identity in public, while continuing with their normal life. They preserved the illusion of wellness to protect their families from sadness and worry. As a coping mechanism, the women immersed themselves in hidden worlds, distanced themselves from those who might treat or label them differently, and continued their roles as sisters, daughters, mothers, and wives. Consequently, they did not practise being survivors in their community. Similar results were reported from Brazilian women with breast cancer, who made efforts to hide their illness (da Costa Vargens and Berterö 2007).

In Israel, an Arab woman with breast cancer described her preference to be socialised at the hospital with Jewish patients, who were living according to the positive Western concept of survivorship (Goldblatt et al. 2013). When discussing the negative Arabic cultural perception of cancer imposed on her behaviour: “*we came for treatment as if we are hiding; we wear glasses and do not want anyone from our home towns to see us*” (Maria, p. 871). The question here is how some women and not others adapted different meanings of survivorship and different identity. Hidden living provides some explanations of why many women like Azizah, Haia, Shahad, Asera, Asma, and Nourah did not know the term ‘survivor’ and questioned its meaning. Western literature has reported an unfamiliarity with the survivor identity among older women with breast cancer (Park et al. 2009). The present results resonate with some studies, which found that adoption of the survivor identity was not universal among those who had breast cancer (Kaiser 2008; Khan et al. 2011; O’Callaghan et al. 2016). In a qualitative study, Smith et al. (2015) found that participants did not use any cancer-related terms when asked about their self-perceptions in relation to their illness. Instead, they conceptualised themselves within the context of relationships (e.g., mothers, housewives) and personality (e.g., caring, healthy).

In my study, some women like Asma, Shahad, Amar, and Haia used different images to describe their survivorship experiences, such as a ‘rescuing’ from drowning, ‘thriving’ and ‘rebirth’, which implied living, just as Greek and Mandarin Chinese cancer survivors used terms like ‘saved’, ‘alive’, ‘escape from death’ and ‘not dead’ (O’Callaghan et al. 2016). These senses of ‘living’ and ‘restoration to life’ were also reported among Puerto Rican and African-American women who had survived breast cancer (Davis et al. 2014; Dyer 2015). Two women, Sahara and Anoud, used military language as ‘fighters’ and being involved in a ‘war’; however, the meaning was different, as Sahara’s battle is against breast cancer itself, and Anoud’s battle is against the negative cultural beliefs. The concepts of fighting and beating breast cancer were commonly reported in Western qualitative studies (Kaiser 2008; Smith et al. 2015; Williams and Jeanetta 2016). However, the fighting against the cultural norms is unique to this study and it has suggested a different type of being in the world.

Being normal

The results of this study showed another group of women who had made the decision to live as normal a life as possible and to be-in-the-world, almost as if their illness was not even part of their lives. For example, Shatha, Ohoud, and Leena did not wish to view their lives within the context of what might happen as a result of breast cancer and death. Instead, they chose to embrace normality, which, to them, meant their ability to work and engage in daily social activities, take care of their children, and do household activities, despite physical symptoms, such as fatigue and lymphoedema. They wanted their life to be as it was before being diagnosed with breast cancer, especially in regards to their families, plans, and opportunities. This desire explains why those women identified themselves as someone who had had breast cancer and preferred to be the same person as before their diagnosis. This was addressed, too, among Brazilian women; most of them viewed themselves as the same women as they always were, but without a breast, and that this would not stop them from living their lives normally (da Costa Vargens and Berterö 2007). This tendency was consistent with the grounded theory study carried out by Little et al. (2002), who found that cancer patients restore a sense of continuity in their lives after breast cancer by backing to their pre-experience identities, drawing on past memories, and finding ways to preserve continuity between past memories, present experience, and constructions of the future. Many studies have

found that survivorship was defined from factual and functional perspectives, as one no longer dealt with the cancer (Kaiser 2008; Khan et al. 2011; Smith et al. 2015). Perceiving normality in the survivorship definition stresses the impact the disease has on individuals' lives and prioritises their ability to conduct normal, everyday activities.

8.3.6 Temporality

Being on time

The time from the onset of symptoms to accessing the medical team is important in the women's experiences, and has had negative consequences for some women, like Aisha, Nourah, Alaa, and Amar. For them, seeking medical care was triggered by the long persistence of symptoms and disclosure to family members, who encouraged them to have a check-up. Women like Anoud and Lama sought help first from a traditional healer and used herbal treatment as a way of dealing with the symptoms of breast cancer and, in their view, this did not imply a delay in medical treatment. This could explain why they were diagnosed with stage II. 53.4% of Saudi cancer patients (n=234) tried complementary and alternative medicine, and 46.7 % continued using it even during treatment (Mohieldin et al. 2016). Saudi women with low breast cancer awareness are more likely to delay in presenting to a healthcare provider (Saati 2013). In some Eastern cultures, cancer patients tended to use traditional therapies because of the failure of the medical treatment to obtain a cure in the advanced stages of the disease, as well as the expense of obtaining medical treatments (Moore and Spiegel 2004).

Additionally, the results showed that some women, like Alaa, Azizha, Asma, Sara, and Amar followed the wrong breast cancer diagnosis pathway and approached non-oncology specialists for advice. This result might be explained by the fact that women accessed private health care due to its convenience, especially prompt doctor services, longer opening times, easy appointments, and open medical files. Governmental hospitals specialising in cancer care are not widely available, as discussed in the section on the Saudi health care system in the introductory chapter. The results also suggest that some women were not fully knowledgeable about choosing a high-quality health care centre, whether public or private. Some women reported seeing private-sector general doctors and surgeons who were not qualified or fully equipped to diagnose cancer, which resulted in misdiagnoses. As in our study, women reported possible initial

misdiagnoses by public and private sector practitioners in South Africa, which delayed a diagnosis and access to medical care (Moodley et al. 2016). Unger-Saldaña and Infante-Castañeda (2011) found that delays were due to patients' socio-cultural context, symptom interpretation, and certain aspects of the local health services. On the other hand, Western health care systems, like in the UK, have specialist pathways for breast cancer that relate to the presence of a lump (National Institute for Health and Care Excellence (NICE) 2015). For example, patients who suspected to have breast cancer are referred by their GP to special breast clinics.

Being through time

This relates to the passage of time and its effect on women's experience. For example, being longer in the past might make their experience difficult to cope with and move on. Women's living with breast cancer through time was manifested in the time spent waiting in the doctor's examination room, finding out the results, starting treatment, waiting for their hair to grow back, and suffering other physical and psychological symptoms. The results showed that some women, particularly Shatha, Asma, Aisha, Asera, and Ohoud, counted their days in remission and felt that time passed slowly during the treatment period; once treatment was completed, they became anxious about when and where cancer might reoccur. This is explained by the experience of transitioning from being patient to survivor, which was considered challenging, especially for American women, who expressed a feeling of insecurity as they missed the safe shelter provided by the health care team during the treatment period (Allen et al. 2009). This anxiety was also generated as Saudi women with breast cancer expressed their satisfaction with the received information during the beginning of treatment and, through time, their satisfaction declined during advanced treatment (Saati 2013). Women like Ohoud, Asma, Nourah, Lama, Shamas, and many others, lost certainty in time, as they did not know what the future held. They were no longer sure about their health condition, which threatened their future plans. Also, they described their world as being no longer secure and normal. Uncertainty and fear of cancer recurrence are commonly reported in both Western and Eastern literatures (Doumit et al. 2010a; Mollica and Nemeth 2014; Wonghongkul et al. 2006).

Time was related to the women's conception of themselves. For instance, at the onset of the breast cancer diagnosis, their self-identity changed and was shifted into the health care system. Women perceived themselves as patients and victims, and some thought that they were close to death, consistent with findings from Brazil (da Costa Vargens and Berterö 2007). When time passed and treatment was completed, some women, like Aisha, Aama, and Anoud called themselves 'survivors' or 'thrivers', as they believed that they had survived death to stay alive. Others, like Nourah, Shahad, Leena, and Amar, defined themselves as survivors based on the passage of time, such as the first five years after curative treatment and the long gap between follow-up appointments. This result is consistent with the findings of Documet et al. (2012), where women defined the moment of surviving breast cancer as when they completed treatment and surgery and were told by another person, such as the doctors, that they had become survivors. On the other hand, Korean women showed unwanted engagement with their unpleasant breast cancer experience, even after five years of finishing treatment (Suh 2013).

Being in between

It is about living between the past (recalling the moments of diagnosis and treatment), present (living hidden and in fear of cancer recurrence), and the future (thinking of health, self, and family). Comparing the present situation with past major life events helped some women either reframe and accept breast cancer, or develop a fear of it. For example, relatives' past experience with cancer taught some women like Aisha, Alaa, and Maha what to expect from cancer, particularly the treatment, how to deal with the side effects, and the need to maintain a positive attitude. These findings are consistent with those of Roundtree et al. (2011), who found that women embraced the attitudes towards breast cancer modelled by others. By contrast, others felt anxious, afraid, and uncertain about life, especially when a family member whom they knew had a negative experience with cancer (da Costa Vargens and Berterö 2007).

As time passed, many of the women in this study remained immersed within themselves in the hidden world that they were in during treatment. Some women for example, surrounded themselves with reminders, such as when to attend a medical appointment, when to take medications, as well as living with bodily changes. Physical symptoms, such as lymphoedema, fatigue, and mastectomy, and the performance of illness-related

activities, such as taking medication and attending follow-up appointments, have become reminders of the breast cancer experience, as evidenced by other studies (Rosedale 2009). Even being described as a ‘survivor’ might act as a reminder of cancer (O’Callaghan et al. 2016). Only the time spent with family has renewed significance for the women in my study. When the women in my study are confronted with the realisation that they will eventually die, whether it be sooner or later, there is more focus on making the most of the time that they have with friends and family. Concerns such as finances or work become less important when it is realised that time and life are not limitless.

Thinking back to the past for some women like Lama, Asma, Asera, and Aisha, where they lived their lives and pictured themselves with experiences from the past, remembered how their husbands were kind to them and how their lives were smooth, how they were planning on getting pregnant and having a baby boy, or dreaming of getting married and being a mother. The present for them in terms of how their marital relationships had changed, how their husbands decided to either divorce them or look for another wife, and how their chances of getting married and being a mother are low. All those past expectations had influenced women’s current experiences; leading them to feel disappointed in the people they know and frustrated from the cultural rules that they have to deal with. Their future relates to how women will manage their relationships, deal with people’s curiosity and judgements. For example, in Turkey, it was found that in couples who had marriage problems before the woman was diagnosed with breast cancer, the relationships became even worse during the treatment, and vice versa (Cebeci et al. 2012). In Pakistani culture, breast cancer was perceived as a cause of reducing women’s chances of getting married (Banning et al. 2009). From the above literature, it seems that Saudi Arabia, Turkey, and Pakistan share similarities in terms of male’s dominant role in the society and women’s limited power.

8.4 Conclusion

The idea behind using the life-world as a framework to map women’s experiences was driven by the theoretical foundation of interpretive phenomenology and the philosophical background of IPA. Both of the latter approaches focus on the individuals’ lived, current situation within the context of their social world and sense of being in the world, or the ‘person in context’, rather than knowing the world only,

which supports the exploration in this thesis. To position my description and interpretation comments in a wider social and cultural picture, which might enhance the understanding of the breast cancer experience among Saudi women, the life-world was considered. It has fractions, such as embodiment, sociality, selfhood, discourse, project and temporality, which were used to map the results in the existing literature. Furthermore, the 'sense of being' was considered through describing each fraction to make sense of women's lived worlds.

The bodily sense appears to be impacted by the long-term side effects of treatment, such as mastectomy, infertility and fatigue. Breast cancer made the women in this study aware of their bodies and their mortality. This affected their social life and interactions with others, for example, they voiced concerns about the cultural stigma of breast cancer and the ways in which family, friends and society might perceive them as vulnerable women. The cultural stigma of breast cancer had threatened their sense of self and had forced them to change the ways in which they engaged with others. They adopted different and hidden roles to cope with cultural expectations and their feelings of uncertainty and vulnerability. This was reported in a few studies from Lebanon and Pakistan, but not in the Western studies.

Women's position in society, gender issues, personal relationships and religion were all considered to be central in the lived survivorship experience. Women's roles were driven by the concept of care and protecting others from pain and sadness. They continued to care for others during their treatment and afterwards, despite their need for support from family and healthcare providers. Only their belief system, in God's will, appeared to help them to accept their experiences. Therefore, the meaning of survivorship has a religious cultural base, reflecting the sense of being under test and grateful to God.

The sense of selfhood for the women in this study is characterised by restoring the same prior sense of self as normal, productive, enduring and self-reliant. However, returning to normal life was not necessarily associated with embracing the survivor identity, as most of the women were not familiar with the term survivor, but with conforming to cultural norms, including living hidden, suppressing their feelings and believing in God's

will. This might explain the differences between Western and non-Western cultures with regards to the preference for being a survivor and the desire to be with other cancer survivors in a support subgroup. On the other hand, some women in this study developed senses of self-growth and became spiritually wise.

The lived breast cancer survivorship experience showed different perspectives over time about appraising symptoms, accessing medical care, dealing with uncertainty, perceiving self and others and making sense of their experiences. Given time, women were able to make sense of their experience of breast cancer from the onset of symptoms. They were able to assimilate the first time that they felt a tumour, the first thought when they heard the words 'breast cancer', the first person they would have liked to tell or not, the first time their hair started to fall out, the first time they touched their breast after surgery, the first time they finished treatment and the first time that they felt either vulnerable, hidden, strong or normal.

The next chapter explores the research quality and validity issues and my reflective experience as a researcher.

Chapter 9 Assessing validity and quality in IPA

9.1 Introduction

This chapter discusses Yardley (2000) principles for assessing validity and quality in IPA. These principles are sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

9.2 Validity and quality assessment

Smith et al. (2009) recommend the use of Yardley's (2002) guidelines and criteria in assessing the quality of IPA because of the accessibility and comprehensiveness of the standards. In this chapter, each of the guidelines are described and linked to the IPA process.

9.2.1 Sensitivity to context

Sensitivity to context was demonstrated in the early stage of the research given that I reviewed the literature on the lived experiences of breast cancer survivorship, women's identities and needs, and the challenges that they encounter. A literature review helps me identify research aims, questions, methodologies, and methods. It also facilitates the discussion of findings that are supported by the relevant literature.

Another reflection of sensitivity to context in this work is awareness of the socio-cultural setting of the study. For example, this research delved into the religious, social, educational, and cultural views that visibly influence women's beliefs regarding breast cancer. The participating women's responses were mainly consistent with and constructed on the basis of their social interactions with others and existing meaning in their life-worlds.

Sensitivity was also shown when I chose IPA as the methodology to analyse the data because it supports close engagement with the idiographic experiences of young Saudi women who completed breast cancer treatment. This engagement enabled understanding of their life-worlds. With IPA, a number of verbatim extracts from the participants' responses were examined for use as support for a given topic, thereby providing the participants a voice whilst allowing readers to see how the interpretations

were formulated (Smith et al. 2009). Sensitivity to context was likewise achieved through the linking of themes to form subordinate and superordinate themes and the use of language that was interesting and enabled rich understanding.

9.2.2 Commitment and rigour

Conducting an in-depth interview requires considerable personal commitment and investment for a researcher to comprehend participants' views (Smith et al. 2009). Although new to IPA, I have sought to develop the information that I possess regarding this method and the skills necessary to carry it out effectively. I attended IPA workshops, which covered the development of interview schedules, the improvement of interview skills through role play, and the development of analytic skills by practicing on examples. I demonstrated my personal commitment to the interviews by asking open-ended questions, taking care to minimise distractions, and by providing the female respondents enough time to think and answer the questions. I showed respect to the women when they revealed private issues or refused to discuss them. An analysis audit was carried out under the supervision of my supervisor, who is an IPA specialist, to make sure that I was on the right track in analysing the data. My supervisor agreed with the themes produced and saw how they had emerged from the transcripts.

A rigorous study is a thorough investigation wherein an appropriate, homogeneous, and relevant sample is recruited (Yardley 2000). The thoroughness of the current research was exhibited through the recruitment of young Saudi female patients who have survived breast cancer according to the inclusion and exclusion criteria. Rigour was also displayed in IPA through balance between closeness and separateness, movement from part to whole, and movement from the descriptive to the interpretive perspective during the analysis. These were necessary to effectively describe and understand the experiences of the participants.

9.2.3 Transparency and coherence

Transparency relates to how clearly the stages of research are described. As indicated in the previous chapters, a clear and detailed guide to the literature review, the selection criteria, and the search strategy were laid out in a grid table. The methodology and methods were comprehensively discussed, with the chapter providing a complete explanation of each step carried out in the study. Following the steps of IPA analysis

helped me provide a systematic way of dealing with data and going through the different lenses of analysis, such as the descriptive and interpretive lenses. Openness was realised through receptiveness to the women's experiences and repeated listening to their stories. Chapter 5, the data management principles and procedures features tables include a detailed presentation of the participants' statements. The use of tables was combined with the double hermeneutics approach, which should ensure transparency. A constant reading and re-reading of the transcripts facilitated engagement with the women's stories and consistent listening to their voices.

Yardley (2000) describes coherence as the degree of fit between research questions and the philosophical or theoretical perspective adopted and the method used to analyse data. Because my research aim was to explore the experience of breast cancer survivorship lived by young Saudi Arabian women, I regarded the qualitative interpretive phenomenological method as the best approach for achieving my aim. IPA principles were consistently adhered to for the purpose of determining the underlying assumption that describes the effects of culture on shaping women's experiences. Through the interpretive phenomenological analysis of the interviews with the young Saudi breast cancer survivors, a number of themes were linked together in a logical manner. Coherence in this work is reflected by the arguments presented in the results chapter and the presentation of different women's views.

9.2.4 Impact and importance

Impact and importance suggest that the validity of qualitative research can be evaluated on the basis of whether these concepts inform readers about an interesting and important issue and how well a study was undertaken (Yardley 2000). The present study demonstrated understanding of the lived experiences of Saudi women suffering from breast cancer and showed the influence of life-worlds on personal and social issues. The social constructionist and both the epistemological and ontological paradigm confirmed that individual meanings are not primarily constructed by the experience of an individual person. Instead, the meaning attached to being a breast cancer survivor is socially and culturally constructed. Interpretive phenomenology, IPA, and lifeworld had definitely influenced the way I think of breast cancer survivorship experience. The study was able to give the Saudi Arabian women a 'voice' by understanding their experiences of surviving breast cancer. Also, it highlighted the main obstacles that

breast cancer patients face in terms of accessing cancer care, the adequacy of the governmental and private health care system, education, and decision-making.

Chapter 10 Conclusion

“Claim your experience. Don’t let it claim you” (Jarvis 2014).

The aim and objectives of this study have been achieved by using social constructivism (Mertens 2005), qualitative research methods grounded in interpretive phenomenology (Heidegger 1996), and IPA (Smith et al. 2009). These methodological approaches help to understand the hidden experiences of breast cancer among a total sample of 18 Saudi women younger than 50 years who were diagnosed with breast cancer and had completed their curative treatment 6-47 months prior to the interview. Each of the 18 women’s stories were analysed using IPA, presenting descriptive, linguistic, and conceptual themes that identify the individual and shared lived experiences. The life-world philosophical framework and its fractions were employed to achieve an understanding of the lived experience of breast cancer from embodiment, social, selfhood, discourse, project, and temporality perspectives (Ashworth 2003).

- What are the unique lived experiences of breast cancer survivorship of young Saudi Arabian women?
- To what extent does the Saudi culture impact on the experiences of Saudi Arabian women who have survived breast cancer?

The questions above have been answered by achieving an understanding that there were cultural meanings in the context of women’s life after breast cancer, such as the fatalistic notion of health and death when it comes to appraising their symptoms and accessing health care. The belief in God’s will appears to be central in shaping the meaning of being a breast cancer survivor in Saudi Arabia. Women showed unmet needs when it comes to psychosocial support, information, and health care. Health care systems appeared to be not ready to support the growing number of women surviving from breast cancer.

IPA approach helped to explore and dwell on the women’s stories and share their experiences. Using in-depth interviews enabled more insight into women’s life-world. This study serves as a vehicle to raise Saudi women’s voice about their lived breast cancer survivorship experience. It contributes to fill the gap in the Middle-Eastern

literature and knowledge of breast cancer survivorship by offering insight into the experience. The findings throw new light on the unmet needs and the hidden living of what these vulnerable women have experienced. For example, women expressed their needs for informational, psychological, and social support. Also, they felt obliged to hide this stigmatising illness and be less social in order to accommodate others' expectations, avoid embarrassment, and feelings of pity.

In this thesis, the results indicated that women's experiences were influenced by cultural, social, and historical perspectives and such factors as gender, age, women's position in society, language, coping, family relationship, education, religion, and cancer stigma. These Eastern aspects permeate women's lives and affect their relations with one another and their perspective on matters. This influence appeared during the interviews when some women discussed cultural beliefs related to breast cancer, such as God's will and the devil's eye, which are not prevalent in the Western belief system, but reflect their being in the world. Certain factors become more or less important in their self-constitution. For example, viewing breast cancer as a stigmatised or chronic disease becomes part of their everyday world, and is not easy to block out.

What applied in Western contexts was not necessary applicable to Eastern cultures. That difference appeared when the Western survivorship framework failed to fit most participants' experiences due to conflicts between their understandings of breast cancer, the stigmatised general view, and the hopeful messages conveyed in the definition of survivorship. This study elucidates the process of building meaning around breast cancer and how the women modified cultural meanings (e.g., belief in the devil's eye, God's will) to fit their lives. It is important to be sensitive to how culture shapes lived breast-cancer survivorship and to whether women embrace the survivor identity.

This concluding chapter identifies the key aspects emerging from the completion of the thesis and considers many implications in a number of areas, for example, educating patients, their families, and health care professionals about breast cancer. Also, it considers issues in health care professional practice, education, services, and organisations. In this chapter, the main limitations of and the key lessons learned from the study are identified. These have all suggested as ideas for future research on the cultural aspects of the breast cancer experience. The results of this thesis help to highlight important issues related to culture, survivorship programmes, and support

systems for future enquiry, which may be developed as part of my professional activity as a lecturer.

10.1 Research implications

10.1.1 Education

- **Breast cancer patient**

My research identifies unmet needs among breast cancer patients, particularly needs for informational, psychological, and social support. Women struggle to make sense of cancer after treatment and resume their daily activities. Therefore, it is important to raise awareness about the concept of ‘living with and beyond cancer’ and how women can map their own future and depend on themselves in cancer management. Self-management has been defined as the understanding of what people can do to help themselves according to research-based evidence and health and social care professionals (Foster et al. 2005). Examples of self-management include education about chemotherapy, pain control, and non-medical activities that help improve social and psychological wellbeing.

Involvement in a support group was a debated topic as it might have positive impacts on health-seeking behaviours but might not work for those who have decided to live a hidden life as a coping mechanism. It is important to understand that every woman is different and has a unique belief and support system. Therefore, the concept of support should be adjusted according to cultural perspectives. For example, faith should be regarded as a tool that might help women to cope with breast cancer besides social, psychological, and educational support.

This work highlights women’s need to take an active role in their health care plans and be informed about what comes next in their treatment and follow-up care regimens. Patients should receive written materials with prior information about their breast cancer diagnosis, treatment, and follow-up. Informing women about treatment regimens is essential to how they accept breast cancer as a long-term condition. Establishing family and children counselling support services is important, especially for rural families in which the mother must leave the children to receive treatment at major cancer centres in large cities.

- **Health care professionals**

This study identifies the breaking of bad news, communication, decision-making, information provision, and support as the main issues which need attention. The health care providers could improve their communication skills by becoming sensitive to their patients' needs. Health care professionals who share a similar cultural background with patients could improve patient's understanding of their condition. Meanwhile, those from abroad should be informed about Saudi culture in order to communicate with patients and provide them with the support according to their cultural and rigorous understanding. Nurses should take an active role in educating patients and supporting their care to reduce the load on oncologists, as well as because they have the closest contact with patients and are in a good position to help these women. Thus, investment in nurses' education and empowering their roles in cancer survivorship are important.

The diversity of women's responses to survivorship presents a challenge to health care providers seeking to address patients' needs. Labelling women as survivors might help some adjust but leave others feeling uncomfortable. Therefore, health care providers should explore patients' views of survivorship to determine whether they are helpful or harmful. This information is important to facilitate positive psychological adjustment after treatment. It is important that health care providers not assume that women and families who do not ask questions about treatment are necessarily doing well and do not need help or information. In assessments, health care providers should cover not only physical concerns but also social and psychological issues, especially those often salient for women, such as domestic abuse and depression.

10.1.2 Health care practice

To build a clear direction of cancer care service, it is essential to administer individual assessments prior clinical consultations for young women across their care pathway, especially after treatment. For example, the use of the Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983), the European Organisation for Research and Treatment of Cancer QLQ-C30 (Aaronson et al. 1993), and the Quality of Life Instrument (Breast Cancer Patient version) (Ferrell and Grant 1995). Personalising survivorship care plans of Saudi women with breast cancer is useful when designing a survivorship programme. Considering cultural individual assessment, by using a cultural competency checklist, as suggested by Surbone (2009), and discussed in

Chapter 3: Literature review. This might help to reduce any developing conflict related to cultural differences among patients, families, and health care professionals. The use of holistic needs assessment (Snowden et al. 2015) to inform the discussion between patient and the health care team based on the personal patients' needs and concerns and support self-management requires consideration.

Personal and group support interventions should be tailored to patients' unique cultural backgrounds. As a start, a health care provider might connect patients with other women who speak the same language, are close in age, and have a similar background, because the participants might not always disclose matters to, or want to burden, their family members. This can provide patients with information and support when doctors are not available. Also, a list of local and national charities and other resources for breast cancer survivors should be available. On the other hand, much work remains to be done to help Saudi breast cancer patients to accept the concept of support groups and build trust on the effectiveness of support group service. For some women who want to maintain confidentiality by keeping their identity hidden, online supportive groups might be an option.

10.1.3 Policy development

Policy makers need to acknowledge women's positions, backgrounds, belief systems, health meanings, and cultural beliefs as important when designing a survivorship model, and permit them to inform appropriate health strategies. For example, certain Islamic concepts – that keeping the body in good health is a responsibility, that neglecting one's health is a sin, and that seeking treatment and preventive measures is a religious obligation for the sick – could be integrated into practice. Therefore, policy makers should pay more attention to the holistic approach when designing cancer care services.

Women are in need to be guided about supportive services. For example, genetic testing should be available to women with high risk, as some of the women in my study now live with the knowledge of the role of genetics in causing breast cancer. Therefore, the need to add the breast cancer genetic test within the pre-marriage listing tests in order to detect inherent diseases is essential. The pre-marital screening test is conducted for soon-to-be married patients in order to identify any inherent genetic blood diseases,

such as sickle-cell anaemia, thalassemia, or infectious diseases, like hepatitis B and C and the HIV disease.

10.1.4 Public

The public needs to be educated about the importance of health promotion, particularly in breast cancer screening. Younger women need to acknowledge the benefit from screening and early detection. This can be supported by presenting positive role models of breast cancer survivors in the public to spread hope. It is important to raise women's awareness of breast cancer as those who conceal their disease and live secretly miss opportunities to access social, informational, psychological support, and resources to improve their well-being.

The public needs to grasp the differences between cultural issues and religious beliefs (e.g., choosing an alternative therapy instead of medical treatment). The religious people need to use their power to encourage women to get screened. Also, they are in a good position to support cancer patients to continue with medical treatment and remind them that God will help them if they help themselves.

10.2 Limitations

My research presents a number of limitations, which were identified by following the Consolidated Criteria for Reporting Qualitative Studies (COREQ): the 32-item checklist (Tong et al. 2007). This checklist involves three domains, which are the research team and reflexivity, study design and analysis and findings. Accordingly, these are the limitations of this research:

1. The Saudi and Arabic literature on breast cancer survivorship is scant and I encountered difficulties in accessing Saudi healthcare reports, whether online or in print.
2. Obstacles arose in the data collection process, particularly time constraints on collecting, transcribing and translating the data.
3. Demographically, the data was collected from one geographical area in Saudi Arabia and, therefore, the findings' generalisability into other settings could not be assumed as the data was collected from one hospital, which provided services for the western region. Thus, it would be interesting to view other regions and to see if experiences were similar, or if some tribal and cultural differences might exist between regions.

4. Conducting interviews in the hospital setting was not helpful for me a researcher because the setting was very busy, although it was practical for accessing the participants easily.
5. Conducting interviews in the hospital was not practical for some women as they wished to finish the interviews quickly and return home to be with their children after school in the afternoon, which is generally a busy time for housewives. Furthermore, conducting interviews in the hospital setting was not helpful for two women as they were in a rush to finish the interviews because their husbands were waiting outside. Therefore, an agreement was made to continue the interviews by phone.
6. As a researcher, I found it challenging to break the ice with interviewees and to encourage them to speak openly about private issues, such as their sex lives. Social norms discourage expressing and sharing negative emotions with others, especially when some women had difficulties either in recalling traumatic events or were unwilling to talk about them.
7. The research was planned to include women with stage I and II breast cancer but, during recruitment, no women were found with stage I breast cancer, so the results reflect the experiences of women with stage II cancer. Furthermore, most of the participants were married and mothers, which might limit the meaning for young, single women.
8. This research did not investigate the participants' educational, social and economic levels. Social and personal relationships should be further studied to determine whether breast cancer is the main reason for marital relationship difficulties or if the couple were already having problems in their relationship before the breast cancer experience. Furthermore, the level of distress or depression and medical histories of anxiety were not included.
9. Despite flexible stages of data analysis, which are easy to follow, IPA is still a time-consuming process. It was difficult to use the computer software package to analyse the data, which might inhibit the close engagement with the data, as required by IPA.
10. Because the data were collected, transcribed in Arabic and then translated into English, my academic supervisors were not able to check the transcripts against the recordings because they were in Arabic. Translation problems arose, as some Arabic words do not have clear meanings in English and some words lost their meanings through the translation process. Therefore, using a translator or back translation might have been helpful.
11. As a young Saudi female, I might share some cultural values that could be reflected in my interpretations of the results, thus they cannot be generalised and applied to all Saudi women with breast cancer.

Although I clarified my position through the research process, engaging very closely with the data generated personal bias and it was difficult for me to set aside my knowledge and experience, especially when IPA recommends that the analysis of one case should not influence the subsequent analysis of the other stories. To remove this limitation, some researchers suggest that, to be uncontaminated by prior knowledge, independent members of the research team should be assigned to different tasks, such as data collection and analysis (Alexander and Clare 2004; Smith et al. 2002). In addition, international collaboration in research might be an option to reduce bias in future research. However, this was impossible as I was responsible for all the stages of data collection, translation and analysis.

10.3 Knowledge contribution

The study findings add an important consideration to research in breast cancer survivorship. Women's stories of breast cancer have found a place in their culture and they used different social, religious and racial terms to describe their experiences. Prior research studies examined 'cancer survivor' as either a preferred or rejected identity, but few described other meanings as to how one constructs an identity from the context of culture. Therefore, this research is original for several reasons:

1. It is the first study in Saudi Arabia that seeks to understand the lived experience of breast cancer survivorship from the perspective of premenopausal women.
2. It used different methodological approaches, such as social constructivism, interpretive phenomenology, life-world and IPA, as discussed and reflected through the research process. IPA allows more room for creativity and freedom in analysis than other approaches. The data provides a highly detailed personal description of women's lived experiences with breast cancer survivorship.
3. It found that culture, family dynamics, relationships, gender, social position and belief systems are very important elements that shape women's perceptions of health and illness, life and survival.
4. It showed that the cultural representations of breast cancer reflect the Saudi women's desire to hide their breast cancer identity in public while continuing with their normal life.
5. It helped to give Saudi women an opportunity for their stories to be told and their experiences with breast cancer diagnosis and treatment to be revisited. Although this thesis was only drawn upon premenopausal women who finished treatment within 5 years prior to the

interviews, the time was not significantly more important than the role of culture in shaping women's experiences.

6. It enhanced the sense of wellbeing and the meaning-making process for some women, although conducting the interviews was associated with a high level of distress. Similar results were reported by Germain et al. (2016), who found, in their qualitative study, that inviting participants to reflect on their experience of bereavement in the final 48 hours of a relative's death and being involved in their research led to beneficial outcomes. For example, sharing their stories with others provided them with a 'sense of cathartic relief'.
7. It showed that the current traditional model of care in breast cancer survivorship did not completely fulfil the women's needs. Notably, the Western concept of breast cancer survivorship did not resonate with Saudi women's experiences. Therefore, this research would inform the development of survivorship programmes to be more culturally responsive. For example, survivorship programmes should not be implemented in isolation from social, cultural and religious views.

10.4 Future work

This thesis has highlighted important issues for future research projects, some of which may be developed as part of my professional activities as a researcher and a lecturer in the nursing school in Saudi Arabia. Future research should continue to explore the breast cancer survivorship experience of Saudi women. For example, longitudinal study aiming to assess patients' needs throughout breast cancer diagnosis, treatment, and survivorship might be the first area requiring further study. This could be helpful to understand how and when to best help and meet the needs of women with breast cancer from the onset of diagnosis, through treatment, and afterwards.

Considering mixed methods, including observations and interviews approaches, would potentially offer rich information to understand the dynamics of the interactions between patients and health care providers, especially during breaking bad news and regular consultation sessions. For example, introducing individualised communication checklists to be given to the patient and her family and health care providers through the breast cancer journey, measured in different points of the breast cancer phases. The patient's checklist may include information about what to expect from the health care team, diagnosis, treatment, and afterwards. The family's checklist can comprise information about how to communicate with the cancer patient, the nature of the disease and its treatment, and family member's needs. Finally, the health care provider's

checklist may involve information about engaging the patient in consultations, informing patients about cancer prognosis and responding to their needs. All this may help to develop a knowledge base for communication and educational materials that reflect women's culture and their lifeworld. Another area of research that might be considered is using mixed methods to identify the characteristics and reasons for those women who refuse to take part in supportive groups, in order to develop supportive resources tailored to their cultural needs. For example, online supportive forums are useful to maintain their confidentiality and identity.

The role of culture in shaping women's lived breast cancer survivorship experience was significant in this study. Thus, acknowledging it in cancer care may help in facilitating the development of breast cancers survivorship models. The first step might be implementing and developing a cultural competency tool (Kagawa-Singer et al. 2010) that might be used to enable healthcare teams to assess the cultural sensitivity of their patients. For example, the following checklist has been adapted from Kagawa-Singer et al. (2010) to reflect Saudi culture.

Table 8: Cultural competence checklist

Levels of cultural assessment	Information needed to assess each level
1. Social structure	Gender, age, marital status, having children, income, level of education, employment, family history of cancer, source of support
2. language	Literacy, translation
3. Health comprehension and awareness	Cancer meaning, treatment plans and options, patient's health rights, causes of cancer, availability of health services
4. Decision-making	Autonomy, position in the society, seeking for information, family involvement
5. Belief system	Religion, fatalism, health belief like using religious and herbal treatment
6. Recovery	Trust on health care team, preference on healthcare provider, meeting expectations and needs
7. lifestyle	Health promotion behaviours like exercise, diet
8. Environment	Place of residence, transportation, availability of cancer supportive foundations

Through my position as a lecturer, adding educational material about culture and religious belief to the course programme (Tervalon 2003) might be helpful. Nursing students might be part of learning and strategic sessions related to developing trustful relationship with patients, effective communication, utilising religious beliefs, and delivery of social and psychological support. This could help nursing students to be better prepared how to interact and deal with cancer patients followed by observation and discussion with the oncology health care team. Clinical simulation may also play a role in preparing nursing students dealing with breast cancer patients. Participate in publications and organised events and conferences might allow women to voice their experience with breast cancer. Also, research collaboration with partners nationally and internationally is highly advisable considering the breast cancer map adapted by (Hall et al. 2015), and changed according to current breast cancer status in Saudi Arabia; see Figure 7 below.

At the end surviving breast cancer for Saudi women was not associated with the passage of time or getting cured, their experiences were influenced by cultural, social, and historical perspectives. As Anoud said, *'fighting battle' not against the disease itself, but also against the negative cultural beliefs*.

Breast Experience Map

Highlighting common experiences among Saudi young women with breast

Breast cancer ranks as the most common cancer composing of 27.4% of all female

cancers in Saudi Arabia (Kingdom of Saudi Arabia Ministry of Health Saudi Cancer Registry, 2012)



The Status of Breast Cancer in Saudi Arabia

Year	Number of Incidence	Percentage per all newly diagnosed female cancers	ASR per 100,000 for female population	Median age at diagnosis
2009	1308	25.1% (5,205)	22.7	48 years (Range 19-99 years)
2010	1473	27.4% (5,378)	24.9	49 years (Range 21-120 years)

Screening

Diagnosis

Treatment
Decision

Active
Treatment

Survivorship

Main Points

- lack of awareness
- Embarrassment
- To whom shall I go?
- Shock
- Fear of Death
- How do I tell my family?
- Lack of shared decision making
- Autonomy
- Gender issue
- Dealing with side effects
- Bodily change
- Anxiety
- Coping
- Transition
- Identity
- Fear of cancer recurrence

Objectives

- Early detection
- Self and clinical breast exam
- Accepting the diagnosis
- Empower women with information
- Promote physical-psychosocial wellbeing
- Adjusting to new life

Strategies

- Genetic testing
- Raise breast cancer awareness
- Clear cancer care pathway
- Breaking bad news
- Encourage connecting with other women with breast cancer
- Discuss all treatment options openly
- Encourage women to ask
- Express feelings
- Use assessment tools
- Acknowledge physical symptoms of treatment
- Spiritual support
- Self-management
- Follow-up summary
- Improve follow-up service
- Living with uncertainty
- Rehabilitation

Figure 8: Breast experience map among Saudi Arabian women

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Appendix A

Search strategy table (2000-2017)

No.	Search term	No. hits Medline (ovid)	No. hits CINAHL	No. hits PsychINFO
1.	exp Breast Neoplasms/	258179	24542	8403
2.	(breast adj3 (cancer* or carcinoma* or tumo?r* or neoplas* or malignan*)).mp	305725	616147	11584
3.	1 or 2	305739	71628	11584
4.	Survivors/	20552	14233	10873
5.	Survivor*.mp.	80938	33280	26396
6.	Living with cancer.mp.	317	363	238
7.	Post treatment.mp.	26040	6887	6283
8.	Life after treatment.mp.	238	398	50
9.	4 or 5 or 6 or 7 or 8	106758	40307	32579
10.	3 and 9	6052	376	2054
11.	((patient* or survivor*) adj2 (experience* or perception*)).mp.	76488	17633	17562
12.	Perception	27521	65033	20821
13.	Self-concept/ Meaning	52121	16383	40411
14.	Identit*.mp.	127000	21945	116476
15.	Self-perception.mp.	2984	1746	24158
16.	11 or 12 or 13 or 14 or 15	443982	100623	200244
17.	10 and 16	698	58	258
18.	Limit 17 to (English language and female , academic journal and yr="2000 -Current")	323	50	355
19.	Culture*.mp.	147029	86053	149926
20.	3 and 11 and 19	25	41	15
21.	Limit 20 to (English language, academic journal and female and yr="2000 -Current")	9	30	15
22.	(Challenges or concerns or barriers).mp.	328690	119512	209459
23.	22 and 10	589	362	383
24.	Limit 23 (English language, academic journal and female, middle aged and yr="2000 -Current")	551	229	355
25.	(Follow-up or rehabilitation or monitoring or check-up).mp	1621450	121134	223268
26.	(Health care strategy* or service* or plan* OR health care delivery).mp.	1888837	39449	427637
27.	25 or 26	3351500	159807	608654
28.	27 and 10	2302	61	597
29.	Limit 28 to (English language and female, academic journal and yr="2000 -Current")	2036	58	562
Total	10 and 18 and 24 and 29	19	3	19

Appendix B



10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

- Are the results of the review valid?
- What are the results?
- Will the results help locally?

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

There will not be time in the small groups to answer them all in detail!

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Screening Questions

1. Was there a clear statement of the aims of the research?

Yes Can't tell No

HINT: Consider

- What was the goal of the research?
- Why it was thought important?
- Its relevance

2. Is a qualitative methodology appropriate?

Yes Can't tell No

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

Is it worth continuing?



Detailed questions

3. Was the research design appropriate to address the aims of the research?

Yes Can't tell No

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

4. Was the recruitment strategy appropriate to the aims of the research?

Yes Can't tell No

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Was the data collected in a way that addressed the research issue?

Yes Can't tell No

HINT: Consider

- If the setting for data collection was justified
 - If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
 - If the researcher has justified the methods chosen
 - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
 - If methods were modified during the study. If so, has the researcher explained how and why?
 - If the form of data is clear (e.g. tape recordings, video material, notes etc)
 - If the researcher has discussed saturation of data
-

6. Has the relationship between researcher and participants been adequately considered?

Yes Can't tell No

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
 - (a) Formulation of the research questions
 - (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration?

Yes Can't tell No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous?

Yes Can't tell No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings?

Yes Can't tell No

HINT: Consider

- If the findings are explicit
 - If there is adequate discussion of the evidence both for and against the researchers arguments
 - If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
 - If the findings are discussed in relation to the original research question
-

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not applicable
1. Were the criteria for inclusion in the sample clearly defined?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Were the study subjects and the setting described in detail?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Was the exposure measured in a valid and reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were objective, standard criteria used for measurement of the condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Were confounding factors identified?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Were strategies to deal with confounding factors stated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were the outcomes measured in a valid and reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Was appropriate statistical analysis used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info

Comments (Including reason for exclusion)

Appendix C



RESEARCH CENTER DEPARTMENT - JEDDAH

INTERNAL MEMO

TO: **Yassir Bahader**
Consultant Radiation Oncology
Oncology Department - Jeddah

DATE: 23 Rabia Al Awal 1436
14 January 2015

FROM: **Hossam Abdelrahman**
Chairman
Institutional Review Board Committee - Jeddah

REF: RC-J/57/36

SUBJECT: **APPROVAL OF RESEARCH PROTOCOL IRB 2014-49: PERCEPTION OF BREAST
CANCER SURVIVORSHIP AMONG SAUDI ARABIAN WOMEN**

In reference to the attached request, we would like to thank you for accepting to supervise Ms. Wafa Almegewly, who is a Second year full-time PHD student in Nursing Studies at the School of Healthcare Sciences – Cardiff University, on her submission of the above mentioned research protocol.

Expedited review was done and it was noted that the protocol is simple, straight forward and would benefit both the health services community and breast cancer research in Saudi Arabia.

On behalf of the Board, scientific and ethical approvals are granted, and you may start with the conduct of the protocol. Please submit to us the first Biannual Progress Report of the Final Report, on or before 14 July, 2015.

HAA/ess

Attachments: As Stated

School of Health Care Sciences
Head of School and Dean Professor Sheila Hunt

Ysgol Gwyddorau Gofal Iechyd
Pennaeth yr Ysgol a Deon Yr Athrawes Sheila Hunt



21 August 2014

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Wafa Almegewly
c/o School of Healthcare Sciences
Eastgate House

Dear Wafa

Title of project: Perception of Breast Cancer Survivorship Among Saudi Arabian Women

At its meeting of 20 August the School's Research Ethics Committee considered your research proposal. The decision of the Committee is that your work should:

Pass –and that you proceed with your Research after discussing the reviewers' comments with your supervisor

The Committee has asked that the lead reviewers' comments be passed onto you and your supervisor, please see attachment and comments below.

- It is not clear whether there will be a translation of the documents.
- It is not clear how you make initial contact with the participants.
- The attached comments mention the need for Cardiff University sponsorship but please disregard that comment.

Please note that if there are any subsequent major amendments to the project made following this approval you will be required to submit a revised proposal form. You are advised to contact me if this situation arises. In addition, in line with the University requirements, the project will be monitored on an annual basis by the Committee and an annual monitoring form will be despatched to you in approximately 11 months time. If the project is completed before this time you should contact me to obtain a form for completion.

Please do not hesitate to contact me if you have any questions.

Yours sincerely

Mrs Liz Harmer – Griebel
Research Administration Manager
cc : Sally Anstey & Dinah Gould

*Cardiff University is a registered charity, no. 1136855
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Appendix D

Introductory Information Sheet

Title of the Study: Perception of Breast Cancer Survivorship among Saudi Arabian Women

Dear Ms or Mrs,

My name is Wafa ALmegewly, PhD student at School of Healthcare Sciences, Cardiff University, the UK. I am looking to research perception of life after breast cancer treatment for Saudi Arabian women and would welcome the opportunity to talk with you in a face to face interview. I would like to inform you of that the study above has been permitted by a specialist hospital. The participants I need to help in this study are as the following:

Saudi woman	<input checked="" type="checkbox"/>
Age group pre-menopausal between 30-50 years	<input checked="" type="checkbox"/>
Diagnosed with early stage of breast cancer I-II	<input checked="" type="checkbox"/>
Who completed their curative treatment 6-47 months prior to the interview	<input checked="" type="checkbox"/>
Able to speak, read and write in the Arabic language	<input checked="" type="checkbox"/>

What is research and why is this study being done?

Breast cancer is a significant problem, comprising 25.1% of all newly diagnosed female cancers in Saudi Arabia. The increased long term survival of women like you with breast cancer suggests the need for specific information on life after breast cancer treatment is provided for women in Saudi Arabia. This information is crucial to both healthcare professionals and patients in order to provide the most appropriate support. There is an absence of breast cancer rehabilitation programmes in Saudi Arabia to address the life after breast cancer treatment concerns (e.g., fear of recurrence, stress, body image and fertility) and need (such as emotional support, coping and health education).

Different patient perspectives also exist on what it means to be a woman living beyond treatment for breast cancer. Some studies found that people with cancer were more likely to integrate the term 'survivor', while others preferred to be called 'patient' or

‘someone who had cancer’. Life after breast cancer treatment is, potentially, a challenging event for women, because they are no longer receiving active treatment and are looking forward to living their lives in light of their experience with the disease. For other women it may be a relief to no longer have to visit hospital and receive treatment. This study is trying to explore the experience of all women following treatment for breast cancer and to understand their unique perception of their experience.

This study aims to add to the existing body of literature about how women with breast cancer identify themselves in relation to life after breast cancer treatment within the context of culture. It is important to understand how findings this study and from existing research will be applied to, and resonate with, Saudi Arabian culture.

What are the possible benefits of taking part?

I do not expect there to be any disadvantages or risks associated with you taking part in this study. However, talking about your experience with illness could be a sensitive topic for you to expose. Multi-disciplinary team at a specialist hospital will be aware of the research process to provide psychological support to you. If at any stage you feel distress talking about your experience, I will evaluate the situation and remain with you until you reach a stable emotional state by demonstrating care and empathy and giving you time to express your feelings. You will be offered to either change the question to manage the interview pathway or terminate the interview without giving any reasons.

If you are interested and fit all the above categories, please feel free to talk to me to explain and give you more information or complete the contact details below to call you back.

Your name:
Your mobile number:
Suitable time to call:

Yours sincerely,

Wafa ALmegewly

PhD student

School of Healthcare Sciences

Cardiff University

Almegewlywh@cardiff.ac.uk

مقدمه تعريفه عن البحث

العنوان: مفهوم النجاة من سرطان الثدي لدى النساء السعوديات.

عزيزتي الأنسة/السيدة..

إسمي وفاء حمد المغيولي، طالبة دكتوراه في كلية العلوم الصحية في **جامعه كاردف** في بريطانيا. أنا بصدد عمل دراسة عن مفهوم الحياة بعد الانتهاء من فترة علاج سرطان الثدي لدى النساء السعوديات، لذا أود انتهاز الفرصة ودعوتكم للمشاركة معي للإجراء المقابلات وجه لوجه لتحدث عن تجربتكم مع المرض. وأحيطكم علماً بأن هذه الدراسة تمت الموافقة عليها من قبل المستشفى. لمن أراد المشاركة في البحث لابد من توفر الآتي:

<input checked="" type="checkbox"/>	امراه سعودية
<input checked="" type="checkbox"/>	عمرها يتراوح ما بين ٣٠-٥٠ سنه ، قبل انقطاع الطمث
<input checked="" type="checkbox"/>	تم التشخيص سرطان الثدي في مراحل مبكره (الاولى - الثانية)
<input checked="" type="checkbox"/>	تم الانتهاء من مرحله العلاج الإكلينيكي بمدته تتراوح ما بين ٦-٤٧ شهراً
<input checked="" type="checkbox"/>	إتقان اللغة العربية تحدثاً قراءه وكتابة

التعريف بالبحث والغرض منه؟

يُعد سرطان الثدي أحد أكثر الأمراض انتشاراً في المملكة العربية السعودية وتشكل ٢٥,١٪ من مجموع أمراض السرطان التي يصاب بها النساء. وبفضل من الله تطور العلم وأزداد معدل النجاة من سرطان الثدي. لذا من الضروري معرفة كل ما تمر به كل امراه أصيبت بهذا المرض للإرتقاء بمستوى الرعاية الصحية المقدمة وذلك يكون بتسليط الضوء على أمور مثل:
(الخوف من رجوع المرض، القلق، الثقة بالنفس والخصوبة) واحتياجات مثل: (الدعم النفسي، التأقلم والتكيف الصحي).

اختلفت الآراء حول مسمى اللاتي عشن فترة ما بعد انتهاء العلاج من سرطان الثدي. هناك دراسات اشارت أن المصابات بالسرطان على الأرجح يفضلن مصطلح " ناجيه"، بينما أخريات فضلن مصطلح "مريضه" أو " كنت مصابه بالمرض". الحياه بعد الانتهاء من علاج المرض قد تُشكل تحدي للمرأة لأنها لم تعود تتلقى العلاج المكثف في المستشفى وتتطلع لعيش حياتها والاهتمام بصحتها في ظل تجربتها مع المرض. بينما للمرأة أخرى، قد تشعر بالامتنان لأنها لا تراجع المستشفى باستمرار وتتلقى العلاج الإكلينيكي كالعلاج بالأشعة مثلاً. هذه الدراسة تهدف إلى استكشاف تجربة جميع من أتممن فترة العلاج من سرطان الثدي ومدى وعي إدراكهم الفريد لتجربتهن.

من المهم معرفة أن هناك العديد من الدراسات السابقة التي تناولت موضوع الحياة بعد إتمام العلاج من سرطان الثدي وما يتعلق به ولكن نتائج هذه الدراسات غير مطبقة على بعض الثقافات والمجتمعات كما هو الحال في المملكة العربية السعودية.

لذا تهدف الدراسات الحالية الى فهم وإضافة معلومات جديدة على الأبحاث السابقة عن نظرة النساء اللاتي أصبن بالمرض لأنفسهن بعد الانتهاء من العلاج في ظل تأثير ثقافة وتقاليد المجتمع السعودي.

عزيزتي إذا أحببتى المشاركة في البحث وأنطبقت عليك المواصفات أعلاه، لا ترددي في التحدث معي شخصياً للتزويدك بالمعلومات الكافية وسأكون حريصه على إجابته جميع أسئلتك أو تفضلني بالتكرم بتعبئة بيانات الإتصال في الخانات السفلية لمعاودة الإتصال بك للشرح ملخص الدراسة.

الأسم الرباعي:
رقم الهاتف/موبايل:
الوقت المناسب للإتصال:

شاكره لك حسن تعاونك وإعطائي من وقتك.

الباحثة:

وفاء حمد المغبولي

طالبة دكتوراه

كلية العلوم الصحية

جامعة كاردف

Appendix E

Participant Information Sheet

Title of the Study: Perception of Breast Cancer Survivorship among Saudi Arabian Women

Introduction:

This study is seeking to explore and understand life after breast cancer treatment for Saudi Arabian women and consider to what extent the culture of Saudi Arabia impacts on their experience. The research objectives are the following:

- To identify how Saudi Arabian women perceive their life after breast cancer treatment.
- To understand their experience e.g., challenges, identities, feelings, benefits and relationships of being breast cancer survivor in Saudi Arabia.
- To explore what strategies from health care providers may support women who are living beyond (after) breast cancer treatment.

Dear participant,

My name is Wafa Almegewly, I am a PhD student at School of Healthcare Sciences at Cardiff University in the UK. I would like to invite you to take a part in this study. Before you decide whether you want to take a part or not, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it either with other members of health care or family if you wish. Please contact me if anything is unclear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

1. What is research and why is this study being done?

Breast cancer is a significant problem, comprising 25.1% of all newly-diagnosed female cancers in Saudi Arabia. The increased long-term survival of women like you with breast cancer suggest the need for specific information on life after breast cancer

treatment is provided for women in Saudi Arabia. This information is crucial to both healthcare professionals and patients in order to provide the most appropriate support. There is an absence of breast cancer rehabilitation programmes in Saudi Arabia to address the life after breast cancer treatment concerns (e.g., fear of recurrence, stress, body image and fertility) and need (such as emotional support, coping and health education).

Different patient perspectives also exist on what it means to be a woman living beyond treatment for breast cancer. Some studies found that people with cancer were more likely to integrate the term 'survivor', while others preferred to be called 'patient' or 'someone who had cancer'. Life after breast cancer treatment is, potentially, a challenging event for women, because they are no longer receiving active treatment and are looking forward to living their lives in light of their experience with the disease. For other women it may be a relief to no longer have to visit hospital and receive treatment. This study is trying to explore the experience of all women following treatment for breast cancer and to understand their unique perception of their experience.

This study aims to add to the existing body of literature about how women with breast cancer identify themselves in relation to life after breast cancer treatment within the context of culture. It is important to understand how findings this study and from existing research will be applied to, and resonate with, Saudi Arabian culture.

2. Why have I been asked to take part?

You have been invited to take part in this study because you were diagnosed with early breast cancer stage I-II and you had finished your treatment at range of 6 and 47 months and your age is between 30 and 50 years. You are able to speak read and write in Arabic language.

3. Do I have to take part?

It is up to you to decide to join the study. If you agree to take part, you will be given this information sheet to keep and asked to sign a consent form. You are free to withdraw at any time during the study, without giving a reason. Also, if you decide not to take part now or in the future, it will not affect the care you receive.

4. What will happen to me if I take part?

If you choose to participate in this study, you will be asked firstly to fill in the consent form. Secondly, talk about your experience with your illness since diagnosis until treatment in a single interview. Then, you will be asked to talk about your experience with finishing breast cancer treatment and how life has been since then. Interviews will be audio-recorded and will last approximately one to two hours and they will take place at a private counselling room in a specialist hospital in Jeddah, Saudi Arabia. Please be aware that if during the interview you tell me information that may put others at risk I will need to inform the appropriate health careers or advice you where to get help.

5. What are the possible disadvantages and risks of taking part?

I do not expect there to be any disadvantages or risks associated with you taking part in this study. However, talking about your experience with illness could be a sensitive topic for you to expose. Multi-disciplinary team at the specialist hospital will be aware of the research process to provide psychological support to you. If at any stage you feel distress talking about your experience, I will evaluate the situation and remain with you until you reach a stable emotional state by demonstrating care and empathy and giving you time to express your feelings. You will be offered to either change the question to manage the interview pathway or terminate the interview without giving any reasons.

6. What are the possible benefits of taking part?

Your treatment follow-up plan will be the same whether you are taking part in this study or not. I cannot promise the study will help you, but the information I get from this study may benefit others in the future. You will be helping me to understand the meaning of life after breast cancer treatment, as well as your experience with the disease. Furthermore, your participation could open a window for other women who shared the same experience and wished to improve their current situation and the cultural taboo about breast cancer. Sharing your experience with me might help health care professionals tailor support and care according to your needs.

7. Will my taking part be kept confidential?

Yes, I will follow ethical and legal practice guidance of Cardiff University and all the information about you will be handled in confidence. You will not be identified by name and all procedures of handling storage and destruction of data will be kept

confidential. I will collect data from the interview which I will do by taping the interviews and the information will be stored on my computer within the university with a password. The recordings will be locked in a secure cabinet with control access until transcribed and verified and then destroyed. After 15 years of keeping the data, Cardiff University will archive and then destroy the information.

8. Will anyone else know I am doing this?

Your participation in this study is completely voluntary and any information you share in connection with this study will be kept completely confidential. Details such as your name, location and contact number will be kept confidential throughout the study, publication and presentation by giving you a different name or number. Information will be only shared with my supervisors, sponsor (Ministry of Higher Education, Saudi Arabia) and an external translator who will translate the transcript from Arabic to English language.

9. Who is organising and funding the study?

This study is sponsored by Research Innovation and Enterprise Services, Cardiff University and funded by the Ministry of Higher Education, Saudi Arabia.

10. Who has reviewed the study?

The study has been reviewed and approved by the Research Ethics Committees at Cardiff University and the specialist hospital in Jeddah to protect your safety, rights, wellbeing and dignity.

11. What if something goes wrong?

I do not expect any harm to come to you from taking part in this study. However, if you are not happy about any aspect of the study, please feel free to contact me on the details below.

Contact for further information

If you have any queries about anything concerning the study, please feel free to contact me:

Wafa Hamad Almegewly

E-mail address: almegewlywh@cf.ac.uk

Thank you

معلومات للمشاركة في البحث

عنوان البحث: مفهوم النجاة من سرطان الثدي لدى النساء السعوديات.

مقدمه عن البحث:

هذه الدراسة تهدف الى إستكشاف وفهم طبيعة الحياه بعد إتمام فترة العلاج من سرطان الثدي لدى المرأة السعودية. وإلى أي مدى ثقافة المجتمع قد تؤثر على تجربتهم مع المرض.

أهداف الدراسة كالآتي:

لمعرفة منظور النساء السعوديات لحياتهن بعد الإنتهاء من فترة علاج سرطان الثدي. لفهم تجربتهن من حيث: (التحديات، تحديد الهوية، المشاعر، العائد الايجابي ، العلاقات). لإستكشاف ماهي الآلية التي يستخدمها الممارسون الصحيون لمساعدة اللاتي أتممن فترة العلاج من المرض.

عزيزتي المُشاركة....

أنا اختك، وفاء حمد المغيولي، طالبة دكتوراه في كلية العلوم الصحية في جامعه كاردف في بريطانيا. أدعوك للمشاركة معي في البحث ولكن قبل إتخاذ القرار سواء بالموافقة أو الرفض أرجو أن تعرفي الهدف من عمل هذه الدراسة ولماذا تتطلب مساهمتك الكريمة فيها. أرجو منك أخذ الوقت الكافي لقراءة معلومات المشاركة عن البحث ومناقشتها سواء مع أحد أفراد الطاقم أرجو أن لا تنتردي بالتواصل الطبي أو عائلتك إذا أردتي. في حال وجود اي معلومات غير واضحة، معي لأقوم بشرحها لك .

١- التعريف بالبحث والغرض منه؟

يُعد سرطان الثدي أحد اكثر الأمراض انتشاراً في المملكة العربية السعودية وتشكل ٢٥,١٪ من مجموع أمراض وبفضل من الله تطور العلم وازداد معدل النجاة من سرطان الثدي. لذا من السرطان التي يصاب بها النساء. الضروري معرفة كل ماتمر به كل إمراه أُصيبت بهذا المرض للإرتقاء بمستوى الرعاية الصحية المقدمه وذلك يكون بتسليط الضوء على أمور مثل: (الخوف من رجوع المرض، القلق، الثقة بالنفس والخصوبة) واحتياجات مثل: (الدعم النفسي، التأقلم والتنقيف الصحي).

أختلفت الآراء حول مسمى اللاتي عشن فترة مابعد انتهاء العلاج من سرطان الثدي. هناك دراسات اشارت أن " أو" كنت المصابات بالسرطان على الأرجح يفضلن مصطلح " ناجيه"، بينما أخريات فضلن مصطلح "مريضه مصابه بالمرض". الحياه بعد الإنتهاء من علاج المرض قد تُشكل تحدي للمرأة لأنها لم تعود تتلقى العلاج المكثف في المستشفى وتتطلع لعيش حياتها والأهتمام بصحتها في ظل تجربتها مع المرض. بينما للمرأة أخرى، قد تشعر

بالإمتنان لأنها لاتراجع المستشفى بإستمرار وتتلقى العلاج الأكلينيكي كالعلاج بالأشعة مثلاً. هذه الدراسة تهدف إلى استكشاف تجربة جميع من أتممن فترة العلاج من سرطان الثدي ومدى وعي إدراكهم الفريد لتجربتهم. من المهم معرفة أن هناك العديد من الدراسات السابقة التي تناولت موضوع الحياه بعد إتمام العلاج من سرطان الثدي ومايتعلق به ولكن نتائج هذه الدراسات غير مطبقة على بعض الثقافات والمجتمعات كما هو الحال في المملكة العربية السعودية.

لذا تهدف الدراسة الحالية الى فهم وإضافه معلومات جديدة على الأبحاث السابقة عن نظرة النساء اللاتي أصبن بالمرض لأنفسهن بعد الإنتهاء من العلاج في ظل تأثير ثقافة وتقاليد المجتمع السعودي.

٢- لماذا تُطلب مني المشاركة؟

لقد تمت دعوتكم للمشاركة في البحث لأنه قم تم تشخيصك بالمرض في مراحل المبكره الاولى والثانيه وقد أتممتي (الجراحي، الكيميائي، الأشعاعي) بمدة تتراوح ما بين ٦-٤٧ شهراً. عمرك يتراوح ما بين فترة العلاج الإكلينيكي ٣٠-٥٠ سنة وتتقنين اللغة العربية تحدثاً، قراءه وكتابة.

٣- هل علي المشاركة في البحث؟

الأمر متروك لكم لإتخاذ القرار في الإنضمام الى دراسته. في حال الموافقة سوف تستلمين هذه الورقه التي تشرح لك معلومات عن البحث وإقرار خطي بالموافقه. وبنفس الوقت لك مطلق الحريه في الإنسحاب في أي وقت خلال الدراسة، دون إبداء مبررات. ايضاً في حال عدم المشاركة الان أو في المستقبل فذلك لن يؤثر على الرعاية الصحية التي تتلقينها في المستشفى.

٤- ماذا سوف يحدث لو شاركت في البحث؟

إذا اخترتي المشاركة في البحث فسوف يُطلب منك أولاً ملئ إقرار خطي بالموافقة للانضمام للبحث. ثانياً الحديث عن تجربتك مع المرض في مقابلة شخصيه معي وجهاً لوجه للمدة قد تستغرق ما بين ساعة الى ساعتين لا أكثر. سيطلب منك أن تتحدثي عن تجربتك عن مرحلة {التشخيص بالمرض وتلقي العلاج، مرحلة ما بعد اتمام العلاج}. المقابلات سوف تقام في المستشفى. علماً بأن هذه المقابلات سوف تسجل صوتياً لدراستها وتحليلها.

٥- ماهي المساوئ المحتمل حدوثها في حال المشاركة؟

لا أتوقع أن يكون هناك أي مخاطر مرتبطة بالإنضمام في الدراسة ومع ذلك قد يكون التحدث عن تجربتك مع المرض موضوع حساس للروح فيه. لذلك الفريق الطبي في قسم الأورام في المستشفى سوف يكون على علم بالبحث وعلى إستعداد لتقديم المساعدة. سوف يكون لديك الخيار في اختيار الأحداث المهمة في تجربتك في نهج سردي قصتك مع المرض. أيضاً سوف يُعرض عليك إما تغيير السؤال لإداره مسار المقابلة أو طلب إنهاء المقابلة بدون ذكر أي مبررات.

٦- ماهي منافع اشتراكي في البحث؟

خطة متابعه علاجك لن تتغير سواء شاركت في البحث ام لا، أيضا لا أستطيع ان أعد ان هذه الدراسة سوف تساعدك لكن ثقي بأن المعلومات التي سأحصل عليها قد تفيد الاخرين في المستقبل. مع ذلك بعض النساء تجدن بعض الراحة عند التحدث عن تجربتهن مع المرض كوسيله علاجية. علاوة على ذلك سوف تساهمين في توضيح طبيعة حياتك وتجربتك الشخصية مع المرض. بالإضافة الى ان مساهمتك قد تتيح المجال لغيرك من النساء اللاتي يتقاسمن نفس تجربتك ويرغبين في تحسين وضعهن الحالي عبر تغيير ثقافة المجتمع عن سرطان الثدي. بالإضافة الى أن تقاسم تجربتك معي قد تساعد العاملين في مجال الرعاية الصحية لفهم احتياجاتك وتلبيتها.

٧- هل مشاركتي في البحث ستكون سرية؟

نعم، جميع المعلومات الي شاركتي بها سنعامل بسرية تامه. جميع معلوماتك الشخصية مثل إسمك سوف تكون سرية ومجهولة للاخرين في عمليه تخزين المعلومات وتحليلها. بعد تسجيل المقابلات صوتياً سأقوم على الفور بتخزينها بحاسوبي الشخصي وحمايتها بكلمه سر. جامعه كاردف سوف تؤرشف المعلومات ثم تتلفها بعد مرور ١٥ سنة من تخزين المعلومات.

٨- من يعلم بمشاركتي في البحث؟

المشاركة في هذه الدراسة هي طوعيه تماماً وأي معلومات لها علاقة في البحث سوف تُعامل بطريقه سرية تامه. المعلومات فقط سوف يطلع عليها الباحثة والمشرفات الأكاديميات على البحث من جامعه كاردف في بريطانيا والمترجمة القائمه على ترجمة نصوص المقابله من اللغة العربية الى الإنجليزية.

٩- من هو داعم الدراسة؟

الدراسة برعايه الملحقية الثقافية السعودية في بريطانيا وايرلندا تحت مظلة وزارة التعليم العالي.

١٠- من راجع ووافق على الدراسة؟

هذه الدراسة قد تمت مراجعتها والموافقة عليها من قبل لجنة اخلاقيات البحث العلمي في كلية العلوم الصحية في جامعه كاردف لحماية حقوق المشاركه في البحث ولجنة أخلاقيات البحث العلمي في مستشفى جده. **بيانات الإتصال:**

إذا كان لديك أي إستفسار بشأن الدراسة فلا تردددي في الإتصال بي

اسم الباحثة: وفاء حمد المغيولي

ايميل: almegewlywh@cf.ac.uk

في الختام أتقدم بوافر الشكر والإمتنان لمساهماتكم الكريمة في الدراسة سائلين المولى عز وجل أن يجعله في ميزان حسناتكم ويوفقنا وإياكم لما فيه الخير لشعبنا وأمتنا.

مساهماتكم في هذه الدراسة محل العرفان والتقدير، شكراً جزيلاً

Appendix F

Interview Guide

Introduction (after the participant has read and signed the consent form and had any questions answered):

I have some questions I would like to ask you, but the interview will be fairly informal- more like a conversation than an interview. I am interested in your experiences specifically related to your breast cancer and how this has been for you.

Are you happy to go ahead and get started?

Part 1. Breast Cancer diagnosis and experiences during cancer treatment

To start off, please tell me about your experience with breast cancer beginning with how you came to be diagnosed with cancer.

➤ **Probes:**

- How was the cancer discovered? You or oncologist or primary doctor or someone else?
- What sort of thoughts were in your mind at that time?
- Is it possible to remember how you felt at that moment?
- Has any member of your family and friends had experienced cancer? If yes. Who was that person and whether his/her experience with cancer affected yours?
- How did your breast cancer diagnosis affect your family, your social life (relationships) and other parts of your life such as your job?
- What sort of treatment(s) did you have?
- Could you tell me a little about the operation and how it affected you?
same for chemotherapy and or radiotherapy.
- What and who helped you to cope with diagnosis and treatment? Is there a person in your life who you avoided

talking to about your illness? If yes then could please tell me why?

- How was all that for you? I would really like you to help me to try and understand your experience.

Part 2. Life after treatment

So we have covered a lot of what happened during treatment. Now I would like to talk to you in more detail about your life after treatment.

1. How was it for you, when your treatment ended?

➤ Probes:

- (Was it positive or negative experience?) were there any good things that you felt or thought when your treatment ended
- Were there any more difficult or worrying things that you felt or thought when your treatment ended?
- Anything that you felt or thought that was unexpected
- How did you feel about your life now the treatment was over? (What sort of things did you feel stressed/excited /challenged about? e.g., personally (self-concept, confusion, lonely), socially (being social, back to work, public view, resuming your tasks as a wife, mother and sister) and medically (fear of recurrence, self-monitoring, side effects of hormonal therapy, lymphedema, follow up- appointments).

2. In what sort of ways are you different now from before you had breast cancer?

3. Are there any ways that you have not changed?

➤ Probes:

Many people talk about or describe women in your position as cancer survivors or heroes, while others preferred to be called patients, victims, and someone who has had cancer.

- What does the word survivor / survivorship mean to you in general?

- Would you prefer that people used another term? If yes, what word would be a better one do you think?
- What specifically does that chosen word mean for you as a woman and in your role as a...(wife, mother, daughter etc)?
- How does it feel in relation to your health?
- Would you say that having had cancer has made any difference to how you are in society/the world?
- Are there any ways that I have not thought of or asked you about that have influenced your experience of living with and beyond breast cancer?

Finally, I want to ask you about the professionals caring for you

- In what sort of ways do you think health care providers may help you cope with your experience of surviving breast cancer?
- Is there anything they might be able to do at the time you are diagnosed....?
- Or is there anything that they might be able to help with when your treatment has been completed?
- Is there anything else you would like to share with me so that I can really understand how this has been for you (and of course your family)?.

Thank you for taking time to share your story with me and I would appreciate if you can tell me how do you think about the interview?

دليل المقابلة الشخصية

المقدمة: (بعد إتمام قراءة وتوقيع إقرار الاشتراك في الدراسة والإجابة على جميع استفسارات المتطوعه)
لدي بعض الاسئلة التي أود أن اطرحها عليك، و أرجو أن تتخذ هذه المقابلة طابعا ودياً غير رسمي كالردشة الى حد ما ،أنا مهتمه بتجربتك مع سرطان الثدي و تأثيرها عليك.
أولاً: فترة تشخيص المرض و الفترة العلاجيه و تأثيرهما عليك:
في مستهل الحديث , أخبريني عن تجربتك إبتداءً من بداية تشخيصك بسرطان الثدي.

- من أكتشف الورم ،أنت أم طبيبك أم شخص اخر؟ وكيف ؟
- هل من الممكن أن تتذكرى ماذا شعرتى وقت تشخيصك؟
- ما نوع الأفكار التي طرأت لك أثناء تلك الفترة؟
- كيف كان تأثير تشخيصك بسرطان الثدي على عائلتك و حياتك الإجتماعية و النواحي الاخرى أيضاً من حياتك , كا مهنتك ؟
- ما نوع العلاج التي خضعتي له؟
- هل من الممكن ان تخبريني أكثر عن علاجك (جراحي-اشعاعي-كيميائي) وتأثيره عليك؟
- ما تأثير ذلك ككل عليك؟

ثانياً: حياتك بعد العلاج:

لقد تكلمنا بشكل كافٍ عن علاجك و ما مررت به اثناء تلك الفترة أود منك الان أن تخبريني بتفصيل أكثر عن حياتك بعد العلاج، إذا سمحتي لي.

1. متى أتممتي علاجك؟ وما كان شعورك بعد إنتهائك منه؟
- ما تصنيفك لهذه التجربة (ايجابيه ام سلبيه)؟ هل هناك أي شيء أو إحساس إيجابي خرجت به بعد انتهائك من العلاج؟
- هل كانت هناك صعوبات أو أي اموراً مقلقة شعرتي بها بعد إنتهائك من العلاج؟
- هل شعرتي أو فكرتي بشيء لم يكن متوقعا؟
- كيف تشعرين الآن تجاه حياتك بعد إتمامك للعلاج؟ و ما نوع الاشياء التي قد تثير حماسك او تغيظك أو يصعب عليك فعلها؟
- في أي شكل من الاشكال انت مختلفه الان عما كنت بالسابق قبل إصابتك بالمرض؟
- هل هناك اشياء لم تتغير فيك سواء قبل أو بعد الاصابه؟

الكثير من حولنا يتداولون أو يصفون النساء اللاتي مررن بتجربتك بأنهن "ناجيات من السرطان"

- ماذا تعني كلمة "ناجية" لك؟
- هل تفضلين أن يتداول الناس مصطلح اخر؟ وماذا تفضلين أن يستخدموا بدلا من "ناجية"؟
- ماذا يعني لك أن تكوني "ناجية من السرطان" بشكل عام؟ و ماذا يعني لك بشكل خاص في دورك في الحياة كأم أو زوجه أو أخت... الخ ؟
- كيف هو شعورك تجاه هذا المصطلح فيما يتعلق بصحتك؟
- هل من الممكن أن تقولي أن تجربتك مع السرطان جعلتك مختلفه في المجتمع اوفي العالم؟

- هل هناك امراً لم نتطرق له وكان له تأثير على تجربتك في التعايش سواء مع او مابعد اصابتك بالمرض؟
- في الختام, أود أن أسألك عن الطاقم الصحي المهتم برعايتك:
 - بأي شكلٍ من الأشكال تظنين ان الطاقم الصحي ساعدك على التعامل والتأقلم مع تجربة النجاة من سرطان الثدي؟
 - هل هناك أي شيء كان بإستطاعتهم فعله وقت تشخيصك؟
 - هل هناك أي شيء كان بإستطاعتهم فعله لمساعدتك به بعد العلاج....؟
 - هل لديكِ امراً أو أي شيء اخر تودين مشاركتي إياه لكي أستطيع حقاً استيعاب ما مررتي به انتِ وبالطبع عائلتك؟

في الختام أتقدم بوافر الشكر والإمتنان للمساهمتك الكريمة في دراسته سائلين المولى عز وجل أن يجعله في ميزان حسناتكم ويوفقنا وإياكم لما فيه الخير لشعبنا وأمتنا.

شكراً جزيلاً

Appendix G

Consent Form

Title of the Study: Perception of Breast Cancer Survivorship among Saudi Arabian Women

Name of the researcher: Wafa Almegewly

Please read each section carefully before you initial each box.

<p>I confirm that I have read and understand the Participant Information Sheet, for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</p>	<input type="checkbox"/>
<p>I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.</p>	<input type="checkbox"/>
<p>I agree to be interviewed by the researcher and the use of audio-recording, and understand that verbatim quotations from my interview may be used anonymously in the report produced from this study and in papers produced for publication and for conference presentation, but I can withdraw the use of any part of the material at any time before the report is published.</p>	<input type="checkbox"/>
<p>I agree to allow the researcher access to my medical notes in order to find specific details about my illness as part of this study.</p>	<input type="checkbox"/>
<p>I understand that if, during the interview, information is disclosed that may put me or others at risk, the appropriate health care team will be informed.</p>	<input type="checkbox"/>

I understand that data collected during the study may be looked at by Research Governance staff working in Cardiff University for the purpose of monitoring and auditing the conduct of the research. I give permission for this.	<input type="checkbox"/>
I understand that data collected will not be transferred to any other organisation.	<input type="checkbox"/>
I agree to take part in the above study.	<input type="checkbox"/>

Declaration by participant:

I hereby consent to take part in this study.

Participant's name:

Signature: _____ Date: _____

Declaration by the researcher:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:

Signature: _____ Date: _____

إقرار خطي

عنوان البحث: مفهوم النجاة من سرطان الثدي لدى النساء السعوديات

إسم الباحثة: وفاء حمد المغيولي

أرجو التمعن بقراءة كل قسم قبل وضع علامة في المربع المخصص

<input type="checkbox"/>	أقر بأنني قرأت وفهمت ملف معلومات المشاركة في البحث أعلاه وقد تسنى لي استيعاب المعلومات وطرح الأسئلة التي تم الإجابة عليها .
<input type="checkbox"/>	أقر بأنني أفهم أن مشاركتي هي طوعيه ولي الحق في الإنسحاب عن المشاركة في أي وقت بدون إعطاء مبررات .
<input type="checkbox"/>	أقر على إجراء مقابلة شخصية مع الباحثة وتسجيلها صوتياً وايضاً أقر أن أي اقتباسات من المقابلة سوف تستخدم بسرية تامه بدون ذكر أسماء في أوراق بحثية للنشر ولكن أستطيع منع استخدام أي جزء من المقابلة الشخصية في أي وقت قبل نشر البحث .
<input type="checkbox"/>	أقر بالسماح للباحثة بالإطلاع على ملفي الطبي كجزء من الدراسة عن طبيعة المرض .
<input type="checkbox"/>	أقر أنه في حال تم الإفصاح خلال إجراء المقابلة الشخصية عن معلومات قد تعرضني انا او الآخرين للخطر فإن الفريق الطبي المعني سوف يتم إبلاغه.
<input type="checkbox"/>	أقر بأن المعلومات المعطاة خلال الدراسة سوف تُخزن في جامعه كاردف من قبل موظف لجنة تحكيم الأبحاث وبذلك أمنحهم الموافقة بالإطلاع على معلوماتي المقدمة للبحث.
<input type="checkbox"/>	أقر بالمشاركة في البحث المبين اسمه أعلاه .

تصريح المشاركة:

أنا أوافق على إقرار المشاركة في البحث

إسم المشاركة:

التاريخ:

التوقيع:

تصريح الباحثة:

أنا أقر بإنني قمت بشرح البحث لفضياً للمشاركه وأجبت أسئلتها المتعلقة بالبحث. كما أقر بأنها فهمت البحث وأعطيت إقرار خطي للمشاركة.

إسم الباحثة:

التاريخ:

التوقيع:

Appendix H

Reflective Journal

Day (X)

Researcher Name: Wafa ALmegewly

Research title: Perception of breast cancer survivorship among young Saudi Arabian women

Date:

Location: Oncology Outpatient Clinics

Participant's nickname:

Participants' information	Observation	My impression / reflection

1. What are the main issues or themes that struck you in this contact?

2. Summarise the information you go (or failed to get) on each of the target questions.

Question

Information

3. What new or remaining target questions do you have in considering the next contact?

Appendix I

Table of the common themes mentioned by the study's participants

Theme Name	Thinking of death	Male involvement in patient's care	Living hidden	Lack of husband's support	Devil's eye	Fatigue	Living with reminders	God's will	Women position	Survivor/fighter identity	Need for group support	Information need	Negative communication
Nourah	√	√	×	×	√	√	√	√	×	×	×	√	×
Aisha	√	√	√	√	×	√	×	√	√	×	√	√	√
Sahara	√	×	√	√	√	√	√	√	√	√	√	√	√
Shatha	√	×	×	√	√	√	√	√	×	×	√	√	×
Asma	√	×	×	√	×	√	×	√	×	×	√	√	√
Anoud	√	×	√	×	×	√	×	√	√	√	×	√	×
Lama	√	√	×	√	√	√	√	√	√	×	×	√	√
Asera	√	×	×	√	×	√	×	√	√	×	√	√	×
Shahad	√	×	√	×	×	√	√	√	×	×	×	√	×
Leena	√	√	×	×	√	√	√	√	×	×	√	√	√
Ohoud	√	×	√	×	×	√	×	√	×	×	×	√	×
Shamas	√	√	×	√	√	√	×	√	√	×	×	√	√
Alaa	√	×	×	×	×	√	×	√	×	√	√	√	×
Sara	√	×	√	×	×	√	×	√	×	×	√	√	×
Amar	√	×	×	×	√	√	√	√	×	√	×	√	×
Azizah	√	×	√	×	×	√	√	√	×	×	×	√	×
Haia	√	×	×	√	×	√	√	√	×	×	×	√	×
Maha	√	×	×	×	√	√	√	√	√	√	×	√	√